Portfolio: Volume 1

Parents of Children with Autism Who Blog: A Thematic Analysis

Submitted to the University of Hertfordshire in partial fulfillment of the requirements of the degree of Doctor of Clinical Psychology

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September 2014

Word count: 29,733

(Excluding tables, references and appendices)

Table of Contents

Table of Figures

Table of Tables

CHAPTER 1: ABSTRACT

This study used thematic analysis to investigate the blogs of parents of children diagnosed with an Autism Spectrum Condition, with a particular focus on themes that emerge when parents write about themselves, their child and their family relationships.

The first stage of the study involved a broad analysis of the first six months of entries presented within eight blogs. Themes which emerged during this stage included ‘Coping’, ‘Searching for an explanation - Meaning making’ and ‘Sense of belonging vs not belonging’. The second stage of the study involved a deeper analysis of two of the eight blogs, used as case studies, which were selected due to differing on aspects of the themes found during the first stage of analysis. Themes which emerged from the second stage were a superordinate theme of ‘Searching for an explanation - Meaning making’, with subordinate themes of ‘Relationship with ASC’ and ‘Relationship with society’.

There were only brief mentions of family relationships within the blogs, except the relationship with the child and it seemed that parents often made sense of their experiences through their relationship with ASC and their relationship with society. Many of the parents who blogged reported changes in their relationship with society due to feeling that others do not understand and a sense of not belonging. It seemed that blogging provided a sense of belonging and a way of being understood for these parents, as well as a source of information to help parents explore ASC and their relationship with ASC. The themes that emerged may provide important information for clinicians and the implications of the research findings are discussed. The limitations of the study are noted and there are suggestions for future research.

CHAPTER 2: INTRODUCTION AND LITERATURE REVIEW

Overview of the chapter

This chapter will begin by outlining the researcher's position and theoretical stance to give context and a framework for the overview of the literature which follows. The literature review will focus on families, families of children with a 'disability' and families who have a child that has been diagnosed with an Autism Spectrum Condition. The context of the internet as a form of expression and blogging in particular will be considered, especially with regard to blogging in a health context, parents who blog and parents of children with an Autism Spectrum Condition who blog. Finally the present study will be introduced by considering the clinical relevance, the research aims and the research questions.

Theoretical stance and research position

The theoretical stance of the present study will be a combination of systemic theory and social constructionist theory, which will be briefly outlined below and will also be used to in order to frame the literature review and analysis. These theories and approaches have been chosen as they are complementary, due to their emphasis on interpersonal processes and contexts helping to shape shared meanings, which are often conducted in interactions and conversations between people (Dallos & Draper, 2005). They have also been chosen due to the researcher's own position and beliefs regarding families who have a child who is diagnosed with an Autism Spectrum Condition, which will be outlined below.

Theoretical stance

Systemic Theory

Systemic theory emerged from ideas of systems theory, which examines why the whole is more than the sum of its parts and how, in systems, feedback regarding the past influences future performance (Carr, 2000). Bateson et al (1972) postulated that the family operates as a system with boundaries and sub-systems, such as male and female and parent and child subsystems (Colapinto, 1991). The family also represents a subsystem within wider systems, such as extended family, schools, organisations and the local community (Bateson, 1979). Although the family is a separate sub-system to wider society, the family boundaries need to be semi-permeable in order to intake information and resources to ensure survival and adaptation but not being so permeable that a coherent boundary cannot be maintained (Colapinto 1991).

Bateson (1972, 1979) also suggested that the family are connected by patterns of interaction that determines the behaviour of each family member. A change in the behaviour of one family member, therefore is assumed to influence all other family members, however, not in a linear pattern but more likely in circular causality (Carr, 2000). Stability or homeostasis is postulated to be necessary for families to survive as a coherent system, therefore rules and patterns of interaction develop in order to keep the homeostasis (e.g. Jackson, 1968a, 1968b, as cited in Carr, 2000) as well as family scripts (Carr, 2000). The family, however, also need to be able to adapt to changes, for example during times of transition from one part of the life cycle to another and dealing with unexpected events and challenges (Carter & McGoldrick, 1989).

Social Constructionism

The Social Constructionist stance on meaning making, postulates that knowledge and meaning is constructed and co-constructed in interaction with others (Burr, 2003). Social constructionism views ‘problems’ as constructed between people as a result of or supported by dominant discourse, rather than locating them within individuals (Dickerson, 2010). This is particularly true within groups of people, such as the family, which social constructionism would view as a social reality constructed by the individual family members, rather than as an absolute truth (Gray, 1997). The family then partly represents a collective of meanings constructed within interactions between family members. These collective meanings then shape how decisions are made within the family and what is and is not acceptable within the context of the family (Gray, 1997).

Statement of position in research

The researchers own assumptions and biases about the world and the concepts being considered influences how the data is analysed when using qualitative techniques. It is important, therefore, that these assumptions and biases are made explicit from the outset (Holloway & Todres, 2003).

For the remainder of this section of this chapter, therefore, the tense will change and personal pronouns will be used, in order to reflect my own opinions and assumptions to allow for the transparency that is necessary for this kind of research. Furthermore a second self-reflexivity section will be included in the discussion, in order to provide transparency to the reader regarding how themes and codes emerged and the role of the researcher within this process (Braun & Clarke, 2006).

I am a 30 year old White British woman raised mainly in a rural area in Britain. My family would probably be considered ‘working class’ as no member of my family had ever attended university prior to me and both of my parents worked in semi-skilled, low-paid occupations throughout my childhood. I began working with children diagnosed with ‘autism’ and/or ‘learning disabilities’ at the age of 15 as a volunteer and found that I enjoyed it immensely. I found the behaviour of the children fascinating and began to be interested in how to manage this behaviour. I believe it was these experiences that first got me interested in psychology as a subject and it was around this time that I decided I would like to be a Clinical Psychologist.

When I was 18 years old I had personal experience of living within a family who had a family member diagnosed with ‘autism’ and a ‘moderate learning disability’. We regularly needed to manage behaviour that was challenging and the family member needed almost constant supervision. The family had limited respite care, therefore the responsibility for caring for and supervising was mainly within the family. I lived with the family for 2 years and throughout that time I saw the strain that the behaviour put upon the whole family and the way that this influenced their relationships with one another. I then became more interested in how families are affected by such difficulties.

During my bachelor’s degree I completed research that focused on parents of children diagnosed with an Autism Spectrum Condition (ASC) which was a quantitative analysis of their expectations for the future, comparing the likelihood of achievement with the importance of various expectations. I began to consider the importance of parental expectations when they consider the future of their child diagnosed with ASC.

My interest in this area continued during my Master’s degree entitled ‘mental health in learning disabilities’. My thesis this time moved away from the direct family influence and focused on quality of life of adults with a learning disability who are placed in out of area placements. Despite not focusing on the family as such, my interest in this research, was the potential influence of moving away from family members on quality of life.

Alongside my interest in family relationships I have always been interested in society and wider systemic issues, particularly in how society influences people. I had not, however, heard of social constructionism prior to applying for clinical training. Whilst preparing for my interviews I read about the subject and found myself attracted to social constructionist ideas, as it felt that it moved away from blaming individuals entirely for their circumstances and behaviour and took into account other factors. Throughout my clinical training I have remained attracted to social constructionist ideas and chose a specialist placement that involved working with parents of children with a diagnosis of ASC, using narrative techniques, in an attempt to move away from a diagnosis being seen as ‘within’ the child.

Literature review

The literature review will first outline the literature search strategy and define the terms ‘autism’ and family relationships. Then, due to much of the research literature regarding the impact of ‘disability’ on families, not separating ASC from other diagnoses and conditions, the literature review will first consider research and theory regarding childhood ‘disability’ and families in general, followed by ASC and families. Finally the literature review will consider research regarding internet use and blogging, parents who blog and parents of children with a diagnosis of ASC who blog.

Literature search strategy

Electronic resources and books were found by searching on databases such as Psychinfo, Web of Science, APA, PubMed and Google Scholar, as well as the University of Hertfordshire's library book search facility. The search terms used were combinations of the words 'Autism', 'Autistic', 'Aspergers', 'ASD', 'ASC', 'Disability', 'Disabilities' alongside 'Family', 'Families', 'Parent', 'Mother', 'Father', 'Carer', 'Caregiver'. Other terms used in combination with the above terms were 'Impact', 'mental health', well-being', 'Coping', 'Identity', 'Relationships', 'Meaning making', 'Resilience' 'Social construction', 'Internet use', 'Blog' 'Weblog', 'Qualitative' and 'Thematic analysis'.

Resources were excluded if they were not written in English, or had not been translated if they had been written in another language. Appropriate references and additional articles were also found by examining the reference sections within the articles found using the strategies and search terms above, by exploring more recent articles that had cited the original articles and also by making enquiries from supervisors.

Medical definition of Autism Spectrum Conditions (ASC)

The term Autism Spectrum Disorder (ASD) is an umbrella term classified within the fifth edition of the Diagnostic and Statistical Manual (DSM-V) as a pervasive developmental disorder usually identified in early childhood (American Psychiatric Association, 2013). The new DSM-V has now classified a number of pervasive neurodevelopmental disorders under this term, which were previously separate in earlier editions, such as Autistic Disorder, Asperger's syndrome and Pervasive Developmental Disorder Not Otherwise Specified (American Psychiatric Association, 2010), as well as other, less common conditions.

The focus of the present study is on parents of children who have been diagnosed with an Autism Spectrum Disorder, however the term Autism Spectrum Condition (ASC) has been chosen and will be used throughout the present study. It has been chosen instead of 'Autism Spectrum Disorder' or 'autistic', due to the potential pathologising effects of the words 'autistic' and 'disorder'. It has also been chosen instead of the term 'autism', as this does not encapsulate the whole spectrum.

People diagnosed with ASC are often characterised by the medical model in terms of difficulties that they have in social interaction, communication and stereotyped or repetitive behaviours (Wing & Gould, 1979). The prevalence of people diagnosed with such conditions is approximately 1%, which accounts for around 540,000 people in the UK (Knapp, Romeo & Beecham, 2007). However, despite being clustered, people diagnosed with these conditions have variable presentations; for example, they can vary considerably in level of verbal ability and presence of comorbid conditions such as ‘learning disability’, behaviour that challenges, physical health conditions, genetic disorders, epilepsy, and so on.

Other explanations and descriptions of ASC

The variability of difficulties experienced by people who receive an ASC diagnosis, has been part of the criticism of the medical model’s explanation of ASC (Bishop, 1989). Other criticisms include the lack of clarity regarding the diagnostic criteria and whether there are discreet categories and deficits or a continuum of ‘normality’ (Frith, 1991), as well as the change over time that can occur, for example with age (Molloy & Visil, 2002).

In addition the medical model itself has been criticised significantly, for example, many feel that labels used by the medical model can be used to define people, which can in turn influence the expectations of others, leading people to have a tendency to view a person as a set of symptoms and interpret their behaviour using these labels rather than seeing other aspects of the person (Malloy & Vasil. 2002). Diagnostic labels also tend to locate ‘illness’ or ‘disability’ firmly within an individual, rather than as a result of social contexts and constructions such as social norms and a sense of what is ‘normal’ and ‘abnormal’ within a particular society at a particular time (Burr, 2003).

The medical model, may, however, have gone some way to absolving some of the guilt that parents, particularly mothers, may have felt regarding their child’s diagnosis based on historical explanations for ASC. If it is a medical condition there is nobody to blame, it is just something that happens. This could, therefore be a more attractive way of framing a set of difficulties, as ‘symptoms’, both for parents and for clinicians, who may also feel a sense of guilt for the previous blame culture.

For example, Bettleheim (1972) coined the term ‘refrigerator mothers’ to describe the mothers of children who had received an ASC diagnosis. This term described cold, neglectful mothers who withhold affection from their children, resulting in children with ‘symptoms’ of ASC. At a time when culturally parents were encouraged not to spoil their children (Grinker, 2007) due to fear of engendering dependence, it seemed that parents, particularly mothers, were to blame for any development where their child was perceived as outside of the norm. This blame of mothers was damaging and is still part of some of the rhetoric around ASC and other difficulties which have been labelled illnesses or disabilities. Many of these difficulties and ‘diagnoses’ are still linked to some parental influence either in utero, childbirth or in childhood (Caplan 1998). Some parents therefore are still likely to feel blamed or guilty, even if they are not overtly criticised in today’s society (Grinker, 2007).

In contrast to historical and medical explanations, social constructionist theorists view ASC as a neurological difference which has been labelled as a deficit by medical professionals (Molloy & Vasil, 2002). This view postulates that the medical way of labelling such differences then seeps into the culture through the labels becoming part of everyday vocabulary. These differences are then often seen as something that someone 'has' or 'is' e.g. 'she *has* autism' or 'he *is* autistic', rather than just as something that someone does/says/thinks/feels that is different to what the majority of people do/say/think/feel (Burr, 2003). It is postulated that these discourses are invested in by social and political powers. The social model of disability, in contrast to the medical model, distinguishes between deficits and disabilities, arguing that although deficits exist, it is society that socially constructs these deficits as disabilities (Molloy & Vasil 2002).

Due to the history of ASC and the feelings of guilt and being blamed that has historically been evoked in families, as well as the fact that this is a diagnosis that is usually made in childhood, the current study will focus on the families of children who have been diagnosed with an ASC.

Family relationships

The present study will focus on parents and family relationships. Traditional research of the family assumes that the family exists as a separate and distinct entity that distinguishes it from what is not a family (Gubrium & Holstein, 1990, as cited in Gray, 1997) with membership based on a combination of legal, affectional, biological and historical conditions (Carr, 2000). Parsons (1971) definition of the family, for example, was of a middle-class, nuclear, urban family, featuring strong affectional bonds. This definition could be described as sitting within cultural ideas of 'normality' and although the modern family unit may not possess any of the characteristics cited by Parson, traditional societal views of the 'normal family' are still pervasive, for example, the family life cycle model suggests ways in which people believe the family 'should' be (Dallos & Draper, 2005). These views are perpetuated by the media, professionals and even social and psychological research (Giddens, 1991; Gubrium & Holstein, 1993).

It has been postulated that many individuals tend to compare themselves and their families against this societal expectation of 'normality' and it has been suggested that even those who are not experiencing any major difficulties tend to regard their family life as not 'normal' and believe that most other families do achieve this ideal (Bernardes, 1985). As mentioned previously, these traditional views are however being challenged by social constructionist ideas, which describe the family 'reality' as consisting of co-constructed or 'collective representations' of meanings shared by its members (Gray, 1997). These constructs of reality are sustained by daily interactions within the family and with the family and professionals, official organisations and wider society (Miller, 1991; Gubrium, 1992; Gubrium & Holstein, 1993; Holstein & Gubrium, 1994; Dallos & Draper, 2005).

Childhood ‘disability’ and families

Historical context of ‘disability’ and families

‘Every woman who gives birth to a handicapped child does so in a climate of rejection and fear’ (Evans, 1993, p.9).

Western cultures place great emphasis on beauty, success and intellectual achievement. Those who do not conform to these ideals within Western society, therefore, are often faced with attitudes and practices that stigmatise, marginalise or dehumanise and where they are seen as burdens on families and society (Goffman, 1963; Turnbull & Turnbull, 1990). These attitudes and practices help to create cultural meanings and expectations of what it is like to have a disability or to parent someone with a disability (Kearney & Griffin, 2001). This inevitably means that these experiences are reported in the literature and viewed by professionals as a comparison with ‘normality’. ‘Coping’, therefore, is viewed as being successful if the family live a relatively ‘normal’ life (Gray, 1997).

Historically therefore, studies of families where one member has a diagnosed disability have tended to focus on the ‘trauma’ of the experience (Wolfensberger & Menolascino, 1970; Blancher, Baker & Bradock, 2002), particularly with regard to the ‘negative’ effects on parents. In recent years, however, there has been a paradigm shift away from just a ‘negative’ focus and towards including some ‘positive’ aspects of the experience (Blacher & McIntyre, 2006).

‘Negative’ impact of childhood ‘disability’ on families

Due to the vast differences in presentation of people diagnosed with ASC, the impact of having such a diagnosis is also variable. As these are conditions that are diagnosed in childhood, the focus of this research will be on the effects on families. Much of the research in this area does not distinguish between different diagnoses and tends to focus on the ‘negative’ impact of having a family member diagnosed with a long-term disability. For example, Kearney and Griffin (2001), discussed how the birth of a child with a disability is often viewed as a ‘tragedy’ from which a family might not recover.

The majority of the research has focused on the negative effects on parents, particularly on mothers, who have been found to report more levels of distress (Gray, 2002) and higher levels of daily ‘hassle’ than fathers, as well as an increase in daily stress over time, compared to father’s more constant level of stress (Trute, Hiebert-Murphy & Levine, 2007). This may be due to the increased amount of time that mothers spend with their children or perhaps due to the traditional identification with the home and children as being a mother’s domain and responsibility (Belsky & Rovine, 1990; Erel & Burman, 1995; Trute et al, 2007).

In contrast other researchers have found no difference between mother's and father's perception of 'negative' family impact, or parental ratings of their child's difficulties (Trute et al, 2007). It is challenging, however, to compare such research, due to the limited number of studies that include fathers and the small number of fathers that participate even when they are included, therefore any findings of similarity or differences between parents needs to be interpreted with caution.

Reported 'negative' effects of parenting a child with a disability include psychological and emotional distress, stress, anxiety, depression, anger and physical health problems (Gray & Holden, 1992; Gray, 1994; Fidler, Hoddapp & Dykens, 2000; Hauser-Cram, Warfield, Shonkoff & Kraus, 2001; Gray, 2002; Baker, McIntyre, Blacher, Crnic, Edelbrock & Low, 2003; Blacher, Neece & Paczkowski, 2005; Trute et al, 2007). In addition, it is suggested that financial strain (Parish, Seltzer, Greenberg & Floyd, 2004) and career difficulties can also be experienced (e.g. Gray, 1997; Gray, 2002). These families have also been found to experience low morale due to daily stressors (Singer, Irvin. L., Irvin, B., Hawkins, Hegreness & Jackson, 1993).

Stress in parents has been associated with a number of later 'negative' outcomes for children, families and parents (Crnic & Low, 2002). For example higher levels of perceived negative impact and lower levels of perceived positive impact soon after diagnosis have been linked with later lower levels of parental well-being (Trute et al, 2007). Parental symptomology has also been linked with parenting stress (Chang & Fine, 2007) and everyday parenting 'hassles' (Crnic & Low, 2002). In turn parenting 'hassles' has been associated with family relationships that are decreased in quality (Crnic & Greenberg, 1990).

Other researchers have highlighted that the diagnosis of a 'disability' itself may only play a part in the 'negative' impact on families and literature has suggested that the presence of 'comorbid difficulties' that accompany some 'disabilities' are also implicated in these effects (Trute et al, 2007). For example, when 'behavioural problems' or a 'mental health difficulty' have been identified alongside another diagnosis such as 'intellectual disability', it has been found to have more of an effect on parental well-being and perceived negative family impact (McIntyre, Blacher & Baker, 2002; Baker et al, 2003; Maes, Broekman, Dosen & Nauts, 2006). Some studies even suggest that the presence of 'behaviour problems' account for the majority of variance between maternal well-being and diagnostic group (Blacher & McIntyre, 2006). Perceived negative family impact has also been found to be affected by difficulties with adaptive behaviour (Blacher & McIntyre, 2006) and additional physical health problems, which have been found to be among the most stressful factors for parents of children with 'disabilities' (Weinhouse, D., Weinhouse, M., & Nelson, 1992).

Parental reactions such as fear, grief, guilt, anger, mourning and frustration have been well documented especially within the context of the ‘trauma of dashed expectations’ (Landsman, 1998, p.76, as cited in Kearney & Griffin, 2001) or mourning the ‘perfect’ child (Solnit & Stark, 1961). The implication assumed by many is that parents of children with a ‘disability’ will go on to experience high levels of stress and sadness which will inevitably result in distress and family dysfunction (Beckman, 1991). This grief has also been described by some as ‘sorrow’, where parents have many fears and worries for the future and feel powerless, particularly in the face of the negativity and hopelessness they perceive from other people (Kearney & Griffin, 2001).

Traditional grief models postulate that the type of grief experienced by these families is similar to how people experience the death of a loved one (e.g. Lindemann, 1944; Engel, 1961; Kubler-Ross, 1969; Bowlby, 1980). These models cite that ‘healthy’ adjustment is achieved through acceptance. Other theories, such as Olshansky’s (1962) ‘chronic sorrow’ do not assume that acceptance is necessary for adjustment to occur. These ideas and theories have implications for how professionals respond to families, by influencing them to look for acceptance and realistic expectations and assuming pathology or dysfunction when these are not found (Kearney & Griffin, 2001).

Some research has also examined whether these ‘negative’ family effects appear consistent cross-culturally and have found that ‘negative’ family effects can be found in other cultures (e.g. Koegal, Schreibman, Loos, Dirlich-Wilhelm, Dunlap, Robbins & Plienis, 1992; Pearson & Chan 1993). Whilst other research has found that some cultures experience similar levels of stress but higher levels of depression and lower morale when compared to ‘Anglo’ mothers (Blacher & McIntyre, 2006). .

There is also literature regarding being a sibling of a person with a disability, which has found more asymmetrical role relationships and possible ‘role strain’ due to multiple obligations (Stoneman, 2005). Many families who have a child with a disability have also been found to experience effects related to societal reactions, such as stigma, the loss of typical family socializing experiences (Gray 1993; Gray, 1994; Gray, 2002) and difficult reactions and attitudes from school and other services (Blacher & Hatton, 2007).

‘Positive’ impact of childhood ‘disability’ on families

Despite much being written regarding ‘negative’ family effects of having a child with a disability, there is little research into how families adapt positively to their situation, demonstrate resilience or experience positive effects (Hayes, 1997). Turnbull and Turnbull (1993) suggest that the plethora of findings of ‘negative’ impact of ‘disability’ on families may be partly due to ‘pervasive negative generalisation’. This is the focus of research on negative aspects of the experiences or due to ‘negative interpretation'; where positive elements of the family experience are interpreted as 'pathological', for example as denial or an attempt to alleviate guilt (Kearney & Griffin, 2001).

In some of the research that reports higher levels of stress or distress in parents of children with 'disabilities' than other parents, the scores on the measures used demonstrate that parent's level of functioning is within the normal range (e.g. Trute, et al, 2007). Despite reporting higher levels of stress, therefore, these parents often do not reach a 'pathological' level.

It has been suggested that actually the majority of families of children diagnosed with disabilities adapt to their situation positively (Behr, Murphy & Summers, 1992, as cited in Bennett, DeLuca & Allen, 1996; Summers, Behr & Turnbull, 1989). Positive adaptation has been defined as having successful marital relationships, an ability to love the child for who they are, having 'well-adjusted' children and ability to accept the realities of the disability (Summers et al, 1989). Some parents of children diagnosed with 'disabilities' have reported positive contributions of their child, including love, blessings, learning life's lessons, pride, fulfilment and joy (Turnbull, Guess & Turnbull, 1988; Turnbull et al 1993; Kearney & Griffin, 2001).

Feelings of joy have been found to possibly emerge as a result of perceived strengthening and development of new perspectives, often through what parents report as seeing little things that their children do and realising that their child is not dying (Kearney & Griffin, 2001). In addition other research has found that mothers of children diagnosed with 'disabilities' see their child as being a 'giver of gifts' and they report that they are less judgemental than before they had their child and that they are more able to put things into perspective, reassess their values and realise their true priorities (Landsman, 1999, as cited in Kearney & Griffin, 2001).

As mentioned previously, some diagnoses have significantly more positive outcomes for families than other diagnoses. For example, families where a child has a diagnosis of Down's syndrome have been found to report significantly higher levels of family cohesion, less family conflict, more positive appraisals and fewer negative appraisals than other 'disabilities' (King, Baxter, Rosenbaum, Zwaigenbaum & Bates, 2009) and one study even found that families of children with a diagnosis of Down's syndrome report higher levels of family cohesion than 'typical' families (Moos & Moos, 1986, as cited in King et al, 2009).

Scorgie & Sobsey (2000) identified what they called 'transformations' of parents of children diagnosed with 'disabilities'. They defined two types of transformations in these families: personal transformation and relational transformation. Personal transformation can occur in a number of ways, for example, in new roles within the family, the community and in their careers, in new traits, such as being more sensitive, confident, outspoken or assertive, or in new convictions and faiths, such as religious faith and a change of life perspective (Scorgie & Sobsey, 2000; Hastings & Taunt, 2002). Relational 'transformations' can also occur, such as improved relationships with family members and improved family interactions (e.g. Scorgie & Sobsey 2000; Taunt & Hastings, 2002), as well as viewing the child with the diagnosis in more favourable ways. For example Patterson and Garwick (1994) investigated parents of 'medically fragile' children and found that parents tended to focus on positive aspects of their child's personality and behaviours and minimised the limitations or health problems.

Autism Spectrum Conditions (ASC) and family

In terms of studies focusing on ASC specifically, again much of the research has focused particularly on mothers, as it has been found that mothers of children diagnosed with ASC are more likely than fathers to experience the impact (Gray, 1997), again a finding that needs to be interpreted with caution due to the small number of fathers who participate in research.

'Negative' impact of ASC diagnosis

It has been postulated that families who have a child diagnosed with ASC may face difficulties in day-to-day living and social activities due to the child's potential language difficulties, toileting and eating habits and behaviour issues such as 'obsessions' and 'aggression' (Gray, 1994; Gray, 1997). These difficulties are postulated as potentially part of the reason why research has shown that parents of children diagnosed with ASC tend to report higher levels of stress, lower family cohesion, more negative appraisals, less positive appraisals and more difficulty with adjustment than families of children with other diagnosed 'disabilities' or no diagnosed 'disabilities' (Konstantareas & Homatidis, 1989; Koegal et al 1992; Orr, Cameron, Dobson & Day, 1993; Sanders & Morgan, 1997; Donovan 1998; Sivberg, 2002; Duarte, Bordin, Yazigi & Mooney, 2005; Higgins, Bailey & Pearce, 2005; Trute et al, 2007). Additionally research has shown that parents of children with a diagnosis of ASC report difficulties in relationships with extended family members due to perceived criticism of parenting and denial of the ASC diagnosis (Gray 1998).

These differences in impact are especially evident when comparing ASC with other diagnostic groups such as mothers of children with a diagnosis of Down's syndrome (Holroyd & McArthur, 1976; Sanders & Morgan, 1997). When comparing these groups, families with children diagnosed with ASC have been found to report more family conflict, more negative appraisals and less positive appraisals (King et al, 2009). When comparing these two diagnoses with cerebral palsy, ASC still fares the worst, with parents reporting more 'behaviour problems' and mother's lower well-being than parents of children diagnosed with either Down's syndrome or cerebral palsy (Blacher & McIntyre, 2006).

Similar to research with children with other diagnoses, the presence of identified ‘behavioural difficulties’, particularly those that involve ‘aggression’, ‘violence’ or ‘severe obsessions’ have been reported to be more likely to have a detrimental effect on parent’s distress and stress levels (Gray, 2002).

It has been found, however, that some of the ‘negative’ effects improve over time (Gray, 2002). This could be partly due to parent’s reports of less difficulty with behaviour and communication problems over time (Gray, 2002), which could be due to actual improvement in the child’s behaviour and communication, or possibly due to parent’s increased understanding and management or having different expectations of their level of communication or behaviour (Gray, 2002).

It is my contention that given negative societal appraisals of ‘non normative’ families, too much emphasis has been placed on ‘negative’ effects of a child’s ‘disability’ on the family.

Positive impact of ASC diagnosis

In terms of the effects of ASC on families, some research has found that parents report a similar level of family cohesion as ‘typical’ families (King et al, 2009). In addition parents of children with a diagnosis of ASC in elementary school report similar levels of family conflict as ‘distressed families’ and parents of children diagnosed with ASC who are high school age, reported levels of conflict that were lower than ‘distressed’ and ‘typical’ families (Moos & Moos, 1986, as cited in King et al, 2009). Another reported positive effect of parenting a child diagnosed with ASC includes mother’s high ratings of affection between themselves and their adolescent or adult child (Orsmond, Seltzer, Greenberg, Krauss, 2006).

Coping, meaning making and family adjustment

Bristol (1984) found that families who have close bonds, who provide support for one another and who communicate emotion adapt to the stress of caring for a child diagnosed with ASC better than families that do not have these characteristics. In addition, Seligman and Darling (2007) postualte that the most optimum way of managing and coping with a child diagnosed with a ‘disability’ is to balance between coping styles that involve disengagement and coping styles which involve more enmeshment’. Therefore it seems that a balance of adaptability and cohesion characterises a ‘well-functioning’ family (Seligman & Darling, 2007). Families that adjust well to difficult circumstances are often viewed as being ‘resilient’. Resilience, in a similar way to stress is related to a variety of factors which can influence how a family manage in difficult circumstances. These are likely to include both internal factors, such as personality of individual family members, as well as external factors, such as what resources and support networks the family have.

The family adjustment and adaptation response model (Patterson, 1988) could provide a way of linking traditional views on stress and resilience (Patterson, 2002). This model postulates that family stress occurs when demands outweigh capabilities and family adaptation occurs when demands and capabilities are balanced, which seems to be mediated by meaning making. This meaning making, therefore, appears to determine whether the family is able to utilise some of the capabilities, such as resources or coping behaviours (Patterson, 1988).

This theory of family adaptation and adjustment has been explored within research literature regarding families of children with chronic health conditions. For example, Trute et al (2007) found that parents appraisal of the family impact of the disability and levels of parental self-esteem predicted family adjustment in the long-term. This demonstrates that families can change their world views concerning life and disability and learn to see the positive contributions made by their child to other family members and to the community (King et al, 2006). These family belief systems and world views may provide a stable base and a shared sense of meaning that may help families to have stronger bonds (McCubbin & McCubbin 1986) and guide decision making (Rolland 1994; Kumpfer 1999).

One study investigating families of children diagnosed with ASC specifically with regard to meaning making, used Personal Construct Psychology and repertory grids to examine constructs of mothers in relation to perceived stress (Sharma, Winter & McCarthy, 2013) They found that mothers reporting higher levels of stress related to difficult behaviours also reported greater discrepancies in their construing of ‘the autistic child’ and their child ‘imagined without autism’ and this was not related to the child’s ability level. It seemed therefore that the more the mother perceived ‘abnormality’ in the child the more stress she was likely to report. This highlights the importance of meaning making and thought processes in how families cope with and adapt to having a child diagnosed with ASC.

Internet use and blogging

It has been proposed that one way that families of children diagnosed with a ‘disability’ make sense of their situation is to use the internet (Reinke & Solheim, in press). One relatively new area of enquiry is examining the content of internet blogs. A blog (short for weblog), as defined by the Oxford English Dictionary, is a personal website or web page which links to other pages regularly, on which an individual records opinions (Oxford English Dictionary, 2014). An additional definition by Herring, Scheidt, Wright and Bonus (2005) describes blogs as regularly updated internet pages with entries in reverse chronological order. Blogging has become more and more popular, with an estimated 10% of all online adults in the United States of America (USA) maintaining an online blog or journal (Lenhart, Purcell, Smith & Zickuhr, 2010).

Expressive writing has been shown to be beneficial, possibly due to the increased self-talk and awareness as well as being potentially cathartic, assisting with distancing and helping to organise thoughts (Wright & Chung, 2001; Pennebaker, 2004; Kerner & Fitzpatrick, 2007). It has also been found that interpersonal dialogue can help to make social abilities clearer and reflect a person's behaviour within relationships (Daiute & Buteau, 2002). In addition blogging has also been found to have other benefits, such as feeling a sense of community and social support (Ko & Kuo, 2009; Boniel-Nissim & Barak, 2013).

People blog for a variety of reasons but some research has found five main reasons; documenting one's life; providing commentary and opinions; expressing deeply felt emotions; articulating ideas through writing; and forming and maintaining community forums (Nardi, Schiano, Gumbrecht, & Swartz, 2004).

Blogging about health

Research has shown that approximately half of Americans that blog have blogged about health (Envisions Solutions, 2008, as cited in Lu, 2013). It is felt that blogging can be a form of expressive writing for some people and the sense of anonymity can help people who blog to feel more able to express their feelings, whilst being protected from stigma (Bargh, McKenna, & Fitzsimons, 2002). Research has also investigated people with Asperger's syndrome who blog and found that many reported that they are happy with themselves and identify as an 'aspie', however, there was also anger and frustration at others who want to change them (Clarke & van Amerom, 2007).

Blogging and parents

Research has found that approximately 133 million journals exist online and of these journals around 16% of men and 36% of women focused on updates regarding the family (Sifry, 2008, as cited in Lopez, 2009). Parent blogs, often referred to as 'mommy blogs', due to the larger proportion of women who use them, often contain many reflections on aspects of identity and parenthood (Morrison, 2010a, 2010b). It has been found that common theme include 'cute' stories about their children, self-deprecating stories about themselves and thoughts on parenthood within modern society, There are also themes around the sense of building a community online and asking for advice regarding solving problems or dilemmas, as well as grappling with a new identity and role as a mother (Morrison, 2010a, 2010b). It is important to note, however, that it is unclear from the research by Morrison (2010a, 2010b), how the analysis was carried out and which methods were used, therefore the analysis may not have been rigorous and the results will need to be interpreted with caution.

It has been suggested that one of the reasons why blogging may be so popular amongst parents is due to the physical distance that is often present in modern society between parents and their own families and support networks. This can result in lack of adult company and feelings of isolation. It is proposed, therefore that blogging may be a way of reaching out to others and finding other forms of support outside the family (Heisler & Ellis, 2008).

There has been very little research in the area of parents with children with disabilities who blog. There has, however, been discourse analysis of blogs written by parents of children diagnosed with Attention Deficit Hyperactive Disorders (ADHD) and/or Attention Deficit Disorder (ADD). It was found that parents use blogs to discuss medication use, their views on ADD and ADHD as a diagnosis and their feelings of being ‘experts’ in the pharmaceutical side of the diagnosis (Clarke & Lang, 2012).

Internet use, blogging and parents of children with ASC

Parents of children diagnosed with ASC may be more likely to need to feel social support and express their feelings due to some of the difficulties that can occur when raising children with additional needs. As previously stated, this has been found to include increased risk of ‘stress’, ‘anxiety’, ‘depression’ and personal changes, such as effects on career opportunities and development.

Research has shown that parents of children diagnosed with ASC often use the internet as a virtual support group (Huws, Jones & Ingledew, 2001) and online support is often sought as a way of finding other people in similar circumstances. Recent research that involved using Interpretive Phenomenological Analysis (IPA) to analyse interviews of parents of children diagnosed with autism who use the internet for support found themes, regarding constant seeking of answers and needing to be connected and be understood (Reinke & Solheim, in press), suggesting that these parents may have been using the internet to find information but also to connect with others who may understand them.

In terms of blogs specifically, previous research (Fleischmann 2005; Fleischmann & Miller, 2007) has examined blogs of parents of children with a diagnosis of ASC using grounded theory to examine the narrative process of adjustment that parents undertook throughout their blog. This research focused mainly on ‘coping’ and how a narrative developed over time. They found narrative themes including family relationships, the process of receiving the diagnosis, warning signs in the child’s development, family roles, parental coping, family impact on the coping process and the role of the meaning of the story.

Rationale for the present study

The majority of previous research has been quantitative and with a heavy focus on the negative impact on the family, with the person diagnosed with ASC seen as a ‘stressor’ rather than a family member. It has also focused mainly on mothers. However, there has been a more recent shift towards qualitative methods and focusing on some of the more positive aspects of family experience. Examining the internet and blogs is a relatively new area of enquiry and there has been very little research that has investigated how parents of children with ASC use the internet. The research that has been conducted has focused mainly on ‘coping’ and seeking support. There have been even fewer studies that examine blogs of parents of children diagnosed with ASC and the research that there has been has examined narrative themes that develop over time in blogs. Although this prior research has highlighted narrative themes that include family roles and relationships, there has been no investigations of blogs that focus specifically on these aspects of parent’s experiences.

The clinical relevance of research within this area is that there are a wide range of responses to having a child who is diagnosed with ASC and it is important to investigate the range of responses to a family member receiving a diagnosis, both on an individual and family level, rather than just focusing on the ‘negative’ aspects (Trute & Hiebert-Murphy, 2002). Family variables and the family system have also been found to play a central role in the course of a child’s development and developmental outcomes (Hauser-Cram, Warfield, Shonkoff & Kraus, 2001), and the child’s development and difficulties in turn can have effects on the family itself. In addition, the themes that emerge when an individual describes themselves and others may give information about how parents who have a child with a diagnosis of ASC makes sense of the world and in turn how this may guide their decision making processes. As clinicians it is important that we are aware of these processes as they could affect how parents interact with their children, family members and clinicians and how they seek help, manage difficulties and make decisions.

An additional consideration is the far reaching implications of blogs that are read by other parents who have children with a diagnosis of ASC. The influence of such blogs on others may be important for how others may see themselves and their family members, when comparing their lives to the lives of the bloggers. From research, it is clear that many blogs can be a source of information and social support for people and therefore it is important to have more awareness of the content of these blogs.

Research Aims

The present study aims to extend research that has examined blogs written by parents of children with a diagnosis of ASC previously (Fleischmann 2005; Fleischmann & Miller, 2007). This previous research found some narrative themes related to family impact, roles and relationships and the aim is to focus further on these themes in the present research. The present research will also use a different qualitative method to prior research, and thematic analysis will be used to focus on themes present at the beginning of the blog, rather than examining the changing narrative and ways of coping over time.

Research Questions

- What themes emerge when parents of children with a diagnosis of ASC write about themselves when blogging?
- What themes emerge when parents of children with a diagnosis of ASC write about their children when blogging?
- What themes emerge when parents of children with a diagnosis of ASC write about their family relationships when blogging?

CHAPTER 3: METHOD

Overview of the chapter

The rationale, aims and research questions were outlined at the end of the last chapter. This chapter will begin by outlining the research design and the reasons for choosing a qualitative approach and thematic analysis in particular. It will go on to discuss the procedures that were undertaken in terms of data collection, sampling strategy and data analysis. Participants will be briefly described and ethical considerations will be outlined.

Research design

The design was a cross-sectional thematic analysis of six to twelve months of entries on eight blogs written by people who identified themselves as the parent of a child with a diagnosis of ASC.

Why a qualitative approach?

The methodology of the research is qualitative, as it aims to examine themes of relationships with self, child and family in blogs written by parents of children who are diagnosed with ASC.

Through staying as close to individual’s experience as possible, qualitative techniques aim to understand lived experience (Elliott, Fischer & Rennie, 1999). They can explore facilitators of change and potential barriers to any change (Starks & Brown-Trinidad, 2007) and are particularly suited to research of an exploratory nature, therefore well suited to research exploring themes of familial relationships in parents of children with autism who blog.

Choosing a specific qualitative method of analysis

Thematic content analysis (TCA)

The present study does not involve any interviewing or co-construction of data, therefore it seemed more appropriate to use a qualitative method which is thematic in approach.

TCA was therefore chosen and an additional consideration was that it is a technique that can be used across a variety of theoretical frameworks and epistemologies, including constructivist paradigms. Constructivist ideas consider dominant societal discourses as well as experiences, meanings and realities (Braun and Clarke, 2006). Thematic analysis attempts to capture these experiences by coding the data and looking for emerging themes in order to build understanding from the data itself (Charmaz, 2006).

I will now present a brief overview of other qualitative techniques and the reason why thematic analysis was more suited to the present study than the other listed methods.

Discourse analysis (DA)

Discourse analysis investigates how language is used to construct relationships and identities (Starks and Brown-Trinidad, 2007). This approach, therefore, lends itself to social constructionist research. Although the present study investigates identities and relationships within a social constructionist framework, language is not the focus of the research, instead it is an exploratory study of themes that emerge through the description of identity and relationships. It is perhaps prudent when investigating an area with a dearth of research, to first begin with descriptions of the content of themes that emerge within the area, before moving on to analysing the language that is used and how the content is discoursed and presented. As such, thematic analysis is more suited to the research area, given this method tends to remain closer to the data, and explores content rather than discourse, whereas discourse analysis allows the researcher more freedom to interpret data and its linguistic positioning (Braun & Clarke, 2006). It may, however, be interesting for future research to investigate use of language by using discourse analysis to analyse internet blogs with this population. This may be especially pertinent, given the possible disparity between lay and professional discourses with respect to families of children who are diagnosed with ASC.

Interpretative Phenomenological Analysis (IPA)

TCA and IPA have similarities in that they attempt to describe lived experience. IPA, however, is best understood within a phenomenological epistemology (Smith, Jarman, & Osborn, 1999; Smith and Osborn, 2008), which tends to use interviews conducted by the researcher themselves and preferably within the context where they experience the phenomenon (Starks and Brown-Trinidad, 2007). The present research is instead examining themes within a naturally occurring context of the internet and the researcher will be analysing written text posted at a particular point in time. This means that the researcher will not be conducting interviews or personally collecting the data, nor interacting with participants in order to understand ‘deeper’ experiences, as interpreted by both participants and researcher.

Narrative analysis

Narrative analysis involves focusing on the way that people interpret their world through stories that they privilege and tell themselves and others (Riessmann, 1993; Wells, 2011). This is an approach that could have been used for the present study, as there are elements of story-telling within blogs. However, the present study was not focused on change over time but on particular aspects of experience, namely family relationships which were likely to be outlined at the beginning of each blog.

As this is a relatively new area of enquiry, it was felt that it was important to first explore themes using thematic analysis, in order to ascertain *what* parents write about when blogging, before moving on to narrative analysis and other techniques such as discourse analysis to analyse *how* parents use stories and language to communicate.

Grounded theory (GT)

Thematic analysis and grounded theory are similar in terms of the process of analysis, however the theoretical basis of these methods does differ. Grounded theory methods use selective coding in order to attempt to create a theory from the data and is deductive to an extent (Braun & Clarke, 2006). This approach, therefore, does not sit well within a social constructionist stance, which attempts to create a summary of the data, as it emerges from participant accounts and is therefore more inductive in nature. As mentioned in the introduction, the present study will use a social constructionist stance in an attempt to understand experiences of parents through examining themes which emerge from the data. It is, of course, impossible to remain neutral, as any analysis will be influenced by the researcher's own position, history, assumptions and so on. In an attempt to acknowledge these positions which influence interpretation, the research will be approached in a self-reflexive way and a reflexive journal will be kept (Burr, 2003), a self-reflexive section was presented within the introduction and a further section will also be presented within the discussion.

Quantitative vs Qualitative thematic analysis

The present study attempts to explore meaning, rather than quantifying individual experiences. As this is a relatively new area of research and is not seeking definitive answers, it seems that the most effective way of capturing the data will be through analysing as richly and deeply as possible. This richness may be lost through examining the frequency of themes as opposed to the meanings of data in blogs.

Procedure and data collection

Participants were not recruited as the researcher examined pre-existing information written on blogs on the internet. This method was chosen because of the ease and speed of recruiting participants via the internet in past studies (Smith et al 1999) and the richness of data provided within this medium. Furthermore, the analysis of such public lay data may provide helpful findings for both lay and professional groups working with children with a diagnosis of ASC.

Sampling strategy

Blog selection

The first stage of sampling involved searching two search engines; 'google' and 'bing' (exact wording of this search will not be reported here in order to protect identities). The results from the 'bing' search engine provided a lot of overlap with the 'google' search and less accuracy than 'google', therefore it was deemed unnecessary to use two search engines. The 'google' search yielded 18,800,000 pages. Webpages identified in this search were initially explored in order to determine if they were written by a person who identified themselves as a parent of a child with an Autism Spectrum Condition (ASC). Those websites which were not clearly written by parents of children with ASC were not selected for further analysis. Furthermore, websites which did not contain personal narratives but were designed for information giving were not analysed further. One-off blogs and newspaper articles were not used due to the limited data they contain.

Google prioritises webpage findings in descending order of relevance from most to least relevant regarding the entered search terms. The relevance of documents in 'google' is ascertained by giving websites a relevance score, which determines the order in which they are presented. Part of the relevance score is also regarding the popularity of a website by determining the number of others that have set up links to the website, which is known as 'link popularity' as opposed to 'click popularity' that is more open to manipulation (Brin & Page, 1998; Meric et al, 2002; Barroso, Dean & Hölzle, 2003).

Websites which are presented earlier in the web search are therefore likely to be more relevant and popular than those that are presented later in the web search. In addition these pages are most likely to be read by other parents searching for blogs, as they are the first to emerge when searched for and therefore are also likely to be those with the most active writers and/or readers.

A one year period of blogging was chosen in order to account for any possible seasonal variation across the year. Given the amount of data provided within one year of blogging entries and the depth of analysis required, a maximum of eight blogs was set, as this was deemed manageable whilst providing enough data for analysis, given the time constraints of the research.

Blog extraction

The next stage of sampling involved extracting the first twelve months of entries on the first eight blogs that fulfilled the criteria and transferring them into word documents. Personal data such as location was anonymised and pseudonyms were created for people that were named. The reason the first twelve months of entries was selected, rather than the most recent twelve months, was because it was felt that they would contain more descriptions of self and family, by way of introduction and orientating readers to the blog, therefore being more relevant to the research questions of this study. For this reason any biographical or introductory information on other parts of the website were also analysed.

This extraction of twelve months of entries from eight blogs yielded over 2,000 pages of data, which it would not have been possible to analyse in detail for the purposes of the present study. Blog 1 was therefore used as a pilot study to allow a decision to be made about whether to analyse fewer blogs or more blogs over a shorter period of time. Twelve months of data from Blog 1 was therefore examined using the data analysis method presented below and the first and second six months of entries were then compared. They were deemed similar enough to thematically analyse only six months of the other seven blogs (see Appendix 2). Although it may be the case that other blogs may differ across their first and second six months of a year's posting, the decision was made to rather analyse a larger number of blogs over a shorter period of time.

Participants

Detailed demographics of participants were difficult to ascertain due to the nature of the blogging websites. Where this information was available, this has been reported, although names have been changed to pseudonyms and only general locations have been reported to ensure anonymity.

Blogs that were used were those containing narrative written by individuals that identified themselves as being a parent of a child with an autism spectrum condition. No other inclusion or exclusion criteria were applied.

Data analysis

In order to be systematic the research followed guidelines outlined by Braun and Clarke (2006). This provides a rigorous way of analysing data for patterns by developing codes and themes.

Stage 1: Overview of all 8 blogs

The twelve month excerpt of blog 1 and six month excerpts from the other seven blogs extracted using the method above were read individually in their entirety at least twice in order to familiarise the researcher with the data. During the second read through sentence by sentence coding of initial ideas, interpretations and thoughts that emerged were written into the margin on the left hand side. Writing initial thoughts regarding the data is a way of ensuring self-reflexivity and keeping track of biases and assumptions that emerge during the analysis.

The next stage of Braun and Clarke's (2006) method of thematic analysis involves coding features of interest, however due to the amount of data (over 1,000 pages), it was not possible to do this for all eight blogs. Therefore at this stage a list of potential codes was made and these codes were compared and contrasted. Thematic maps were produced based on this broad overview of all eight blogs, in order to examine and demonstrate potential links between themes and ascertain which themes may be overarching and which may be subordinate. This was ascertained by returning to the blogs to check the maps fit with the data. The first half of the blogs, which were the most salient and relevant based on the google search (blogs 1-4) were then read again to examine these initial codes and the thematic maps were revised accordingly.

Stage 2: Case studies

Two blogs were selected as case studies to be examined in further depth and detail. These two blogs (blogs 2 and 3) were chosen due to their differing views in relation to the overarching themes identified during stage one as illustrative case studies of these thematic differences. Appendix 3 demonstrates an overview of some of the similarities and differences between blogs 2 and 3 on the three overarching themes from Stage 1. These two blogs were read again and coded on a sentence by sentence basis, with codes for this stage written in the right hand margin. A list of these codes was made, which included the number of sentences within each blog that contained that code. This list of codes was then examined and collated into potential themes (see Appendix 4 for the list of codes and Appendix 5 for the process of collapsing these codes into themes). This was completed in the same systematic way for both of the blogs being analysed.

Once themes were ascertained for these two blogs, they were reviewed to see if there was enough data to support them, if they could be broken into separate themes or if themes could be further merged. Themes were then further defined and named (Braun and Clarke, 2006) and thematic maps were produced to demonstrate overarching and subordinate themes. Codes, themes and thematic maps were regularly compared with one another (Guest, MacQueen, & Namey, 2012) and were independently checked by the primary research supervisor and field supervisor, in order to ensure reliability.

The aim was not to provide themes and codes that reflected the entire data set but rather to provide deep and rich descriptions focused on the research questions, namely the self-concept of the parent and family relationships as presented by the parent (Braun & Clark, 2006). The research did not have a pre-existing coding frame and an inductive data-driven approach was used (Braun & Clarke, 2006). Although there were research questions, these were not used as a framework but rather the aim was to code each sentence of each blog, even if it was not related to the research question. This was in order to allow the data to emerge without expecting particular answers, whilst being aware that the researchers own position influences interpretation, therefore reflecting on this regularly.

The aim was to move beyond these descriptive themes and codes by using psychological theory and previous literature to provide interpretations of potential meanings of the themes (Patton, 1990). Due to the social constructionist stance of the researcher, this interpretation is not necessarily regarding individual focus and motivation but rather assumes that such experiences and meanings are interpreted through relationships with society and are enabled by certain social conditions (Braun and Clarke, 2006).

Throughout the analysis and subsequent write up a reflexivity journal was kept. This was due to the subjective interpretive nature of this type of research, making it necessary to be aware of reflections.

Ethical considerations

The study received ethical approval from the University of Hertfordshire's Health and Human Sciences Ethics Committee (see Appendix 1).

Internet research

Legal guidelines suggest that internet content can be used for research if the website is in the public domain (Eysenbach & Till, 2001). The British Psychological Society code of ethics and conduct also states that consent is not necessary when observing others if people would 'reasonably expect to be observed by strangers' (British Psychological Society, 2013).

Consent and confidentiality

Given these guidelines, there was no need to gain informed consent for participation in the study from those who write the blogs. It was also felt that many parents who blog do so in order to share information and their experiences with others and therefore this research may actually assist in this process and does not appear to contravene these aims and principles.

It was important, however, that only blogs that were easily available and accessible via search engines were used. Websites and blogs that required a password, subscription or membership were not included in this research, in order to not invade privacy (British Psychological Society, 2013). For the same reason, where names or personal details such as location were used, these were anonymised by using pseudonyms and removing certain details, in order to maintain anonymity. In addition, the website address is not published alongside the data.

All of the blogs researched are still currently active, therefore when the research is published the particular search term used to search for the blogs will not be included and paraphrased quotations will be used in place of direct quotes to ensure that the data cannot be traced back to individual blogs (British Psychological Society, 2006).

CHAPTER 4: RESULTS

Overview of the chapter

The first stage of the results section involves a presentation of the qualitative themes which emerged from the surface Thematic Analysis of all eight blogs. This overall analysis is presented in order to provide context for the second stage of this section.

The second stage of the results section involves more detailed Thematic Analysis of two of the blogs, which were used as case studies, chosen due to representing differing perspectives on the three overarching themes found during the first stage of analysis.

Stage 1: Thematic Analysis of all 8 blogs

The first two tables presented give an overview of the demographics and general information contained in all 8 blogs. In addition a third table demonstrates an overview of all the three themes, as well as emerging sub-themes and sub-components which surfaced during the initial surface analysis of all 8 blogs. Each theme is then presented in a thematic map (Figures 1-3), demonstrating the relationship of themes to sub-themes and sub-components. Furthermore each theme is explained in a written description, and a table with paraphrased quotations from the data (Tables 4-6).

Stage 2: More detailed Thematic Analysis of 2 blogs used as case studies

Figure 4 demonstrates an overview of the superordinate theme, its two subordinate themes and further sub-themes, which surfaced during the thematic analysis of two studies used as case studies. Table 7 provides a further breakdown of the subordinate themes, including sub-components. Both subordinate themes are then presented in a thematic map (Figures 5 and 6), demonstrating the relationship to sub-themes and sub-components and also in a table containing paraphrased quotations from the text. Furthermore each subordinate theme is explained in a written description and the two blogs used as case studies will be compared and contrasted in terms of their thematic structure and emphasis.

Stage 1: Thematic Analysis of all 8 blogs

Table 1 demonstrates an overview of the main features and demographics of all 8 blogs analysed. All of the parents had sons and the majority of the blogs were written by mothers (75%) based in the United States of America (75%), although there were also representations from Canada and New Zealand. Three of the parents (37.5%) did not have any other children, one parent (12.5%) had an older son with developmental delay, another parent (12.5%) had two sons with an Autism Spectrum Condition (ASC) and the final three parents (37.5%) had a younger son with no diagnosis. Half of the parents did not state the severity of ASC that their child experienced (50%). Of those that did state the severity, one stated that it was ‘mild’ (12.5%), one stated that it was ‘moderate’ (12.5%) and two stated that it was ‘severe’ (25%). Interestingly both fathers felt that the severity of the diagnosis had changed over time, one from mild to severe and the other from severe to mild. In addition three of the parents (37.5%) mentioned co morbidities including ADD (12.5%), ADHD (25%) and food allergies (12.5%).

In terms of the reason for blogging, many parents mentioned more than one reason. Half of parents (50%), stated wanting to benefit others by inspiring, helping or informing. Others mentioned benefits to society in general and the ASC community specifically, by promoting ASC for those unfamiliar (12.5%) and benefits to the online ASC community by strengthening and promoting understanding and acceptance (12.5%). There were also stated reasons which included benefits to self, such as ‘ranting’ (25%), fun diversion (12.5%), way of tracking child’s development (12.5%), celebrating (12.5%) and therapeutic benefits (12.5%). Finally one parent (12.5%) was blogging as it was suggested as being potentially beneficial by a therapist, whilst they were undergoing a new therapy.

Table 1: Summary of main features and demographics of all 8 blogs

	Blog 1	**Blog 2**	**Blog 3**	**Blog 4**	**Blog 5**	**Blog 6**	**Blog 7**	**Blog 8**
Length of analysed part of blog	148 pages (54,000 words)	58 pages (24,000 words)	48 pages (19,000 words)	172 pages (66,000 words)	300 pages (136,000 words)	125 pages (47,000 words)	27 pages (11,000 words)	171 pages (73,000 words)
Mother/Father?	Mother	Father	Mother	Mother	Mother	Mother	Mother	Father
Dates	Feb 2005- Feb 2006	Apr-Oct 2011	Aug 2007- Jan 2008	Jan-July 2011	Oct 2012- April 2013	Oct 2010- April 2011	July-Dec 2004	May-Nov 2010
Blogging until?	April 2014	August 2014	March 2014	March 2014	May 2014	August 2014	July 2014	July 2014
Location	USA	USA	USA	USA	USA	New Zealand	USA	Canada
Relationship status	Living with child's father	Living with child's mother	Living with child's father	Living with children's father	Living with children's father	Living with children's father	Living with child's father	Living with children's mother
Child age & gender	Male, age 6	Male, age 8	Male, age 5	Males, aged 5 & 8	Male, age 4	Male, age 5	Male, age not stated	Male, age 5
Time since diagnosis	Not stated	6 ½ years	2 years	3 years for both	2 ½ years	2 years	Not stated	2 ½ years
Siblings?	None	None	None at the time of analysis, FAQ section says she had another later	Two children with ASC	Older (age 6), developmental delay but caught up	Younger (1 year), no diagnosis	Younger (age 3 ½), no diagnosis	Younger sibling (age 3), no diagnosis
Severity	Not stated	Severe (previously mild)	Moderate	Not stated, except that one more severe than other	Severe	Not stated	Not stated	Mild (previously severe)
Co-morbidity	Possible ADHD	ADD and ADHD		Food allergies				
Reason for blog (quotations paraphrased to protect identity)	"I thought it may be an enjoyable distraction and perhaps a useful way to note Adam progress."	"...my wife dislikes my MOANING about ASC so much on social media. ...page which is anonymous so I can moan about ASC and rejoice in my son" "...if I can earn a bit of money it will make it easier"	"This is where I moan about the mad life of bringing up a child with ASC... I tell it all; honest, raw and sometimes not very pc…it's therapeutic"	"I decided to impart my experience in order that others may find an easier path with their children." "...it's possible to make some money doing something I love."	"to aid other parents of children with ASC." "...to pay for my child's tuition fund and to...purchase something nice for myself."	"...for others to enjoy and be entertained and to provide information, as well as being revealing for those with no experience of autism."	"Therapists suggested I write a journal throughout therapy in order to see improvement… (Light therapy) To give information to others about the effectiveness of the therapy"	"I share experience and write anecdotes for the online ASC community to be stronger and bigger and to encourage others to accept and understand ASC."
Other/misc	Employed as lecturer	Employed in entertainment. Works flexible hours		Runs support groups	Orthodox Jew	Employed, says it is flexible but not what it is		Employed. Works from home – web developer

Table 2: Summary of views of ASC present in the 8 blogs

	Blog 1	**Blog 2**	**Blog 3**	**Blog 4**	**Blog 5**	**Blog 6**	**Blog 7**	**Blog 8**
View of ASC – potential cause	Genetic, possibly vaccines.	Vaccines not cause. No mention of other potential causes.	Genetics, vaccines & other ‘environmental insults’.	Genetics, vaccines & other ‘environmental insults’.	God’s will.	Vaccines not cause. No mention of other potential causes.	Vaccines.	Vaccines not cause. No mention of other potential causes.
View of ASC – Potential for cure/’recovery’?	Torn between recovery and acceptance	Improvement possible but not recovery.	Recovery possible	Recovery possible	At first felt that recovery was possible, later some acceptance of the permanence of the diagnosis.	Improvement possible but not recovery.	Recovery possible.	Improvement possible but not recovery.
Treatments tried	Craniosacral therapy, Occupational Therapy (OT), Medication, Relationship Development Intervention (RDI), Social Communication/ Emotion Regulation/ Transactional Support (SCERTS), Applied Behaviour Analysis (ABA), vitamins	Gluten Free Casein Free diet (GFCF), OT, ABA, Hyperbaric Oxygen Therapy (HBOT), medication, vitamins, service dog, music therapy, vitamins, anti-fungals	GFCF, other diet restrictions, OT, ABA, Speech and Language Therapy (SLT), HBOT, RDI, toxin free house, vitamins, chelation, Sensory Integration Therapy (SIT), stem cell replacement, vitamins, anti-fungals	GFCF, air and water filtration, toxin free house, vitamins, ABA	SLT, ABA, OT, respite	OT, SLT, ABA, physiotherapy, Music therapy	Sensory Learning Program/Ocular light therapy, floortime, GFCF, OT, Chelation, anti-fungals	GFCF, SLT, ABA

Overview

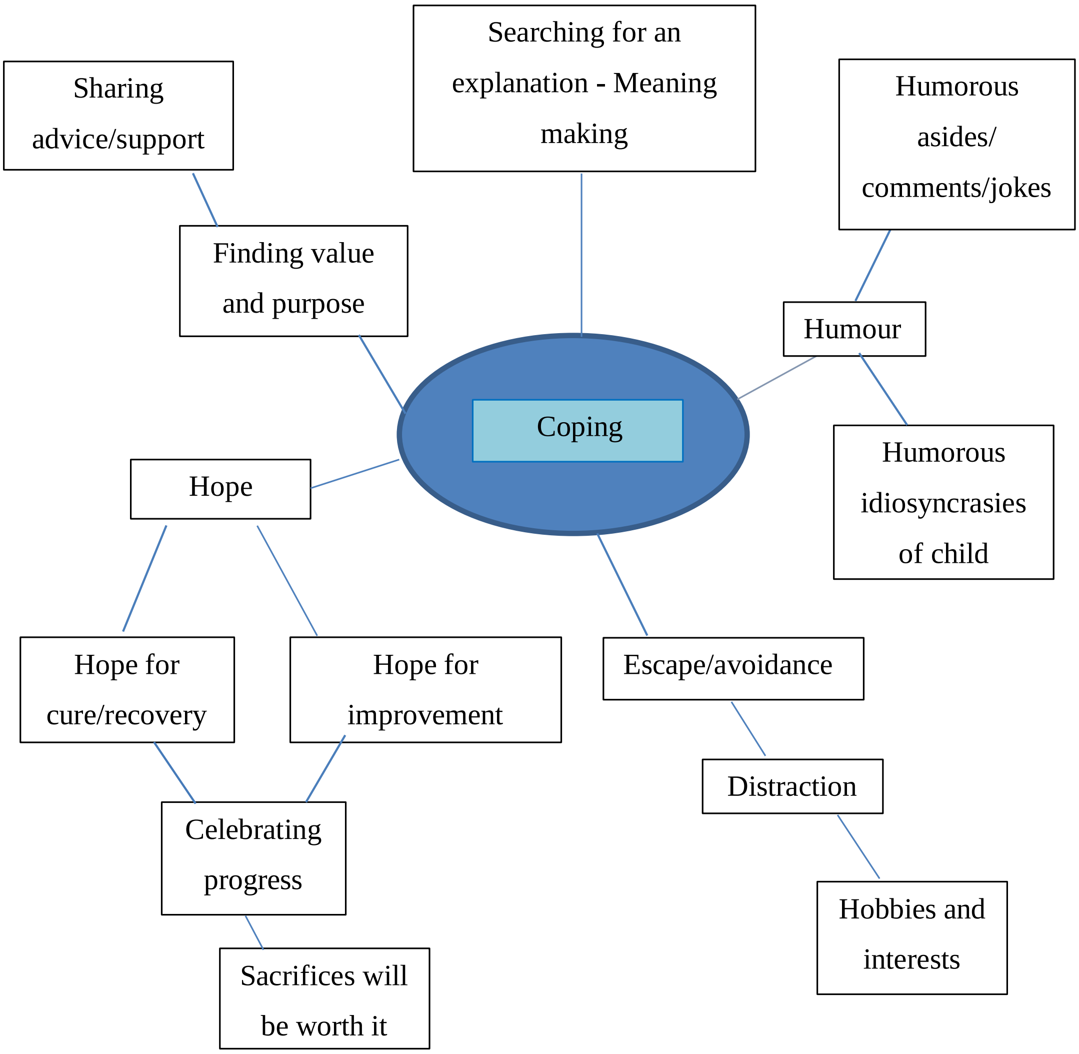
Three themes were found during the first stage of analysis, as presented in Table 3. Each of these themes is further explored below by presenting them in turn, in the form of written descriptions of each of the themes, thematic maps, which explore links between themes and sub-themes (Figures 1-3) and tables (Tables 4-6) with a small selection of quotes from the data. Further quotes are available on request.

Table 3. Overview of themes from Stage 1 of analysis

Themes	**Sub-themes**	**Sub-components**
Coping	Finding value and purpose	Sharing advice
	Humour	Humorous idiosyncrasies of child
		Humorous asides/comments/jokes
	Escape/avoidance	Distraction
	Hope	Hope for improvement
		Hope for cure/recovery
	Searching for an explanation - Meaning making	*See separate overarching theme*
Searching for an explanation - Meaning making	Making sense of diagnosis	Exploring causes of ASC
		Treatment/therapies
		Religion
		Research/reading
	Trying to understand child	Learning child idiosyncrasies
		Comparing child with others
		Learning what works
Sense of belonging vs not belonging	ASC community	Stance on debates in ASC community
		Finding a value and purpose
		Place in society
	Stigma	Normal/normality
		Attitudes of others to child/ASC

Stage 1 analysis. Theme 1: Coping

Figure 1. Stage 1 analysis. Thematic Map of Theme 1: Coping



Overview

This theme is related to how parents cope with the difficulties that can arise from having a child who is diagnosed with an ASC, such as coping with challenging behaviour, dealing with stigma and changes to lifestyle and roles. This theme incorporates coping styles used by the parents including having hope, finding value and purpose, escape/avoidance, humour, searching for an explanation/meaning making and choosing whom to trust. See written explanations and Table 4 below for further detail and for quotations from the data.

Sub-theme: Finding value and purpose

This major theme represents parent's attempts to find a value and purpose in life, seemingly as a way of coping with the challenges of parenting a child diagnosed with an ASC.

Sub-component: Sharing advice/support

Some parents specifically commented on seeing their blog as serving a purpose to others within the ‘ASC community’ and enjoying sharing advice and support with others. In addition some parent’s had particular beliefs about the cause of ASC, some of whom blamed others and spoke of campaigning and raising awareness on this subject, potentially providing a role and a purpose in life.

Sub-theme: Humour

This theme represents how humour seems to be used as a way of coping with the difficulties of parenting a child diagnosed with an ASC. There are frequent mentions of humorous incidents in their lives as well as finding humour in the child’s idiosyncrasies. In terms of the writing style used for the blog, many include humorous asides, comments and jokes.

Sub-component: Humorous idiosyncrasies of child

Many parents spoke of amusing things that their child said or did, often related to unusual use of language and unusual behaviour as a result of difficulties that they related to the ASC. This is seen by the researcher as a potential way of coping by looking at the positive and humorous aspects of the child’s experiences.

Sub-component: Humorous asides/comments/jokes

Many parents blogging style includes humorous asides, comments and jokes. The majority of the blogs use pictures, photographs and cartoons, some of which are amusing. This is seen by the researcher as a way of dealing with some of the more difficult contents of the blog by providing ‘light relief’.

Sub-theme: Escape/avoidance

Many parents mention wanting to escape from ASC and some mention feeling trapped and wanting to avoid thinking about ASC. Some parents mention coping by physically escaping the room or the house and others appear to find distractions inside the house.

Sub-component: Distraction

Many parents mention coping by using distraction as a way of escaping and avoiding thinking about ASC and the difficulties of parenting their child. For example, many parents mention having hobbies and interests, mainly within the home, such as watching television, reading books and going on the internet and some explicitly label these as a means of ‘escape’ or ‘taking a break’.

Sub-theme: Hope

Many parents mention having hope and faith and this appears to be a feeling that helps parents to cope with some of the more difficult aspects of parenting a child diagnosed with ASC.

Sub-component: Hope for improvement

Many parents write about hopeful wishes and desires they have for the future of their child and all of the blogs appear to hope for improvement in their child's perceived difficulties and 'symptoms'. All of the blogs mention progress and achievements of their child and many focus on progress with regards to these perceived 'symptoms'. Some parents mention feeling that sacrifices they have had to make, such as the financial costs, will be worth it for the achievement the child will make.

Sub-component: Hope for cure/recovery

Over half of parents go beyond hope for improvement and mention hope for cure or 'recovery' from ASC. Some parents appear to feel more certain of this than others, with two of the parents reporting feeling undecided or changing their views during the course of the analysed portion of the blog. As with hope for improvement, this sub-component included writing about celebrating progress and feeling that sacrifices will be worth it. Belief in a cause of ASC was another important aspect of this sub-component, as many parents who believed that vaccines and toxic overload caused their child's ASC appeared to have the belief that their child could be cured or 'recover'.

Sub-theme: Searching for an explanation - Meaning making

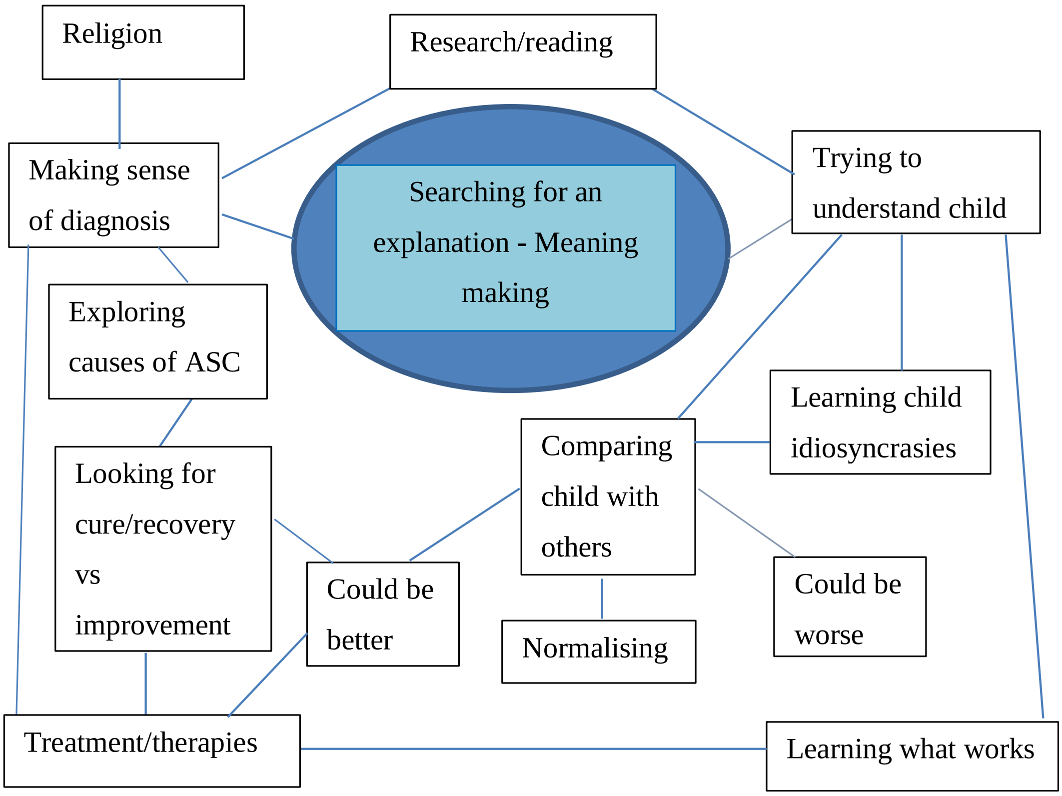
'Searching for an explanation - Meaning making' is a major theme of the overarching theme of 'Coping', as the researcher feels that meaning making is used as a way of coping with the more difficult aspects of parenting a child with ASC. 'Searching for an explanation - Meaning making' is also an overarching theme of its own, which will be explored in more detail below.

Table 4: Stage 1 of analysis. Quotations from theme 1 – Coping (quotations paraphrased to protect identity)

Theme	Sub-themes	Sub-components	Quotations
Coping	Finding value and purpose	Sharing advice	*“As I have debated the dilemma over vitamins and had some success I will give you some advice” Blog 4 p.4* *“When teaching children with autism about emotions you need to make it enjoyable, straightforward and not go too quickly” Blog 6 p.12*
	Humour	Humorous idiosyncrasies of child	*“All of the animals were busy one day when they suddenly saw Daddy – instead of “Daddy is back” Blog 1 p.16.* *“Then my son said “Hey chicken…lookin’ good!” I laughed so much I almost crashed the car”. Blog 8 p.145*
		Humorous asides/ comments/ jokes	*“My friend told me how good this silent cartoon would be for my children. Almost* **no** *speaking (insert angels singing here…)” Blog 4 p.87* *“There are happy times as well. Sometimes there is even fun within the craziness Blog 6 p.2*
	Escape/ Avoidance	Distraction	*“I need time properly away from the children and lots of chocolate, straight away. I escape the house and get into the car.” Blog 4 p.48* *“I used the computer as a sanctuary and distraction increasingly as life became more difficult.” Blog 5 p. 91*
	Hope	Hope for improvement	*“I try to get my son to be more grown up and responsible because I want him to improve and catch up and because I am sure he can.” Blog 8 p.66* *“Finally it happened, after all those promises and dreams of improvement.” Blog 5 p.178*
		Hope for cure/ ‘recovery’	*“I have been advised not to get too excited about potential improvement in case he doesn’t progress as well as he has so far, or in case of stumbling blocks but I can’t help but hope that he may completely recover.” Blog 7 p.22* *“It has been really hard but now my children are recovering and life has improved so much in the last year.” Blog 4 p. 25*
	Searching for an explanation - Meaning making (see separate overarching theme)		

Stage 1 analysis. Theme 2: Searching for an explanation - Meaning making

Figure 2. Stage 1 analysis. Thematic Map of Theme 2: Searching for an explanation - Meaning making



Overview

The thematic map above represents the overarching theme 'Searching for an explanation - Meaning making', which seems to feature in all of the blogs. All of the parents write about trying to understand the child or trying to make sense of the diagnosis. See written explanations and Table 5 below for further detail and for quotations from the data.

Sub-Theme: Making sense of diagnosis

Making sense of diagnosis seems to be a way of parents making meaning of their experiences. Many parents make sense of the diagnosis by exploring the meaning through religion or through questioning why the child may have developed ASC and finding the potential 'cause'. Reading and researching is also used by parents to find out more about other aspects of the diagnosis, such as theories of ASC and treatment and therapy options.

Sub-component: Cause

All parents mention exploring the ‘cause’ of ASC which seem particularly focused on vaccines and subsequent toxic overload, genetic causes and religious reasons. A sub-component of this sub-theme is ‘Looking for cure or recovery versus improvement’, which was explored within the ‘Coping’ overarching theme under the major theme ‘Hope’. As mentioned previously strong belief in the cause of ASC appears to influence views on whether the ASC can be ‘cured’ and also appears to influence treatment and therapy options.

Sub-component: Treatment/therapies

All parents mention treatment approaches and therapies in their blogs and across the 8 blogs there are a wide range of approaches, including ‘traditional’ such as occupational therapy, speech therapy and applied behaviour analysis as well as ‘alternative’ or ‘biomedical’ approaches such as chelation, gluten-free-casein-free diet (GFCF) and hyperbaric oxygen therapy (HBOT). There is a sense of searching for the ‘right’ therapy, especially amongst those who believe in ‘recovery’ and many parents use a multitude of different approaches over time and some a number of approaches at the same time.

Sub-component: Religion

A small number of parents mention exploring religious reasons for the diagnosis but only one (Blog 5) explicitly states feeling that the ‘cause’ of autism is directly related to religion, seeing it as a test and mission given to her by God.

Sub-theme: Trying to understand the child

Many of the parents mention attempts to try to understand their child and many parents mention speech or behaviour of their child that they find puzzling and their subsequent attempts to understand the reasons for this through learning their idiosyncrasies, comparing the child with others, research and reading and learning strategies and treatments that lead to improvement.

Sub-component: Learning child idiosyncrasies

Learning child idiosyncrasies is a sub-theme of the major theme trying to understand the child. Many of the parents report not being able to understand ways in which the child communicates or behaves and their subsequent attempts to understand the idiosyncratic way that their child interacts with the world. Throughout the blogs there are often moments of revelation or clarity where the parent has managed to ascertain the meaning of the child’s utterances or behaviour, which in turn appears to help them to predict future behaviour.

Sub-component: Comparing child with others

Comparing the child with others is a prominent theme in the blogs and includes comparing the child with other known and unknown children and adults. Some of these comparisons seem to be about striving for further improvement and feeling that the child's 'symptoms' or behaviour could be better. Other comparisons seem to be about feeling lucky and realising that things could be worse. Normalising is also used by comparing the child's symptoms and behaviour against themselves and others and seeing similarities with what they regard as 'normal' or 'typical'. Concepts of 'normal' and 'normality' will be explored later in the overarching theme 'Sense of belonging versus not belonging'.

Sub-component: Learning what works

Many parents write about finding solutions, problem-solving and finding strategies and techniques that help them to manage behaviour and symptoms of the child. Interactions with the child often mention teaching, instructing and helping the child to develop and subsequently finding out which techniques are the most effective for their particular child.

Sub-component: Research/reading

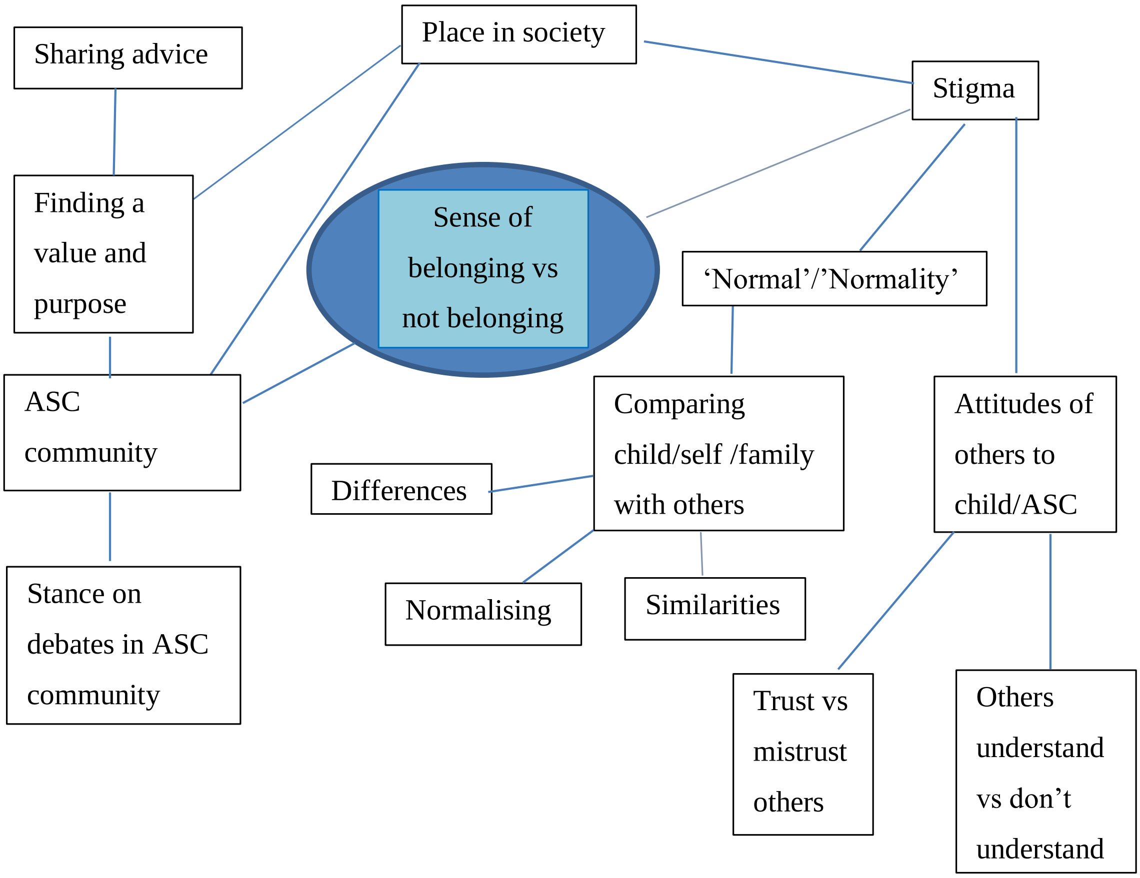
This theme is heavily featured in the majority of blogs and appears to be a way of both making sense of the diagnosis and to try to understand the child. This takes the form of reading books, articles and internet pages written by researchers and professionals, as well as by other parents. Areas that were explored were theories, potential causes and treatment options, as well as the experiences of others and appeared to allow parents to compare their child against things they have read, such as theories of ASC and other parent's experience and exploring parts of the theories, approaches, strategies and experiences of others that may be useful for their particular child.

Table 5: Stage 1 of analysis. Quotations from theme 2 ‘Searching for an explanation - Meaning making’ (quotations paraphrased to protect identity)

Theme	Sub-themes	Sub-components	Quotations
Searching for an explanation - Meaning making	Making sense of diagnosis	Exploring causes of ASC	*“I have learnt a lot over the last few years and now I do not believe the cause of autism is completely genetic. I think it is the way that the body has responded to attacks by the environment which has led to symptoms of autism.” Blog 4 p.43*
		Treatment/therapies	*“Here I have listed the key therapies we found out about and attempted. There are other little things we applied, borrowing from other approaches and theories that we studied.” Blog 6 p.31*
		Religion	*“I was meant to be this child’s parent – it was not by chance or a coincidence or punishment and not a cause for anger. It is a test but there are large, mysterious, celestial explanations – and I have no right to ask why!” Blog 5 p.101*
		Research/reading	*“I often like to read developments in research on autism.” Blog 7 p.26*
	Trying to understand child		*“I began to read between the lines, almost wrenching open the pages to work out and how he and they had got to where they are. What treatments, prayers or route had got them to this amazing place.”. Blog 1 p.5*
		Learning child idiosyncrasies	*“I can make remarkable and surprising connections by making time, recreating his world and using my theory of mind to get into his brain.” Blog 1 p.6* *“….attempting to work out what he is trying to communicate (and he is ALWAYS attempting to communicate something) is like stepping into a murder mystery.” Blog 1 p.2*
		Comparing child with others	*“What is the meaning of this? How can two people with ASC be so astonishingly alike yet remarkably different at the same time?” Blog 1 p.36*
		Learning what works	*“We have discovered that the best way is to treat them like any other child, by giving them an outlet.” Blog 8 p.114* *“Diet proved to be the most effective intervention for our children. Especially our youngest son, who started to speak only weeks after beginning a diet that excluded foods which he may be allergic to.” Blog 4 p.63*

Stage 1 analysis. Theme 3: Sense of belonging vs not belonging

Figure 3. Stage 1 analysis. Thematic Map of Theme 3: Sense of belonging



Overview

The thematic map above represents the overarching theme 'Sense of belonging vs not belonging'. This overarching theme has two main features, which includes examining sense of belonging within society in general and within the ASC community in particular. See written explanations and Table 6 below for further detail and for quotations from the data.

Sub-theme: ASC community

This theme is regarding descriptions of the ASC community, which includes the online ASC community and the sense of belonging or not belonging to this group. Many parents write about this with regards to agreements and disagreements within the ASC community and choosing a stance on debates within the ASC community. There is also a sense in some of the blogs of finding a place within society by belonging to the ASC community, particularly the online ASC community and finding value and purpose within this role.

Sub-component: Stance on debates in ASC community

Many of the parents mention the debates and factions within the ASC community, particularly with regard to people who believe in vaccines as a cause of ASC versus people who do not, people who believe in the possibility of ‘recovery’ versus people who do not and debates about the most useful therapies and treatments, including debates about whether giving traditional medication is acceptable or not. It seems that for some parents taking a side on these debates facilitates a sense of belonging to a particular group with similar views and values.

Sub-component: Finding a value and purpose

‘Finding a value and purpose’ is a sub-component within the sub-theme ‘ASC community’ and as discussed above it is also a sub-theme within the theme ‘Coping’. As discussed previously many parents wrote about wanting to share advice and support with others and it seemed that writing a blog may have helped to facilitate this. Within this sub-theme, however, finding value and purpose is not just in relation to coping but also seems to be related to having a sense of belonging to a community; the ASC community in particular.

In terms of sense of belonging within society in general, stigma is particularly featured within the blogs. Many parents comment on attitudes of others to their child, to them and to ASC in general, particularly with regards to feeling judged or misunderstood by others. This sense of stigma appears to relate to parent’s perceived place in society and whether they feel they belong or not.

Sub-component: Normal/normality

As mentioned in the overarching theme ‘Searching for an explanation - Meaning making’ under the sub-theme ‘Trying to understand the child’, parents often compare their child with other children as a way of understanding their child. In this sub-theme the comparisons are also against what parents view as ‘typical’ or ‘normal’ behaviour in society, for example by comparing the child to children of a similar age, as well as what is ‘normal’ for a child with ASC. Other comparisons are about the parents themselves and their family and comparing them against what the parents feel is ‘normal’ in society. Parents who do not feel that their child, self or family are ‘normal’ compared to other members of society, appear to have a sense of not belonging within certain parts of the society or community.

Sub-component: Attitudes of others to child/ASC

Many anecdotes shared within the blogs are about other people’s negative reactions to the child or guessing that other people’s reactions will be judgemental. The perceived attitudes of others to the child and ASC appears to influence whether or not parents feel that others understand them and whether they can trust others. This includes strangers, professionals and extended family and friends There is variability both within and between the blogs about whether other people can be trusted or not and whether other people can and do understand them, their experiences, their child and ASC.

Table 6: Stage 1 of analysis. Quotations from theme 3 - Sense of belonging vs not belonging (quotations paraphrased to protect identity)

Theme	***Sub-themes***	***Sub-components***	***Quotations***
Sense of belonging vs not belonging	ASC community	Stance on debates in ASC community	*"I am undecided between "biomedical"explanations for ASC, where people advocate treatments that concentrate on finding a cure or the "neurodiversity" explanations, where people with ASC are celebrated for being just who they are and instead concentrate on removing barriers." Blog 1 p.77* *"For the past few days social media has been full of divisive issues that separate autism "parties"… I want to battle with you, not against you." Blog 4 p.25*
		Finding a value and purpose	*"I am a parent of two children who have an ASC diagnosis and I am attempting to be vocal in my own community and make a difference." Blog 4 p.104* *"…if I continue with my very small presence in the ever expanding online ASC community, I may be able to play a small part…perhaps my very miniscule voice will provide the final part necessary to make the community voice go from unheard to changing the world." Blog 8 p.40*
		Place in society	*"Before I felt that I did not below anywhere, now it is odd but I feel like I belong anywhere. I am a mother of a child with additional needs." Blog 6 p.85*
	Stigma		*"…we need to be accepted and understood. When this happens parents and their children will not be judged…then people with autism may not feel like outcasts peering into a world where they do not belong." Blog 8 p.136*
		Normal/normality	*"He screamed and cried – that was alright, because lots and lots of typical 3 year olds do this when their hair is shaved off." Blog 5 p.173* *"He acted in the same way as normal children, like other children at the park. I talked to other parents about normal things…I felt like a fraud at first, pretending I am not the mother of a child with additional needs." Blog 6 p.84*
		Attitudes of others to child/ASC	*"If my son loses his temper and has a tantrum in public, like only a person with ASC can, I see other parents making judgements and think…if you understood, it would be different." Blog 8 p 43* *"I didn't tell anyone my child had ASC. I favoured the term delayed speech; if I trusted the person or was friendlier with them, I went a bit further and said it was PDD." Blog 5 p.25*

Summary of stage 1 of analysis

Overall the results from the thematic analysis in stage one, examining all 8 blogs, demonstrates that the parents who wrote these blogs appear to have developed many styles of coping, which include having a sense of humour, holding on to hope and finding a value and purpose in life. Parents seem to spend a lot of time trying to find answers and make sense of their experience by exploring causes and treatments of ASC, by researching and reading about ASC and by learning through getting to know their child's idiosyncrasies and comparing them with others.

Many parents, however, report a sense of feeling trapped and wanting to escape and experiencing stigma from the attitudes of others to their child. There is a sense from some parents that other people do not understand them, their child or their situation. It seems that due to this stigma and feeling different to others, many parents feel that they do not belong within general society and find it difficult to trust people, whom they feel may not understand them. It seems that sharing advice and choosing a side in debates provides value and purpose and also a sense of belonging within factions of the ASC community, whom it seems they feel have more understanding than other parts of society.

Stage 2 analysis: Two case studies

Overview

Following the first stage of analysis, two blogs (Blogs 2 and 3) were selected as case studies for further analysis. These were chosen due to presenting contrasting views on many aspects of the three overarching themes that emerged during the first stage and the desire of the researcher to investigate these differences further. Appendix 3 demonstrates an overview of some of the similarities and differences between blogs 2 and 3 on the three overarching themes from Stage 1.

During the course of the second stage of analysis, which involved analysing blogs 2 and 3 in more detail, a superordinate theme emerged, with two themes below it. The superordinate theme has the same title as a theme that emerged during stage 1 of the analysis (see stage 1 analysis). Some of the sub-components within the themes were also similar to themes which emerged from the first phase but with deeper analysis of the data, these were expanded and organised in a different way, with more emphasis on the hierarchy of these themes. There were similarities and differences between the two blogs with regard to the themes, which will be discussed. The themes are presented in Table 7 and thematic maps are presented in Diagrams 4-6 with written descriptions and tables of quotations below (Tables 8 and 9).

Figure 4. Stage 2 analysis. Thematic Map of Superordinate theme and its subordinate themes

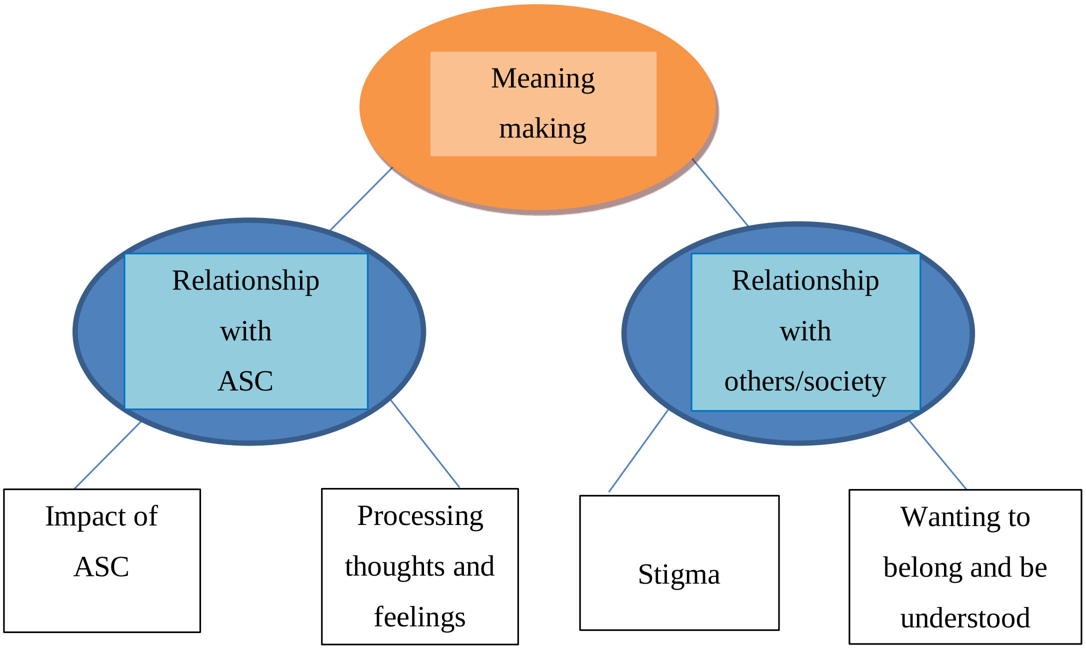
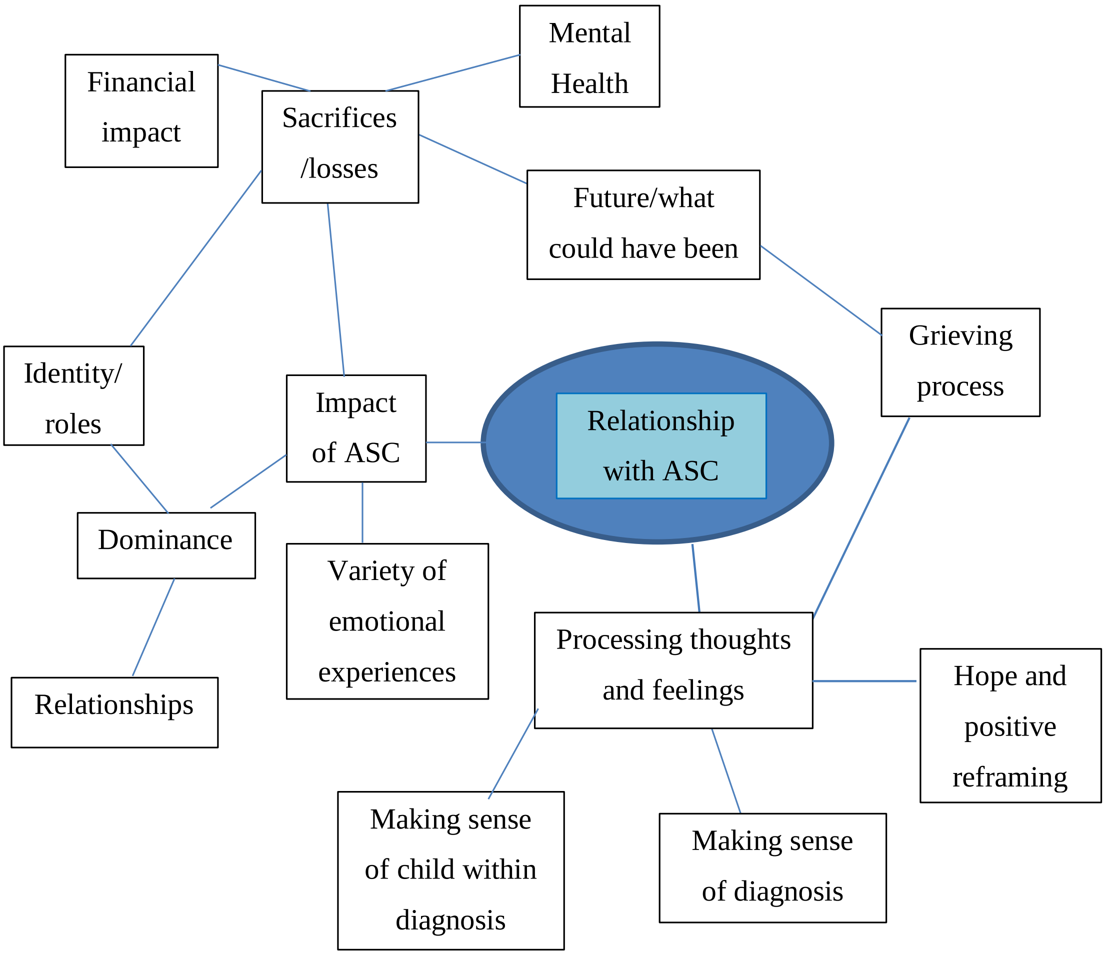


Table 7: Stage 2 analysis. Overview of themes from two case studies

Superordinate theme	**Themes**	**Sub-themes**	**Sub-components**
Searching for an explanation - Meaning making	Relationship with ASC	Impact of ASC	Dominance of ASC
			Sacrifices/losses
			Range of emotional experiences
		Processing thoughts and feelings	Making sense of diagnosis
			Making sense of child within diagnosis
			Hope and positive reframing
			Grieving process
	Relationship with others/society	Stigma	Feeling others don't understand
			Feeling different
		Wanting to belong and be understood	Finding value/purpose
			Taking a side in debates in ASC community
			Sharing knowledge and experience

Stage 2 analysis. Theme 1: Relationship with ASC

Figure 5. Stage 2 analysis. Thematic Map of Relationship with ASC theme



Overview of theme

This theme is related to the relationship with ASC demonstrated by parents in these two case studies. Sub-themes within this theme include impact of ASC, emotional processing and cognitive processing.

Sub-theme: Impact of ASC

Both of the parents spoke about the impact of ASC at length and the dominance of ASC in their day-to-day life. There was also a sense of sacrifices and losses they had experienced as a result of the ASC, although the particular sacrifices and losses and the reaction to the dominance differed between the blogs. Each of the sub-components of this sub-theme will now be considered, with particular emphasis on the similarities and differences between the two blogs.

Sub-component: Dominance

Both parents discuss the dominance of ASC in day-to-day life, such as the amount of time spent going to appointments, planning, preparing and accommodating the child's needs.

Dominance in relationships

Both blogs mention the dominance in terms of altered relationships with society due to the ASC (which will be explored in more detail in the 'Relationships with society' theme).

There are differences between the blogs, however, for example, the father in blog 2 also mentions the dominance of ASC for his wife and reports that he shares day-to-day parenting responsibility with her. There is a sense of closeness and bonding regarding their shared situation but the mother in blog 3 presents as taking the majority of the parenting responsibility and rarely mentions her partner.

Dominance in identity/roles

In addition both parents mention their identity and roles as a parent, although there are differences, with the father in blog 2 tending to emphasise his day-to-day tasks and responsibilities as a parent and the mother in blog 3 particularly focusing on her role in translating, interpreting and predicting the child's behaviour and planning and preparing with regard to the child.

Sub-component: Sacrifices/losses

Similarities between the two blogs within this theme are that both parents mention various sacrifices and losses, although the father in blog 2 mentions many more than the mother in blog 3.

Financial impact

Both parents write regularly about the financial impact of ASC especially with regard to the treatments, therapies and activities they attend.

Future/what could have been

Both parents mention a sense of loss regarding the future and their sense of what could have been if the child had not had the difficulties they experience. For example the father in blog 2 speaks of the choice that he and his wife made not to have any other children due to the difficulties experienced by their first child and the mother in blog 3 speaks about things that are much more difficult now, such as going on holiday and the loss of the possibility of grandchildren in the future.

Identity/roles

Both parents mention their roles as parent. However, there are differences between the two blogs, such as that the father in blog 2 mentions the sacrifice and loss of the professional role of his wife, who is a ‘stay at home mom’ and his own job role needing to be flexible in order to accommodate appointments and childcare responsibilities. He relates these sacrifices and losses of professional role to the dominance of the child’s difficulties. This is as opposed to the mother in blog 3, who does not mention her professional identity at all.

The mother in blog 3 does, however, mention an altered sense of identity, feeling that the difficulties associated with parenting her child and her feelings about ASC have changed her from a happy, smiling person to an *‘ugly version’* of herself, whereas the father in blog 2 does not mention an altered sense of identity.

Mental health

Both parents mention stress but only the father in blog 2 mentions his own and his wife’s mental health, stating that they both take antidepressants and anti-anxiety medication due to ‘stress related ailments’, ‘depression’ and ‘anxiety’, which he relates directly to the pressure of parenting a child with ASC. The mother in blog 3 does not mention any mental health difficulties.

Range of emotional experiences

A variety of emotional experiences feature within these two blogs. Emotions which are discussed are mainly related to the self but also feature in descriptions of the child. Frustration and irritation are mentioned regularly in both blogs, particularly with regard to people who do not understand (this will be explored in more detail in the theme ‘Relationship with society’) and happiness and joy are mentioned infrequently in both blogs with relation to own feelings.

The differences between the blogs in terms of emotional experiences are that the father in blog 2 directs his frustration and irritation more regularly towards the child and family and friends, whereas the mother in blog 3 tends to direct these feelings towards the lack of progress and professionals. In addition, although happiness and joy are mentioned equally infrequently in both blogs, the father in blog 2 does not mention feeling happy or joyful explicitly at all, although it is occasionally hinted at through positive interaction with the child and others and through enjoyable activities. Another difference between the two blogs is the dominance of anger in blog 3, where the mother reports feeling anger towards the world in general as well as specific strangers and professionals. Related to anger are feelings of incredulousness or disbelief, often related to feeling judged or misunderstood by others or due to perceived professional incompetence or ignorance, which is present in both blogs but is a large feature of blog 3 in particular.

In terms of the child’s feelings, both blogs mention the child’s feelings of being upset or distressed and descriptions of ‘meltdowns’ and ‘tantrums’ are heavily featured in both blogs. The mother in blog 3, however, mentions the child being upset and distressed much more frequently than blog 2. Another difference is that happiness and joy of the child feature frequently in the descriptions of blog 3, but are only mentioned explicitly once in blog 2, although he does regularly mention the child's smile when describing him.

Sub-theme: Processing thoughts and feelings

Similarities between the two blogs are that both parents mention some form of processing, which appears to influence their relationship with ASC and they both seem to attempt to make sense of their experiences through various thoughts processes. The main thought processes seem to involve making sense of the diagnosis and making sense of the child within the diagnosis. There are differences, however, in the particular processes that are used.

Sub-component: Making sense of diagnosis

Making sense of the diagnosis seems to be a way of processing thoughts and feelings about ASC cognitively. Both blogs mention attempting to make sense of the diagnosis, especially in terms of exploring a potential cause of ASC, seeking improvement or 'recovery' and seeking information, however the beliefs regarding these elements of the diagnosis do differ between the blogs.

Exploring the cause of ASC

This sub-theme was also present within stage 1 of the analysis and has the same label within this stage, due to the similarity of the theme which emerged from this stage of the analysis.

Both blogs mention exploring the potential cause of ASC, although the mother in blog 3 mentions exploring the cause of ASC more regularly and appears to have more definite views on the potential cause as being vaccines and subsequent toxic overload. The father in blog 2 mentions that he wants his blog free from debate, so deliberately shies away from giving his view on the cause of ASC, as it is seen as a controversial topic. He does mention his views in one post however and writes about how he feels that vaccines were not the cause of his child's ASC.

Seeking recovery/improvement vs settling/acceptance

This was previously a sub-theme named 'Looking for cure/recovery vs improvement', however, upon further analysis of blogs 2 and 3 it was renamed 'Seeking recovery/improvement vs settling/acceptance'. It was felt that this captured the striving versus settling aspects of the experiences presented in these two blogs.

Both parents write about progress and achievements that the child has made and both seem to hope that their child will make further progress in the future. Both blogs also mention the child's lack of progress or a regression in the child's skills or difficulties at times.

However, there do appear to be differences between the blogs regarding this, particularly in terms of attitudes regarding progress or lack of progress, which seems to be related to whether the parents feel hopeful or not hopeful. The father in blog 2 writes about his 'acceptance' of the diagnosis and does not seem to necessarily expect progress from his child, although he is hoping for it, in comparison the mother in blog 3 who is hoping and in fact appears to be expecting complete 'recovery' and as such reports more disappointment when there is lack of progress or a 'regression' in 'symptoms' or skills.

Seeking information

As with the analysis presented during stage 1, research and reading seem to be part of the way that parents make sense of the diagnosis and try to understand their child. The wording of this has been altered for this stage of analysis, however, as parents do not just read and research but they also ask advice of others, through their blog and from professionals. Both blogs attempt to seek information, however, they also both mention ignoring some of the advice and information they are given, due to feeling that the person giving it does not understand them or their situation. The source of the information is also slightly different, with both using the internet as a resource but the mother from blog 3 also mentioning reading books and seeking the views of one particular professional, whom she trusts.

Thoughts regarding own ability to cope

Both blogs feature thoughts regarding their ability to cope. They both comment on mistakes that they have made as well as questions they ask themselves and reports of difficulty making decisions. They also both mention their own negative personality traits which could be linked with a sense of hopelessness and powerlessness, such as blog 2 mentioning procrastination and laziness and blog 3 talking about being a negative person. Although, the father from blog 2 writes about more personal weaknesses than the mother from blog 3, he explicitly mentions that he is not worried about his own weaknesses, although he does not state why he is not worried.

In addition, they both mention wanting to escape and avoid thinking about ASC at times, although the father in blog 2 mentions this desire more frequently and appears to be able to actually 'escape' more regularly than the mother in blog 3. The father in blog 2 often talks about having hobbies and interests outside the house and finding time to spend with his partner by getting a babysitter and going out. Although the mother in blog 3 does not mention hobbies and interests, she does talk about occasionally taking breaks and allowing her husband to take responsibility when she becomes overwhelmed. In contrast to wanting to escape and avoid, both blogs also mention a desire to take control of situations, although the mother in blog 3 mentions this more regularly than the father in blog 2.

The differences between the two blogs regarding thoughts on own ability to cope, appears to be in relation to how taking control manifests differently within the two blogs. For example the mother in blog 3 writes about planning, preparing, predicting, taking risks and by trying new things. In contrast taking control in blog 2 takes the form of fighting, battling and advocating for the child and being in control by parenting in a collaborative way with his wife and sharing roles and responsibilities. These differences may be due to differences in gender roles.

Other differences are in relation to recognition of own strengths, which is mainly a feature of blog 2 and is rarely present in blog 3. This is presented in relation to personal qualities of seeing the self as organised and demonstrating determination and persistent. These thoughts in turn appear to be linked with a sense of feeling in control or wanting to take control.

Sub-component: Making sense of child within diagnosis

This sub-component was present in the analysis during stage 1 as a theme (see the analysis from stage 1 for more detail). As with analysis presented during stage 1, parents in these two blogs seem to attempt to make meaning of their experience by trying to understand their child.

Learning child idiosyncrasies

Learning child idiosyncrasies was present during stage 1 of the analysis as a sub-theme (see the analysis from stage 1 for more detail). Both parents attempt to make sense of their child by learning their idiosyncrasies, although the father in blog 2 reports spending less time trying to predict the child's behaviour and guess the child's thoughts and feelings than the mother in blog 3. It seems from the analysis that the father in blog 2 feels that on the whole he understands his child's idiosyncrasies and on the whole finds his child predictable but the mother appears to still be exploring her understanding of her child.

Comparing child with others

Both blogs feature comparisons of their child with other children with ASC and with 'typical' children in terms of seeing differences. They both also feature a sense of their child having more difficulties than other children. In blog 2 this is prominent in the frequent mention that the child has 'severe' ASC and he often compares his experience with other families and children who have 'improved' but who are not 'at the severe end'. The mother in blog 3 often mentions the vulnerability of her child, either directly by stating that he is vulnerable or by describing him as particularly small and helpless in comparison to other children. These feature may be linked to a sense of hopelessness, either that the child's difficulties are too severe to show much progress or that the child is so vulnerable that there is little hope for their safety in the future.

The differences between the two blogs in terms of comparing their child with others, is that the father in blog 2 particularly focuses on differences, especially with regard to the severity of his child's ASC, in comparison to the mother in blog 2 who mentions more similarities with 'typical' children and appears to normalise her child's difficulties more regularly. This may be related to the fact that the father is not necessarily expecting or hoping for progress and writes more about his 'acceptance' of the permanence of ASC.

Learning what works and doesn't work

As in Stage 1 of the analysis, both blogs feature an element of learning what works when they are making sense of the diagnosis in relation to their child. However, the wording has been changed slightly, following closer examination of blogs 2 and 3, to also include learning what doesn't work.

Both parents mention finding what works, often in the form of progress and achievements that the child has made and through planning and predicting the child's reactions. Both blogs also mention finding treatments and therapies that do not work. The father in blog 2 particularly mentions side effects of treatments and therapies. He speaks about having tried 'biomedical' treatments in the past and feeling that they may have been the reason for his child's regression, where the child appeared to regress from having a 'mild' form of ASC to now experiencing 'severe' ASC.

Sub-component: Hope and positive reframing

Both parents appear to have a sense of hope at times and hopelessness at other times. As mentioned previously mentions of negative personality traits, wanting to escape or avoid and wanting to take control, could be related to the sense of hope or hopelessness that the parents feel. This may be the reason why the father, who appears to have more feelings of hopelessness, also appears to have more thoughts of wanting to escape and avoid. In contrast, wanting to take control could be related to both hope and hopelessness, as feelings of hopelessness may spur a person into action, as may feelings of hope.

Both blogs also seem to use positively reframing as a way of processing their thoughts and feelings. For example, they both mention positive times and experiences that they have had with their child, positive personal qualities of the child and times where the relationship with the child is loving, caring and supportive. There are also some elements of seeing themselves as lucky and realising that their situation could be worse.

Differences between the two blogs are that although they both seem to use positive reframing, the mother in blog 3 tends to do this through normalising the child's difficulties whereas the father in blog 2 seems to use more humour.

Sub-component: Grieving process

Although both blogs mention feelings of grieving for what has been lost and what may have been, only the mother in blog 3 mentions the stages of grief specifically, which seems to be related to attempts to process her thoughts and feelings in order to make sense of her experiences.

Table 8: Stage 2 analysis. Quotations from theme 1 - Relationship with ASC (quotations paraphrased to protect identity)

Theme	**Sub-theme**	**Sub-components**	**Quotations**
Relationship with ASC	Impact of ASC	Dominance of ASC	*"Our lives are centred around Ben and his moods. If he has a good week, so do we, if he has a bad week we are at each other's throats."* Blog 2 p.12 *"My wife lives and breathes ASC 24 hours a day."* Blog 2 p.9 *"Time wise we sorta manage Ben 50/50 (alright 60/40 :-) but my wife is correct, she carries the weight of ASC and a much larger percentage mentally."* Blog 2 p.10 *"I am an ASC mum and I do nothing else; schedule appointments for assessments, treatments, call one department or another, collect results, make appointments for therapies etc."* Blog 3 p.24
		Sacrifices/losses	*"We've almost completely stopped asking our friends with typical children years ago & the same for them inviting us."* Blog 2 p.29 *"That was the time. Happy and very different. Don't misunderstand me, I don't miss high school or anything. Definitely not. However, it was who I used to be. I smiled all the time and life then happened, kind of."* Blog 3 p.1 *"…this is causing me to be an unattractive form of myself."* Blog 3 p.45 *"…the sort of employment she could get that would allow flexibility due to the frequent drama of our life with Ben."* Blog 2 p.2 *"…we waited for too much time and I was always scared in case the second one was worse. I wasn't sure how we could handle two Bens? However, we regret not having a second child straight away before we knew about Ben…"* Blog 2 p.12 *"We are both taking medication for depression/anxiety to cope better with our situation."* Blog 2 p.8 *"It is tough thinking it is unlikely that I will hold my grandchild or see him get married."* Blog 3 p.47 *"We will not be able to continue services much longer, financially."* Blog 2 p.8

Table 8: Stage 2 analysis. Quotations from theme 1 - Relationship with ASC (continued) (quotations paraphrased to protect identity)

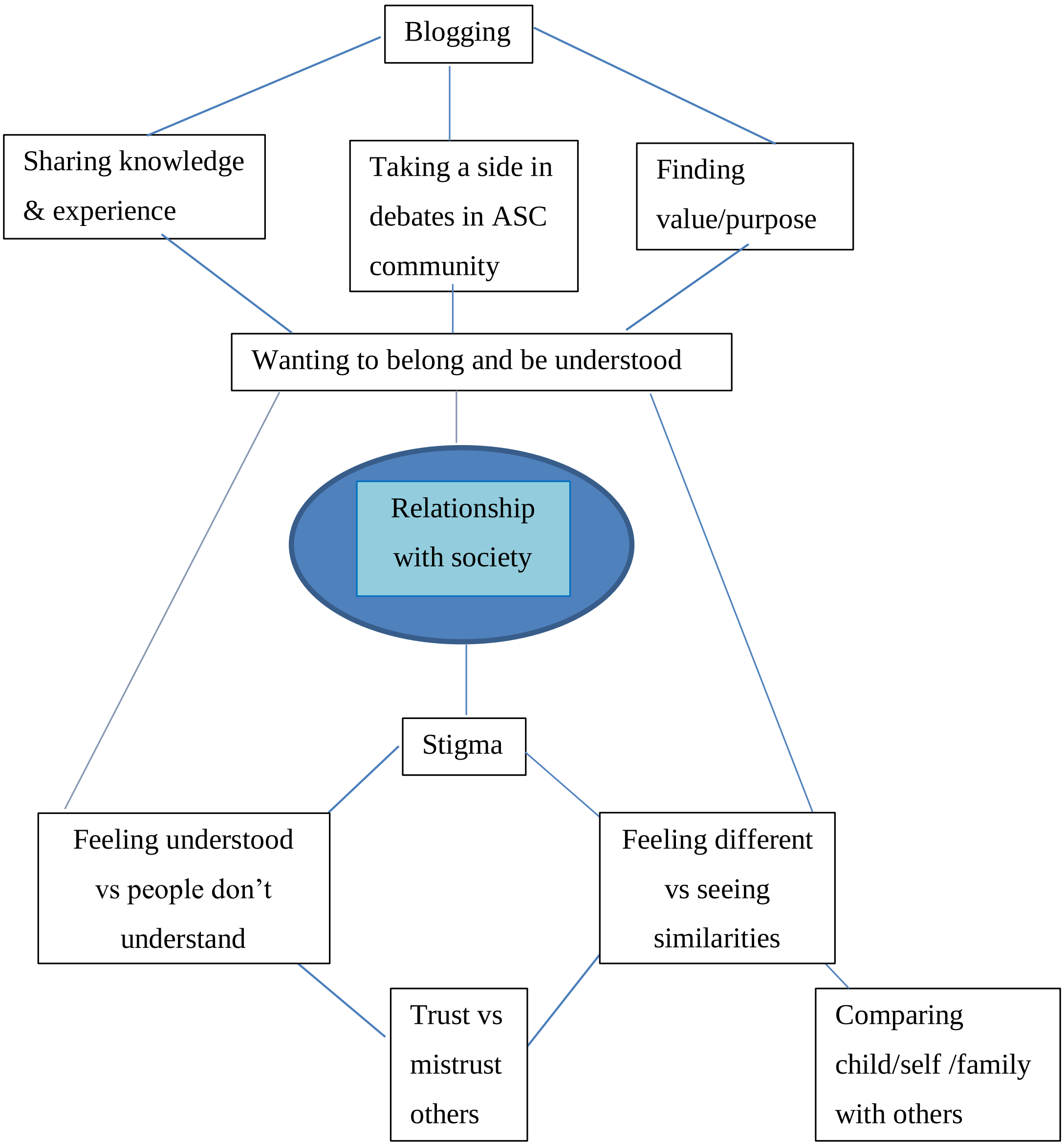
Theme	**Sub-theme**	**Sub-components**	**Quotations**
Relationship with ASC	Impact of ASC *(continued)*	Range of emotional experiences *(continued)*	*"Ben and our lifestyle made me a little depressed and frustrated."* Blog 2 p.52 *"I am cross and unhappy today and have been all week. It is here again. The depression stage that I managed to get rid of last year."* Blog 3 p.42
	Processing thoughts and feelings	Hope and positive reframing	"*My hope is that Ben will get back to where he was several months ago…"* Blog 2 p.31 *"I am very hopeful about this year!"* Blog 3 p.32 *"Just a bit of improvement that continues and does not disappear would really help this mum and dad and kick start our batteries for the big journey ahead."* Blog 2 p.31 *"...perhaps if Ben was less severe, if he was much closer to typical I may find it harder…however, thankfully :-) Ben's a definite case of classic autism."* Blog 2 p.57 *"I am a big supporter of managing with what you are dealt. Yes I still struggle with it, however he is my only child, I love him, I love my wife, therefore for better or worse, this is my life."* Blog 2 p.57 *"We are fortunate that our child is so happy! Entirely unaware of his surroundings. Plenty of smiling and good times at home."* Blog 3 p.1 *"But anyway we will take several steps forward and a few back ANY TIME!"* Blog 3 p.39 *"…the best case is that he will pay attention and possibly gain something from it…however, we do not expect miracles or magic to happen."* Blog 2 p.23 *"Ben has made little improvement over the last 4 years, so if I have lower expectations of what he can do and don't care as much, I have a more positive outlook."* Blog 2 p.58 *"...should you ever stop "instructing" and just try your best to have a happy child?"* Blog 2 p.29 *"So we will continue with our investigative work in search of recovery for my baby."* Blog 3 p.8

Table 8: Stage 2 analysis. Quotations from theme 1 - Relationship with ASC *(continued)*

Theme	Sub-theme	Sub-component	Quotations
Relationship with ASC	Processing thoughts and feelings *(continued)*	Grieving process	*"…it hurts every time I see a typical son and his dad interacting." Blog 2 p.57* *"I am still "dealing"with it. It is just like the stages of loss (Denial, anger, bargaining, depression and acceptance)." Blog 3 p.46*
		Making sense of diagnosis	*"Do I think vaccinations are at fault? Not really. Do I think anything is at fault? I'm uncertain." Blog 2 p.16* *"Hormones and chemicals in what we eat, antibiotic overuse, medication and vaccinations (the worst insult as it is put into our body directly) can unquestionably activate regression in children." Blog 3 p.47* *"I made some queries on Autism Speaks website among some other social media autism pages, asking for advice." Blog 2 p.32* "*Thank you Jenny McCarthy!...I purchased your book today and plan on reading it tonight!" Blog 3 p.17*
		Making sense of child within diagnosis	*"Ben had a big meltdown on the way to his bday party yesterday in the car. I was really pleased with myself, as I managed to figure out the cause of it." Blog 2 p.29* *"…when his computer is faulty he comes to get me and says "that's not it, try again". It is from a game he plays on the computer but, anyway, I will take it!" Blog 3 p.47* *"I have a syndrome where I often think the grass is greener on the other side. I am CONSTANTLY contrasting Ben with other children who are autistic, thinking in my mind "why can't he be more like__?" Blog 2 p.32* *"We have tried lots of biomedical things and sorta got scorched by some (made Ben worse?)" Blog 2 p10* *"My favourite therapy is ABA. Probiotics, Vitamin B12 and glutathione (most children on the spectrum do not have enough of this) are the key ones for Ben." Blog 3 p.46.* *"I am dealing with severe ASC, please remember, the banging his head, playing with saliva, non verbal type." Blog 2 p.15*

Stage 2 analysis. Theme 2: Relationship with society

Figure 6: Stage 2 analysis. Thematic Map of Relationship with society theme



Overview of theme

Many elements of this theme also featured in Stage 1 of the analysis within the theme 'Sense of belonging vs not belonging', however, following closer examination of blogs 2 and 3, the construction of this theme has changed a great deal. Although stigma is still a sub-theme, 'ASC community' is no longer a sub-theme and instead 'Wanting to belong' is the second sub-theme within this theme. A sense of feeling that others either understand or don't understand remains a feature of this theme, as does trusting or mistrusting others. The sense of 'normal/normality' has been replaced with a theme of 'Feeling different vs seeing similarities' and as with the previous stage of analysis this is related to a sub-component of 'Comparing child/self/family with others'. Finding value and purpose is still featured but ‘Sharing advice’ has changed to ‘Sharing knowledge and experience’ as the father in blog 2 does not tend to give advice and neither give support explicitly, in contrast to some of the other blogs. However, they do both seem to find value and purpose through sharing their knowledge and experience. ‘Place in society’ has been replaced with ‘Wanting to belong’ to reflect the dynamic nature and desire rather than a fixed role. For the same reason ‘Wanting to be understood’ has also been added, as ‘Others understand vs don’t understand’ was a feature of the previous ‘Sense of belonging vs not belonging’ theme but there was no sense within that previous theme of the desires of the parents to feel understood, although it was implied. Finally wanting to belong and wanting to be understood have been linked, as it appears that these two desires are related to one another, as it is assumed that people feel more understood if they belong to a particular group and people feel they belong if they are understood.

Sub-theme: Stigma

This sub-theme was also present in the analysis during stage 1 (see the analysis from stage 1 for more detail).

Both parents mention a sense of stigma and feeling judged or misunderstood by others. There is also a sense of feeling different to other members of society and feeling different even in comparison to other families with a child with ASC. In contrast, at times both parents report feeling similar to others and also describe feeling understood by others.

Sub-component: Feeling understood vs people don’t understand

This sub-theme was also present in the analysis during stage 1 under the name ‘Others understand vs don’t understand’ (see the analysis from stage 1 for more detail).

Both parents report times where they feel that others do not understand their situation, this is in regard to extended family members, professionals, strangers and society in general. A major feature of blog 2 is that he appears to feel that others do not understand his experience due to the severity of his child’s difficulties. This relates to people with limited knowledge of ASC who only see the side of ASC presented in the media but also refers to other parents of children with ASC and professionals who may only have knowledge and experience of dealing with children who feature at the ‘mild’ end of the spectrum. Similarly the mother in blog 3 also seems to have a sense that the general public and strangers do not understand but in particular she mentions many incidents where her child’ intentions or behaviour were misunderstood or judged by others. She also appears to feel that most professionals do not understand, due to lack of knowledge regarding ‘alternative’ or bio medical treatment or because of professional incompetence. When these parents seem to feel that others do not or will not understand them there appears to be a lack of trust in the advice that they are given and as mentioned in overarching theme ‘Relationship with ASC’ there is a tendency to hide feelings, as they seem to feel that others will not and cannot possibly understand.

Sub-component: Feeling different vs seeing similarities

As mentioned in Stage 1 of the analysis and in the overarching theme ‘Searching for an explanation - Meaning making’ during this stage of analysis, there is a tendency to compare the child, self and family with others, seemingly as a way of trying to understand both the diagnosis and the child and as a result of stigma. Feeling different and seeing similarities also featured in the overarching theme ‘Relationship with ASC’ with regards to the impact of ASC and cognitive processes of positive reframing. As mentioned previously, both parents report feeling that themselves, their child and their family are different to others but this theme also represents times when they see similarities with others, such as in blog 2, during an interaction with another father who appeared to understand his experience and in blog 3 when she finds a teacher who appears to understand her child.

Sub-component: Trust vs mistrust others

Both parents mention being unsure whether or not to share their feelings with others. The mother in blog 3 mentions deliberately hiding her feelings from others by putting on a brave face but reveals how this is not always possible. The father in blog 2 mentions not wanting to burden family members with his emotions but feeling the need to reveal them at times of crisis.

Sub-theme: Wanting to belong and be understood

As mentioned above, there is a sense within both blogs of feeling different to others due to others not understanding their views or lifestyle. This appears to be linked to a sense of not belonging within society. It seems, however, that both parents do want to belong, for example for the mother in blog 3, this appears to be through belonging to a small faction within the ASC community who agree with her views on debates and the campaigning and raising awareness that she does within this group. For both blogs there also seems to be a sense of belonging to a small group of people who read the blog and carving out value and purpose within this role. There is a sense that blogging is used by these two parents as a way of getting others to understand them, their child and their lifestyle.

Sub-component: Taking a side in debates in ASC community

This sub-theme was also present in the analysis during stage 1 under the title ‘Stance on debates in the ASC community’ (see the analysis from stage 1 for more detail).

It is felt that taking a side in debates within the ASC community is a way of having a voice and belonging to a faction of the ASC community, as has been demonstrated by the mother in blog 3. This is not a feature of the father in blog 2, however, as although he does take a side on some debates, this is rarely mentioned and in fact actively avoided.

Sub-component: Finding value and purpose.

This sub-theme was also present in the analysis during stage 1 (see the analysis from stage 1 for more detail).

There is a sense of wanting to find value and purpose in life within these two blogs. One way this seems to be achieved is through roles and responsibilities as a parent, particularly as a parent with a child with an ASC, who may need an advocate or who may need protecting due to being vulnerable. Other ways this appears to be achieved is through sharing knowledge and experience with others by educating others, by campaigning and raising awareness of ASC and by blogging.

Sub-component: Blogging

It seems that the blog may be being used as a way of belonging to a part of society when they feel that they may not belong to society as a whole. In fact the father in blog 2 mentions feeling ‘close’ to his blog reader’s and irritated when they do not appear to understand his intentions. He also appears to be worried at times about upsetting his blog readers and potentially losing them from his page. There is also a sense of the blog serving the role of giving the parent a value and purpose and a sense of belonging through this role. For example, the father from blog 3 talks about his role as a blogger and the responsibility of keeping the blog as well as feeling a sense of relating with his readers. The other purpose of the blog it seems, is to help readers to understand ASC and to also potentially give hope to others who may be experiencing similar situations, through sharing personal experiences and anecdotes.

Blog as outlet/venting

Both blogs mention blogging as an outlet or ‘venting’ and it seems that this may be related to feeling misunderstood by other parts of society and feeling that blog readers may be able to understand their experiences more due to shared experience, as both parents writing appears to assume that readers can identify with the experience at various points. It seems therefore that they do not feel the need to hide their ‘true’ thoughts and feelings within this arena as much as they do with others, who may not understand their point of view.

Making blog accessible and entertaining

There is a sense of trying to make the blog accessible to readers. This may be in order to have a sense of belonging and to be understood. It seems that the blog is made entertaining and accessible in order to be understood by others and to belong. Both parents have a frequently asked questions section on their blog, which seems to be as a way of being understood. Anecdotes and stories are presented vividly by both parents through detailed descriptions and ‘setting of the scene’, which again seems to be as a way of giving readers a full picture in order that they understand the context. In addition, both of the parents seem to choose to write about things that the reader can relate to and there is very little content of the blogs that is unrelated to ASC and parenting, unlike some of the blogs that were analysed during Stage 1. Both parents address their audience directly, particularly the father in blog 2 and as mentioned above there is a sense of belonging through assuming shared experience, this is demonstrated through words such ‘we parents’ and ‘our autism world’. There appears to be an attempt to entertain as well as inform the readers through the use of humour, photographs images and audio.

Table 9: Stage 2 analysis. Quotations from theme 2 - Relationship with society

Theme	**Sub-theme**	**Sub-components**	**Quotations**
Relationship with society	Stigma	Feeling others don’t understand	*“Our family are INCREDIBLE. They love Ben. They accept him. They understand him.” Blog 2 p.19* *“…kicking the seat in front of him and tried to grasp the head of the man in front. And usually this would mortify us…however on this occasion the man, a father to a teenage boy with autism seated beside him said “don’t worry, we’ve been there.” And we were knew that it was true.” Blog 2 p.47* *“We don’t wish to be a burden for our families. But I almost think it would be better if they saw us having a panic attack or mental breakdown so they comprehend that any usual week for us when you are on the front line 24 hours a day 7 days a week, can be an emergency state of affairs.” Blog 2 p.20* *“…recently when ASC hits the headlines it’s a heart-warming story about a child who is high functioning and doing something amazing and profound. And I think that shows ASC in too positive a light. It means that people think that ASC is not too bad. I think the USA needs to see the dark parts of ASC more frequently, like my son.” Blog 2 p.45* *“My wife also got the treated like she had three heads when she told them she would drive Ben every day. She told me later “I don’t understand what is unusual about taking your child to school?” Blog 2 p.34* *“I didn’t tell him about any unconventional treatments because firstly he didn’t ask and secondly he also didn’t inquire about his diet. Unquestionably, he probably would have rolled his eyes when I told him because, gee, everyone knows that speech therapies are the cure for ASC don’t they? If only he realised all the supplements my son takes!” Blog 3 p.3* *“I wish we could stay in a bubble but we do not. It is hard to see the unkindness around him and this will probably only increase as he ages.” Blog 3 p.1* *“I don’t understand why strangers think they can make comments when they haven’t actually lived through what we experience?...Parents of ASC children often experience this, so much that you learn to ignore, roll your eyes or if they are nice you teach them and the rest you school.” Blog 3 p.17* *“Showing people the dazzling smile is getting harder work each day and I really don’t feel like doing it any more.” Blog 3 p.1*

Table 9: Stage 2 analysis. Quotations from theme 2 – Relationship with society *(continued)*

Theme	**Sub-theme**	**Sub-component**	**Quotations**
Relationship with society	Stigma *(continued)*	Feeling different	*“I was irritated and a bit depressed about our way of life and Ben, and I walked around my home and took photographs comparing our life to that of usual families and showing how is it is different.” Blog 2 p.52* *"We are not uber ASC parents, as my wife terms them…we do not track moods or food in a diary. We do not occupy him as much as we should.” Blog 2 p.15* *“Some parents of children with ASC report improvement and tell us that as they age it gets easier but we do not feel like this. For us each year it has got worse.” Blog 2 p.31* *“…continuous reminders that we are just not that much of a “typical” family.” Blog 3 p.12*
	Wanting to belong and be understood	Finding value/purpose	*“I shared this information as I thought it was thought provoking and sorta inspiring.” Blog 2 p.42* *“My dream is that other parents out there are inspired or given hope by this book (particularly parents who refuse to do anything about their child’s ASC) and also patience on the way for those of us on the path!” Blog 3 p.17*
		Taking a side in debates in ASC community	*“I realise that Autism Speaks is controversial and…some of the Asperger community think AS is not representative of them, and perhaps it is not, however it does seem representative of those with debilitating severe ASC. My child has SEVERE autism.” Blog 2 p.23* *“This article mentions vaccines quite a lot and I realise there are many people on both sides of the debate. But no matter what your views on the debate, I think we are all in agreement that there is an autism epidemic and that LOADS more people have ASC now than the last generation or the one before.” Blog 2 p.42* *“I don’t understand how some parents do not believe in recovery for children?” Blog 3 p.20*
		Sharing knowledge and experience	*“Every so often I give others some real advice, which I enjoy but mainly I make some people cry and others laugh.” Blog 2 p.53* *“Battling for research to pay attention to the correct things that will assist our children.” Blog 3 p.20*

Summary of Stage 2 of analysis

Stage 2 of the analysis followed on from the broad analysis of all 8 blogs in Stage 1. This second stage examined 2 of the 8 blogs in more detail, as case studies.

The results from the thematic analysis in stage two, demonstrate that the parent's relationship with ASC seemed to be an important feature of the blogs and both parents report a significant impact of ASC on their lives. There are also elements of cognitive and emotional processing of thoughts and feelings regarding ASC. This sense of searching for an explanation and meaning making regarding the diagnosis also involved exploring potential causes of ASC and researching, reading and asking advice in order to make sense of the diagnosis and the child. Within searching for an explanation and meaning making there also seemed to be attempts to understand the child through learning their idiosyncrasies, comparing them with others and by learning what works through exploration and experience.

An additional key feature of the blogs appeared to be a contrast between times when the parents were feeling hopeful and times when they were lacking hope. It seemed that these feeling of hope versus lack of hope in turn impacted on whether parents attempted to escape and avoid feelings and experiences or whether they felt the need to take control and be active and proactive.

Both parents spoke about stigma they had experienced from society and the subsequent thoughts of being different to others and that others do not understand them, their experiences, their child or ASC. These thoughts in turn appeared to lead to a desire to belong and for others to understand. Parents seemed to attempt to manage these thoughts by trying to find a place within the ASC community, finding value and purpose and sharing knowledge and experience. Blogging appeared to serve the dual purpose of providing a way of being understood by others and providing a sense of belonging within the ASC community or within a small faction of the ASC community, such as people who hold similar beliefs and people who read their blog.

CHAPTER 5: DISCUSSION

Overview of the chapter

The results of the analysis will be discussed by considering each of the three research questions outlined in the introduction in turn and with reference to theories and prior research. For personal reflection on some of the emerging themes and the research process, please see Appendix 6. Implications for clinical practice will be discussed, limitations of the study will be outlined and possibilities for future research will be considered.

What themes emerge when parents of children with autism write about themselves when blogging?

Searching for an explanation - Meaning making

Searching for an explanation - Meaning making was the superordinate theme and it appeared that this was an important theme, as it was featured throughout the blogs and was present within both stages of the analysis. It is particularly prevalent within parts of the blog where parents write about themselves and their own thoughts and feelings. Previous research has found that the ways in which meaning making is conducted within families determines how well they utilise resources such as coping strategies (Patterson, 1988). It is unsurprising, therefore, that searching for an explanation and meaning making was a dominant theme of the present study, as it is a common finding within the literature. For example, positive appraisal of stressful situations has been linked with family adjustment (Trute et al, 2007). In addition, family belief systems have also been found to create closer family bonds and a shared sense of meaning (McCubbin & McCubbin, 1986). Although the parents writing the blogs appeared to use searching for an explanation and meaning making, coping strategies and positive appraisal, the present study did not find the close family bonds and shared sense of meaning within families that may have been expected. It seemed that parents used various means as a way of making sense of their own experiences, including making sense of the diagnosis, reflecting on the impact of ASC and their own relationship with ASC and dealing with the impact through employing coping mechanisms such as positive reframing.

Impact of ASC on self

As mentioned previously, raising a child with a ‘disability’ is often seen as a ‘tragedy’ and much of the literature is focused on the negative impact on families (e.g. Wolfensberger & Menolascino, 1970; Kearney & Griffin, 2001; Blancher et al, 2002; Gerstein, Crnic, Blacher & Baker, 2009). This study also found much mention of the negative impact of the child’s diagnosis of ASC, alongside less frequent comments on some of the positive aspects of the child and the ASC.

Dominance of ASC

There was a heavy emphasis in many of the blogs of the dominance of the child's difficulties within day-to-day life. Many parents spoke of the amount of time spent planning and preparing for events and needing to supervise their child at all times, due to fear of their child's vulnerabilities, lack of sense of danger and 'challenging' behaviours. The literature is littered with examples of caregiving demands, the need for a mediating and liaison role and restrictions and responsibilities of mothers (e.g. Graham, 1985), mothers of children with health difficulties (Morgan, 1996) and mothers of children with 'disability' (Glendinning, 1983; Beresford, 1995, as cited in Seligman & Darling, 2007). Recent research has found that parents of children with ASC in particular have more caregiving burden than other families with 'typically developing' children (Roper, Allred, Mandleco, Freeborn & Dyches, 2014).

Sacrifices/losses

Within many of the blogs there were discussions of the parent's own sacrifices and losses, which were often reported to be related to the child's difficulties.

Professional role

It seemed from the analysis that the role as a parent, particularly the role as a parent who has a child diagnosed with an ASC, was the most dominant aspect of descriptions of self and identity. Roles and identity, outside of parenting, were rarely mentioned, if at all. This appears to be partly due to the dominance in everyday life of the child's difficulties, as discussed above, as well as sacrifices parents have to make, or choose to make, in not developing other roles or by losing existing roles.

Half of the blogs mentioned a professional role. Interestingly, this included both fathers but only two out of the six mothers, which may suggest that the mothers within these blogs take more day-to-day responsibility for the child than the fathers. This will be discussed in more detail in the question regarding family relationships. Despite half mentioning a professional role, however, the descriptions are often brief and fleeting, sometimes only one sentence, therefore they do not feature at all in stage 1 of the analysis and only briefly as a sub-component of losses and sacrifices in stage 2 of the analysis. Of the blogs that do mention a professional role, a few of the parents write about needing a flexible position and others mention not being able to have a professional role, due to the child's difficulties. This is consistent with previous literature, which has found that career difficulties can be experienced by families who have a child with a 'disability' (e.g. Gray, 1997; Gray, 2002). Some blogs do not mention a professional role at all, which may be because they do not have one, or it is possible that they do have a professional role, but have chosen not to mention it, either because they manage to balance these responsibilities, therefore they do not need to be commented on, or it may be due to the dominance of ASC in their current identity and roles, or wanting to keep the blog focused on ASC.

Other roles and aspects of identity

As mentioned above, the role of parenting seemed to mostly subsume other roles and identities, at least in terms of what parents presented within the blogs. It was interesting, however, that a large element of blog 5 was regarding the mother's role and identity as a member of the Orthodox Jewish community and measuring herself against the perceived values of this society, for example being a 'good homemaker'. She also spoke about being a 'daughter of God', which she described as 'above all' her other roles. However, this was the only blog that mentioned other roles and aspects of identity with any consistency. Had this blog been included in the case studies, therefore, it is likely that this may have been a larger part of the analysis.

Financial

The majority of parents mentioned the financial costs of raising a child with additional needs. There were financial implications for some parents who were unable to work due to their child's difficulties, but there were also other costs. Other financial implications were due to the costs of therapies and treatments, as many parents lived within the USA and highlighted that ASC is not a condition that is covered by many health insurance companies and that those that do provide cover, do not tend to support 'alternative' treatments. Other costs mentioned by parents were related to household adaptations and equipment, such as sensory items, adapted beds and sleeping systems. The present study supports previous findings of families of children with disabilities experiencing more financial costs and strains due to the child's difficulties (Parish et al 2004). There did not appear to be differences between mothers' and fathers' reports of financial difficulties, which is in contrast to previous literature that has found that fathers tend to focus more on financial impact (Rodrigue, Morgan & Geffken, 1992).

Mental health

Many parents mentioned feeling 'stress', which is consistent with the research literature which suggests that parents of children with 'disabilities' report experiencing more stress than other parents (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Fleischmann, 2005). In contrast, some literature has found that although stress can be high in families of children with ASC, this is still within 'normal' limits (Trute et al, 2007). Parents who have high levels of parenting stress and daily parenting hassles have been found to be more likely to have other 'symptomology' (Crnic & Low, 2002; Chang & Fine, 2007). However, in contrast, other research has found little evidence of a higher risk of significant mental health problems within this population (Benson, 2006; Benson & Karlof, 2009). This appears to be in line with the present study that found only two of the eight parents mention having been diagnosed with a mental health difficulty, which is a similar incidence to the general population. It is of course possible that parents who blog do not mention these difficulties due to fear of being judged or stigmatised, so the actual number of parents experiencing these difficulties may be higher.

Range of emotional experiences

Many parents mentioned a range of emotions in relation to their reaction to the diagnosis, their feelings about their child and their situation and in their relations with others. Anger and hope were dominant features of many blogs, as were mentions of feelings of anxiety, worry, sadness and frustration. Happiness, joy, regret and guilt were also present, but were not as dominant. During the second stage of analysis the differences in emotions expressed in blogs 2 and 3 were striking. Blog 3 was dominated by feelings of anger but also hope for the future. Blog 2, in contrast was dominated by a sense of hopelessness and helplessness. Feelings of helplessness have also been found to be common amongst parents of children with a 'disability' (Higgins et al, 2005).

These findings are in line with previous research, which has also found a range of emotional experiences including frustration, anger and shock (Higgins et al., 2005). However, there was not as much guilt and joy as may have been expected following previous research (Higgins et al., 2005; Kearney & Griffin, 2001). However, it may have been that parents did experience these feelings, but chose not to communicate them as regularly as other feelings within their blog.

Coping with impact of ASC on self

Coping

The first stage of analysis highlighted coping as a major theme of the research and this also emerged within stage 2, within the subordinate theme 'Relationship with ASC' under the sub-theme 'Processing thoughts and feelings'. Many parents mentioned attempts to cope with the impact of ASC on their lives and there were a range of coping styles littered throughout the blogs. Coping is a dominant aspect of the research literature and often the way in which parents cope is measured against a sense of what is a 'normal' family life in society (Gray, 1997). The literature also discusses how coping styles can be broadly classified into internal strategies, such as reframing and passive appraisal and external strategies, such as using the support of others, including family, community, religion and professionals (McCubbin & Patterson, 1981; Houser & Seligman, 1991; Seligman and Darling, 2007). Internal strategies will be discussed within this research question and external strategies will be mentioned during the questions regarding family relationships and relationships with others.

In studies of parents with a child with ASC or an intellectual disability, coping strategies have been found to help with high levels of stress (Seltzer, Greenberg, & Krauss, 1995; Smith & Osborn, 2008). The cognitive relational theory of stress (Lazarus & Folkman, 1984) highlights the relationship between the person and their environment and how people appraise 'stress', which in turn influences the type of coping strategies they use. This theory focuses mainly on internal strategies and postulates two categories of coping; ‘emotion-based’, which includes strategies aimed at managing difficult feelings and ‘problem-based’, which highlights strategies where parents are doing something active to change the source of stress or solve a problem. Research regarding the use of these strategies within families has found that the use of problem-focused strategies tend to have better mental health outcomes than emotion-based strategies (Aldwin & Revenson, 1987; Seltzer, Greenberg, & Krauss, 1995).

‘Venting’ and denial are deemed as emotion-based strategies within this model. The present study found frequent mentions of ‘venting’ and some denial in the form of avoidance of thinking about ASC and some families who did not accept that ASC was a permanent condition. For example, the father in blog 2 seems to use more escape and avoidance strategies than the mother in blog 3, but also appears more accepting of the permanence of his child’s diagnosis.

In contrast many blogs also seemed to use planning and taking action to manage their difficulties, which within the model are deemed as problem-based strategies. Some parents appeared to use both forms of strategy. There has been some criticism of the division of coping styles into these two discrete categories (Carver et al., 1989; Skinner, Edge, Altman & Sherwood, 2003), as some elements of coping do not fit into either of these categories. For example, seeking social support could be a form of ‘venting’ but it also may be related to other elements of coping, which may not be as easily classified; for example, a sense of being accepted or practical support that allows distance, such as child care. In addition, the emphasis of coping styles on improving stress and distress in parents of children with ‘disability’ has been criticised by other research that has not replicated the findings (Abbeduto et al., 2004).

Processing thoughts and feelings

Hope and positive reframing

Hope and hopelessness were featured in all eight of the blogs and were particularly prominent in blogs 2 and 3. It appeared that there was a sense of passive appraisal (McCubbin & Patterson, 1981; Houser & Seligman, 1991) and possibly learned helplessness (Seligman & Maier, 1967) in blog 2 where the father appeared to feel that he was unable to control the situation, following repeated disappointments and set-backs. This is consistent with the literature, which found that parents of children with ‘disabilities’ tend to experiences feelings of incompetence (Rodrigue et al, 1990) and have lower morale than other parents, due to daily stressors (Singer et al, 1993). In contrast, the mother from blog 3 had experienced some setbacks, but not as many as detailed by the father in blog 2. She appeared to be spurred into action by anger at the manufacturers of vaccinations, which she was certain had caused the ASC in her child, alongside anger at society for their judgement and lack of understanding. The relationship with society will be discussed in more detail later.

Many parents also mentioned their own strengths and positive qualities, such as being organised and their strengths in the role of advocate for their children, which could be related to themes of hope and positive reframing. This supports previous literature, which discusses how parents often need to play an active role in their child's care by 'fighting' or negotiating for services (Sloper & Turner, 1982; Twigg & Atkin, 1994) and how many parents are 'active participants' in the care of the child and in their role as a parent, often needing to use active and creative strategies to manage difficulties and problem-solve (Beresford, 1994).

In previous literature, which focused on mothers of children with disabilities, avoidance, such as disengagement or distraction, was associated with more likelihood of a diagnosis of depression and more anger, in contrast to mothers who used cognitive reframing (Benson, 2010). In addition, acceptance of the reality of their child's disability has been included within the definition of positive adaptation (Summers et al, 1989). Although it is not possible to generalise from the small number of participants in this study, interestingly both blogs used cognitive reframing but the father in blog 2 appeared to use more avoidance than the mother in blog 3 and the father in blog 2 reported experiencing depression, whereas the mother in blog 3 did not and tended to report more anger. Therefore, the present study partly supports the findings of prior research, but also demonstrates that there is a much more complex use of these strategies, with many parents using a mixture of different strategies and therefore also having a range of different outcomes.

Humour

Parents also appear to cope and positively reframe through using humour. Sometimes this is with regard to the child's idiosyncrasies, actions or speech that are amusing, sometimes this is also finding the funny side of events and experiences. Finally, humour is used frequently throughout the blog, in the form of humorous asides, jokes and comments, seemingly targeted at amusing the blog readers. Previous research has found that humour is used as a way of coping for parents of a child with a 'disability' (Rieger & McGrail, 2013) and that humour can allow a way of creating distance and perspective during times of stress and can enhance functioning and well-being (Martin, 2007). It has also been found that humour can help families with a child diagnosed with ASC to cope and adapt, to begin to accept the diagnosis, to express emotion and to improve communication and social interactions (Rieger, 2004). In addition, previous research has found that parents use humour, partly as a way of making sense of and positively reframing experiences in order to overcome difficult feelings such as grief (Goddard, Lehr & Lapadat, 2000). Research within this area offers an interesting perspective on the experiences of parents and supports the findings of the present study. However, the research in the area of 'coping humour' has been mainly qualitative, therefore not allowing generalisation of findings. In addition, the quantitative research that has been conducted has tended to have small sample sizes within the 'disability' group, therefore the findings in this newly developing area are not yet robust.

Grieving process

Many parents mention a sense of grieving for the losses they had experienced and the life that they could have had, with two parents mentioning the grief cycle and its five stages of grief (Kubler-Ross, 1969) specifically to explain their feelings at various stages following the diagnosis. It seems that understanding the potential grieving process may have helped some of the parents to make sense of the grief that they felt they were experiencing and to normalise this. The literature has found that many parents of children with a 'disability' have feelings of sorrow and grief following their child's diagnosis, particularly with regard to the 'normal' child they have lost, the future they and the child could have had and concerns about the future (Taanila, Tarvelin & Koekkennen, 1998).

It is interesting to note the frequent anger and denial that was present within some blogs, as well as other blogs which appeared to have more themes of acceptance, which could be seen as representing different stages within the grief cycle. This is particularly significant within the two blogs used as case studies, which may represent different stages within the cycle due to the amount of time since diagnosis differing between these two cases. The father in blog 2, who appears to demonstrate more acceptance, received the diagnosis six and a half years before the blog, as opposed to the mother in blog 3, who appears to experience more anger and denial of the permanence of the condition, who received the diagnosis two years previously. This may be in line with previous literature, which has found that the 'negative' impact of 'disability' on parents, siblings and extended family tends to improve over time (Gray, 2002).

Making sense of diagnosis

Making sense of the diagnosis was a major theme of the majority of the blogs, which appeared to be a way of searching for an explanation and meaning making.

Seeking information

All of the parents mentioned researching or reading at some point in their blog. Much of this research was in regard to making sense of the diagnosis. This included reading professional and 'expert' opinions and research as well as the views of other parents. Many parents explored literature and theory, potential causes of ASC and treatments and therapies options, through reading books, newspaper articles and internet pages written by professionals or other parents. Research literature has found that many parents, particularly those with children who have health conditions, seek information online regarding their child's condition (Blackburn & Read, 2005), particularly in parents of children with ASC, who often seek particular information about ways of 'treating' ASC (Altiere and von Kluge, 2009; Kirby, Edwards, & Hughes, 2008). Some of the literature highlights that fathers tend to use more information seeking than mothers (Rodrigue et al., 1992). However, this was not found within the present study, but it is difficult to generalise, given the small sample size.

Exploring cause of ASC

All of the parents wrote about exploring the cause of the ASC and every blog mentioned an opinion on the debate over whether vaccines were the cause. It seemed that trying to find a cause of ASC was a way of making sense of the diagnosis, answering their questions about why it may have happened to them and also assuaging some of the guilty feeling expressed by some of the parents, that they may have somehow caused the ASC. There was a divide amongst the blogs, regarding parents who believed that vaccines had caused their child's ASC and those that believed in other causes. These beliefs about the cause of their child's difficulties are likely to influence the way that they interpret their situation, their relationships, their sense of control and their actions. Therefore, it is useful for professionals to know these views (Ariel & Naseef, 2006; Rolland, 1994).

Exploring 'treatment' and therapy options

Parent's views on the cause of ASC, appeared to influence their decisions regarding 'treatment' and therapy options. All of the parents mentioned some form of 'treatment' or therapy and exploring various options. Many blogs appeared to have a sense of seeking the 'right' answer to either improve or cure their child's difficulties. There was a mixture of use of 'traditional' therapies and 'biomedical' or 'alternative' therapies and many parents reported trying both forms and often multiple approaches at the same time. Previous research has found a wide range of treatments discussed within blogs of parents who have a child with ASC (Fleischmann, 2005) and much information online regarding ASC has been found to discuss specialist diets and expensive therapies (Autism Coach, 2009, as cited in Jordan, 2010).

Those that believed in vaccines and subsequent toxic overload as the cause of their child's ASC, appeared to choose more 'biomedical' and alternative treatments such as chelation, the Gluten-Free-Casein-Free (GFCF) diet and anti-fungal treatments. Those that believed in causes other than vaccine appeared to be less likely to choose these 'alternative' therapies. Previous literature has commented on the prevalence of parents' testimonials for untested therapies and parents' testimonials that following taking the latest vitamins their child 'recovered' (Jordan, 2010).

Seligman and Darling (2007) discuss how parents of children with disabilities often tend to subscribe to the 'medical model', rather than the 'social model' of disability and due to this they often attempt to seek 'treatment' that will enable their child's difficulties to improve in order for them to function within society.

What themes emerge when parents of children with autism write about their children when blogging?

It has been found within the literature that the main influence on stress and anxiety for parents of children with ASC, is the ‘state’ of the child (Fleischmann, 2005). It is not surprising, therefore, that many of the factors and themes that have been mentioned during the discussion of the first question related to self, are also present when parents of children with ASC write about their child when blogging; namely processing thoughts and feelings through making sense of the situation and using positive reframing and a sense of hope.

Processing thoughts and feelings

Making sense of child within diagnosis

Many of the parents write about attempts to understand their child and the blogs are littered with behaviour and language of the child that is viewed as mysterious or puzzling. There are often moments of revelation, where mysteries are solved and the parent suddenly understands the reason for the behaviour, or what the child is trying to communicate. In addition, many of the parents report attempts to predict their child’s behaviour and plan ahead for events based on these predictions.

Much of the behaviour that parents attempt to predict is behaviour that they find particularly challenging. Many of the parents mention ‘challenging behaviour’ or ‘behavioural problems’ and some children had additional diagnoses such as Attention Deficit Hyperactive Disorder (ADHD) or Attention Deficit Disorder (ADD). This is in line with the literature, which highlights that when a child has behavioural problems or a mental health difficulty alongside another ‘disability’, it has been found to have more of an effect on parental well-being and perceived negative family impact (McIntyre et al, 2002; Baker et al, 2003; Blacher & McIntyre, 2006).

Parents often seemed to make sense of their child by comparing them with theory and literature written by professionals and with children presented in books, articles and blogs written by other parents, or with known and unknown children encountered in daily interactions. For example, parents report seeing similarities with other children with a diagnosis of ASC, or with theories of ASC, which seems to help them to understand how the diagnosis may impact their child’s difficulties, ‘symptoms’, skills and abilities. This kind of learning, in order to make sense of the child, has also been found within prior research (Fleischmann, 2005).

In addition, some of these comparisons seem to also be about feeling frustrated with the lack of improvement in their child’s ‘symptoms’ and feeling that the child could be doing better. For example, some parents mention that they wish that the child was more like another specific child who has made a lot of progress, or ‘typical’ children in general. How parents view their child and use comparisons appears to be related to whether the parents feel a sense of hope or hopelessness with regard to the future of their child. Fleischmann's research (2005) of blogs written by parents of children with ASC found similar focus on progress and lack of progress within blogs.

Hope and positive reframing

As well as positively reframing themselves and their situation, there was also a sense of positive reframing of the child, which seemed to be another way of understanding and making sense of their child and their difficulties, but also as a way of holding onto hope for change.

Some of the comparisons that parents made between their child and other people seem to be a form of positive reframing, for example by reflecting on positive moments and times that they share with their child and presenting their relationship with their child as being loving, caring and fun at times. Parents also seem to positively reframe by normalising their child's difficulties and by positive comparisons, such as seeing that their child has fewer difficulties than other children. In contrast, other comparisons seem to be regarding parents feeling that their child is different to other children, either due to their difficulties or due to their uniqueness. Some parents mention that although their child is 'on the spectrum', they are different to other children diagnosed with ASC, due to their position 'on the spectrum'.

The two case studies in particular were found to highlight that their child's difficulties are particularly 'severe' or that their child is particularly vulnerable in comparison to other children on the spectrum, which seems to lead to a sense of feeling hopeless at times regarding the future. Parents with children with more severe difficulties, have unsurprisingly been found to experience higher levels of stress than parents who have children who have fewer difficulties (Hastings & Johnson, 2001; Dunn, Burbine, Bowers & Tantleff-Dunn, 2001). It is interesting to note that despite both children in the two case studies appearing to experience similar difficulties, the parents in these two selected case studies reported different levels of severity of their child's difficulties. The father in blog 2 reports more severe difficulties and also seems to experience less hope for improvement. In contrast, as mentioned previously, the mother in blog 3 felt that her child's difficulties were neither severe nor mild and appeared more hopeful that her child would 'recover' from ASC. The hope that is reported may, therefore, be related to the parents perception of the child's level of difficulties and 'symptoms' rather than learning to accept the diagnosis over time by learning to adapt and cope. There may, however, be a move towards less risk taking in pursuing change as time goes on, which may be as a result of the father in blog 2 having had more time since the diagnosis.

There are also mentions within the blogs of the child's positive qualities, skills and abilities, often in relation to perceived progress and achievements in development and improvement of 'symptoms'.

Previous literature regarding parents of children identified as 'medically fragile' has found that parents tend to focus on the positive aspects of their child and tend to underplay difficulties (Patterson & Gerwick, 1994). In contrast to this research, however, the present study found that, although parents mention positive qualities, this aspect of the child was mentioned far less frequently, than descriptions of the child's 'symptoms', difficulties and challenging behaviour.

All of the parents write about their wish and desire for their child's difficulties to improve and many of the blogs are dominated by discussion of progress that the child has made and development of new skills and abilities. However, some parents appear to believe that further progress is possible, whilst others talk about 'accepting' the fact that further improvements are unlikely to happen. The first stage of analysis highlighted the divide on many debates; 'recovery' versus 'acceptance' was one of these debates. For example, the mother in blog 3 seems to have a 'striving' mentality due to a sense of hope that the treatments and therapies will 'work' and lead to 'recovery', if she finds the 'right one'. This searching for answers is a major theme of her blog and many of the other blogs, in direct contrast with the father in blog 2, who seems to feel that he understands his child and the diagnosis well and as he does not expect 'recovery' or even improvement, he seems to have given up 'striving' and instead speaks about accepting his situation. Traditional grief models (e.g. Lindemann, 1944; Engel, 1961; Kubler-Ross, 1969; Bowlby, 1980) postulate that 'healthy' adjustment is achieved through acceptance, whilst other theories (e.g. Olshansky, 1962) do not assume that acceptance is necessary for adjustment to occur.

These thoughts and feelings about the likelihood of progress do not only seem to impact on the treatments and therapies that the parents try, but also seem to be related to the ways in which parents interact with their child. For example, many blogs mention frequent interactions with the child that involve teaching, instructing and 'working on' aspects of the 'symptoms' or difficulties that the child experiences, this was similarly found within previous literature (Fleischmann, 2005).

What themes emerge when parents of children with autism write about their family relationships when blogging?

Impact of ASC on family relationships

Dominance of ASC

Relationships - Partner

As mentioned previously, there are various external coping styles that can be used by parents, for example using the support of others, such as family, community, religion and professionals (McCubbin & Patterson, 1981; Houser & Seligman, 1991).

The majority of the blogs rarely mention their partner in any detail, especially in comparison to the amount of time discussing ASC and the child. Some of the blogs, comment on feeling supported by their partner, however, they are only briefly mentioned in a peripheral way in most blogs, mainly in terms of practical things that their partner does, such as talking to the child, taking the child out and helping to manage challenging behaviour.

Interestingly, both of the fathers (blog 2 and blog 8) mention the amount of time spent with the child being divided between themselves and their wives, although, they also report that this divide is often not equal, as the majority of the day-to-day responsibility is mainly taken by their wife, as both of the fathers work and their wives are not employed. The mother in blog 1 also mentions sharing responsibility with her husband, for example by calling him at work to ask his advice when incidents occur at home and working together to problem solve difficulties. However, this does not appear to be presented as an even sharing of responsibility, as although he is mentioned more frequently than partners of parents in other blogs, he is not mentioned frequently enough for this to have been a major theme.

The overall sense from the blogs written by mothers was that they were managing the day-to-day practicalities of parenting mainly independently, whereas the blogs written by fathers appeared to demonstrate more balanced responsibility between themselves and their partner, but with an acknowledgement that their wives take more of the day-to-day responsibility. This has also been found in other research. For example, a survey of families of children with a ‘disability’ found that in 96% of these families the mother took most of the responsibility for the care of the child (Beresford, 1995). Other literature has reported higher levels of distress (Gray, 2002) and higher levels of daily hassle (Trute, Hiebert-Murphy & Levine, 2007) in mothers than fathers and an increase in daily stress over time, compared to father’s more constant level of stress (Trute et al, 2007). In addition, parenting hassles have been associated with family relationships that are decreased in quality (Crnic & Greenberg, 1990).

It is postulated that this uneven divide of caregiving responsibilities may be due to the female-dominated care systems, difficulties that father’s may have in managing children with ‘disabilities’, or due to traditional gender biased roles in society (Lillie, 1993; Trute et al, 2007; Belsky & Rovine, 1990; Erel & Burman, 1995). Other literature has hypothesised that mothers may unintentionally make it difficult for fathers to become involved in the child’s care through their close involvement with and attachment to the child (Gill, 1997). It seems therefore that the way that services are organised and family interactions can impact on the father’s participation in the life of the child.

There were only brief mentions of arguments and disagreements between the blogging parent and their partner. The disagreements that were commented on were often regarding the child or the approach that they should take, but these were brief and fleeting and were not major themes of the analysis. This appears to contradict some of the literature, which reports that marital discord and relationship breakdown can be more common in families where there is a child with a 'disability' (e.g. Office of Population Censuses and Surveys, 1989). It may, however, be that parents did not want to write about arguments and disagreements on their blogs due to fear that people may feel that they are not coping well or that they may be judged.

Previous research has suggested that some parents report feeling closer to their partner as a result of the child's difficulties (King et al, 2009). There were no direct comments by the parents regarding feeling closer to their partner due to the disability, although a few of the blogs mention making time to spend with their partner, through shared hobbies and interests, such as television programs, although again these comments are infrequent.

Relationships - other children

Despite the majority of the parents having children in addition to the child with a diagnosis of ASC, as with the partner, they were rarely mentioned. The only parent who commented on another child with regularity was the mother in blog 4, who had another child who also had a diagnosis of ASC. Other mentions of additional children were so infrequent that they did not feature in any of the themes. This was unexpected, as there is prior literature highlighting the impact on siblings of children with 'disabilities', including change in roles due to multiple obligations of siblings (e.g. Stoneman, 2005). It is possible that the siblings are overlooked by parents due to being more focused on the child with a diagnosis, or it may be that parents are trying to keep their blog focused on their experience of parenting a child with ASC, due to feeling that people who read the blog are seeking information regarding their child with ASC, rather than 'typical' siblings.

Relationships - Extended family relationships

Mention of wider family relationships were even more infrequent than mentions of the partner or sibling. When wider family were written about, this was sometimes related to spending time together as a family, or in terms of practical support that parents were receiving from their wider family, through babysitting or attending appointments with them. This is consistent with research which discusses the role of extended family in providing support and helping parents to cope (McCubbin & Patterson, 1981; Houser & Seligman, 1991; Beresford, 1994; Mirfin-Veitch, Bray & Watson, 1996) although this was not as prominent in the blogs as may have been expected, as there were only a few sentences regarding extended family and they appeared to be on the periphery.

Some parents write about how family members are understanding of the child and the parent's situation and others mention that they do not understand or have difficulty accepting the child's diagnosis. This supports research regarding distinguishing between extended family who are supportive and those that are additional stressors (Seligman, 1991), particularly with regard to grandparents who have difficulty accepting a child's diagnosis and the additional stress this can put on parents (Mirfin-Veitch , Bray & Watson, 1997). Furthermore, the importance of social support has been found to positively influence parents' reports of depression and stress (Fleischmann, 2005) and ability to cope (Moltini & Magiolini, in press).

These elements of support, and understanding or not understanding, are also mentioned in terms of friends; however, again they are commented on infrequently. Much of the previous literature has commented on the reduced social networks of families where a child has a disability (e.g. Kazak & Marvin, 1984; Higgins, Bailey & Pearce, 2005). This may be the reason for the limited emphasis on this part of life within the blogs, or it may be, again, that the parents wanted to keep their blogs focused on elements of their experience that they felt would be interesting and informative for their blog readers.

The three research questions outlined at the end of the introduction, have now been considered. It was surprising that family relationships were not mentioned more frequently and that the most dominant relationship appeared to be the relationship that parents had with ASC. An additional relationship that was dominant in the blogs seemed to be the parent's relationship with professionals and wider society. The relationship with ASC has been commented on within the other research questions. However, the relationship with professionals and society was not and due to its dominance within the blogs, it will now be considered under an additional research question.

What themes emerge when parents of children with autism write about wider relationships and social systems when blogging?

Relationship with others/society

Stigma

Many of the blogs mention experiencing stigma and judgement of others, which is an issue that has been commented on within previous discussion of families and in prior research (Goffman, 1963; Turnbull & Turnbull, 1988; Gray, 1993; Gray, 1994; Gray, 2002; Seligman & Darling, 2007). This is an important theme, as social constructionist ideas describe how family constructs of reality are sustained by daily interactions within the family and with the family and professionals, official organisations and wider society (Miller, 1991; Gubrium, 1992; Gubrium & Holstein, 1993; Holstein & Gubrium, 1994).

There are many anecdotes within the blogs which include professionals, other parents and stranger's reaction and attitudes towards the child and the parent. Some of the blogs mention the positive attitudes of others, such as professionals who are helpful and knowledgeable and strangers who are kind and provide assistance during times of crisis. However, a large portion of these anecdotes are in relation to feeling judged, or misunderstood by others or guessing that others may judge or misunderstand them. This again appears to relate to a feeling of not belonging. The research literature suggests that society often holds strong views regarding the social norms that families should abide by and how they should interact and behave (Dallos, 1991). For example, there are frequent mentions of the looks that parents receive from strangers during periods of ‘challenging behaviour’ and feeling judged by professionals, or guessing that professionals will judge their opinions, particularly regarding views on the contentious issues and debates within ASC, such as potential cause, ‘recovery’ versus acceptance and choice of treatment options.

These feelings of being judged may be linked with historical and cultural ways in which ‘disability’ is viewed (Molloy & Vasil, 2002) and how parents, particularly mothers of children with a diagnosis of ASC were historically blamed for their child’s difficulties, such as the ideas of the ‘refrigerator mother’ postulated by Bettleheim (1972). Within the blogs the feeling of being judged is not overtly linked with these ideas and instead is often related to past experiences of actually being judged but the cultural and historical ideas may be covertly part of this dynamic of being judged and feeling blamed. Due to these feelings of being judged many blogs mention the need to hide thoughts and feelings from others, particularly professionals and strangers. This is consistent with previous research, which has found difficult reactions and attitudes from professionals (Blacher & Hatton, 2007). This is an important finding because parents who positively evaluate the services their child receives, such as trusting that professionals have their child’s best interests in mind, have been found to have better outcomes, in terms of their ability to cope with difficulties (Tarakeshwar & Pargament, 2001).

Feeling others don’t understand and feeling different

The comments of others and their perceived attitudes appear to lead many of the parents to feel that others do not and cannot possibly understand them, their child or their situation. In addition to anecdotes that include professionals and strangers not understanding them, there are also frequent mentions of the perceived attitude of society as a whole toward ASC, mainly in terms of misunderstandings that society has regarding ASC. For example, many parents mention that society does not understand the ‘true’ experiences of them or their children. In contrast, some parents comment on times when they did feel that others understood them, for example, the father from blog 3 recalls a time when another father, who also had a child diagnosed with ASC, spoke to him about understanding his situation, following an incident of challenging behaviour.

The feelings of being judged and misunderstood appear to lead many parents to feel different to other people and as mentioned in the previous research questions, there are frequent comparisons of themselves, their child and their family as a whole to other members of society, which are often comparisons which highlight the differences between ‘them’ and ‘us’. This feeling of being different appears to lead to a sense of not belonging within parts of society and sometimes of not trusting others. Thoughts and feelings are sometimes hidden and only revealed when necessary, when it is impossible to hide them any longer, or when parents are sure that they can trust the person and that they will be understood. Previous literature has found that the link between social support and perceived isolation is unclear and that many parents feel a sense of isolated, despite having social support (Dunn et al, 2001), this may be related to parent’s feelings of being different and that others do not and cannot understand them.

Wanting to belong and be understood

Many parents seem to feel that they belong more within the ASC community than they do in society generally, which appears to be due to people within this community being more likely to share their views and experiences and therefore be more understanding. This is in line with recent research, which has found that online support is often sought by parents of children with a diagnosis of ASC, as a way of finding other people in similar circumstances and the feeling of these parents of wanting to be connected and be understood (Reinke & Solheim, in press).

The majority of the blogs, however, mention debates and arguments within factions of the ASC community. It seems that even within the ASC community, there are smaller groups who share similar views and many parents have chosen a particular side on these debates. Other parents seem to have not declared their views on some of these debates and instead seem to prefer to think of the ASC community as a whole and their place within it. Their views on debates, alongside finding value and purpose through sharing their advice on these debates and on other aspects of their experiences, appears to further add to the sense of belonging within this ASC community for some of the parents.

Blogging

Part of the ASC community, which is particularly prominent within the blogs, is the online ASC community. Blogging appears to help solidify this sense of belonging within this particular part of society and many of the parents appear to try to belong to this community through providing entertaining, useful and relevant blogging entries for their blogging audience. Previous literature has found that parents often use the internet to improve feelings of isolation that they experience (Fleischmann, 2005). Blogging also appears to add to the sense of being valuable and having purpose, which seems to be often missing from interactions with society as a whole, outside of their value and purpose to their child as a parent. Previous research has found that parents of children with ASC who blog often go through a period of development during their blog and this research found that themes towards the beginning of blogs tend to be about the difficulties and trying to cope with them and later there are more positive descriptions of self and child, a sense of coming to terms with the diagnosis and there is more sense of mastery and wanting to help others (Fleischmann 2005). Given this research, it is important to note that the present study is capturing a time at the beginning of the blog, which may reflect a time when there are more reports of difficulties and trying to cope with these difficulties.

Implications for future practice

It is important for clinicians to understand how parents frame their own lives and issues they feel are important, we will then be more aware of which areas to focus on and ask questions about, and which areas to research further in the future.

Some of the blogs featured themes regarding feeling the need to hide their thoughts and emotions from professionals, for fear that they would not understand them or for fear that they would be judged. This mistrust of professionals by some parents has important implications for clinical practice and is something that professionals need to be aware of, as these feelings are likely to impact the therapeutic relationship. In addition hidden thoughts and feelings may impact the formulation and direction of any intervention.

In addition the present study seems to have highlighted the different roles of fathers, which has also been found previously (Gill, 1997). It seems that making clinicians and health services more aware that mothers may unintentionally make it difficult for fathers to become involved in the child’s care may highlight a need for clinicians to openly attempt to better engage fathers and meet their needs in order to get them involved more, but also understand what role and support a father can bring which may be different in many ways to a mother.

A further implication for clinical practice is for clinicians to perhaps make service users and families aware of the benefits of the use of the internet chat rooms and blogs for parents of children with ASC as social support, validation and a way of giving and receiving information and advice. The benefits of blogs to help parents feel less alone or alienated when talking to others may help with coping and may even act as an intervention in itself to help combat or prevent the development of possible mental health issues and potential stress. There is the potential that online support may be just as helpful as physical support groups and may provide some protection to families in the way of a sense of anonymity, allowing parents to take more risks in exploring their thoughts and feelings within an environment where they feel they are less likely to be judged and more likely to be understood.

Blogging may provide parents with a sense of being heard and having an outside witness to their story, in a way that may be more difficult in day-to-day life due to this fear of being judged and misunderstood. Michael Whites’ work (2007), amongst others, highlights the importance of outsider witnesses in order for people to receive acknowledgement of the preferred accounts of their lives. Narrative therapists are interested in the many accounts and stories that people tell and acknowledge that lives are multi-storied. However, often the stories that get told about one's life may not be a preferred account and may in fact be a problem saturated account, therefore it is important that when these preferred accounts are allowed to emerge and are witnessed by others. This witnessing can be done by professionals but is often most powerful when the witnesses are members of a community, due to providing a relational context and linking their own lives with others who may be able to relate to their story, or expand and thicken the preferred narrative through questioning and reflecting (White, 2007; Walther & Fox, 2012).

Study limitations

This is a unique piece of research using a relatively new area of enquiry, through the use of analysing the blogs of parents of children with ASC. There is particularly very little research regarding the use of blogs within this group in particular. Although this research could have asked questions directly to families, it is possible that there would have been more self-censoring within this context, particularly when considering the finding that many parents do not feel understood by strangers and professionals and that they therefore hide some aspects of their experiences for fear of being misunderstood or being judged.

The themes that emerged from the data are representative of the researcher's interpretation of the data, this interpretation is unlikely to be the only way of interpreting this data and is influenced by the researchers own social constructions and past experience. It also only represents the views of eight parents who have chosen to blog and it is not expected that this is representative of all parents of children with an ASC who blog, nor of all parents of children with an ASC generally. It does, however, give a general framework from which to attempt to understand the experiences presented by these eight parents at the particular time when they were writing their blogs.

In addition, it is also understood that parents choose what they want to present to others within their blogs and there is likely to be some self-censoring, in which case we are only able to read the aspects of life that the parent wishes to present to the public. Additionally, only a limited portion of time from each blog was analysed, therefore this analysis represents a snapshot in time of views, feelings and interpretations which are unlikely to be static, illustrating the dynamic nature of this form of expression.

In blogs where there was an 'about me' section or a frequently asked questions section, this was analysed, as was outlined within the method section. Both of the blogs used for case studies had a 'frequently asked questions' section, which was regularly updated and both had been updated more recently than the analysed part of the blog. In this section, both of the parents used as case studies wrote about the period of the beginning of their blog being a particularly difficult time for them, which may have skewed the data to some of the more difficult aspects of the experiences of parents of children with ASC. It is also likely, however, to have been particularly significant clinically, as many of the families who present to clinical psychologists will be experiencing distress and difficulty adjusting, as this is the nature of much clinical work.

This was not a homogenous group of people and it was not the aim of this study to find a homogenous group, as it was not intended to be able to represent the entire community of parents of children with ASC from this small sample. However, it is acknowledged that there were many differences within the blogs. The analysed parts of the blogs were written at different times, ranging from 2005-2011 and although all of the parents were located within Western society, mainly based in the USA, their cultural and ethnic background were often not mentioned and it is recognised that the culture and social mores within different parts of the USA are diverse. For example, it has been postulated that members of the Native American community may be less distressed by ‘disability’ in their families and communities than other ethnic groups, due to their cultural values and beliefs (Seligman & Darling, 2007). Given the significant emphasis on societal attitudes and stigma in the themes that emerged from the analysis, the time period and location is likely to have played a large part in the thoughts, feelings and perceptions of the parents within these blogs, meaning that blogs written at a different time or location, may have yielded different themes.

The blogs also differed in terms of length of time since diagnosis, perceived severity of their child’s ASC, the level of the child’s verbal skills, whether there were co-morbid difficulties and whether or not they had other children and if they had also received any diagnoses. All of these elements of the parent’s experience are likely to have influenced their day-to-day lives, their views of ASC, their relationship with their child and their relationships with others, including society.

All of the blogs were written by parents who were still in a relationship with the mother or father of their child, which may only represent a small portion of this community and may have influenced the themes that emerged. In addition, the gender of the parents may have also played a part in the views and relationships of the parents, which is the reason for the selection of a mother and a father for stage 2 of the analysis, however, it may be that a participant group of all mothers or all fathers may have provided different results.

Methodological considerations

The design of the research study needed to be altered during the course of the research, due to the sheer amount of data that was present within the eight blogs during the extraction process. This meant that there was too much data to do a thorough analysis of all eight blogs. There has been transparency regarding this process and the stages that were undertaken within the analysis. However, it is acknowledged that it would of course have been better to have analysed all eight blogs thoroughly, but this was unfortunately beyond the scope of this research. It is also acknowledged that the research questions posed in the introduction may have influenced the researcher's analysis by potentially focusing only on these aspect of the parent's experience.

These potential difficulties were managed through the use of inductive data analysis techniques, which included staying as close to the data as possible by analysing and coding every sentence of all eight blogs, then creating a list of codes during the first stage and undertaking a full thematic analysis of two case studies in the second stage. In addition, the codes and themes were regularly checked by two other researchers to ensure reliability and validity of the codes and themes that emerged.

Future research

This analysis revealed many interesting aspects of parenting a child diagnosed with an ASC. Future research could take this further by analysing and comparing early parts of blogs with later parts, to ascertain any changes in these themes over time. This kind of research has been conducted previously (Fleischmann, 2005; Fleischmann, 2006) but it would be interesting to consider this kind of analysis with a particular focus on family relationships and perhaps also wider relationships and relationships with society.

It may also be interesting to focus in on the experiences of particular demographic groups, such as by only considering blogs of fathers, or by considering views and experience of particular communities, such as the Jewish community. There was a richness of information, particularly within the blog written by the Jewish mother in blog 5, which could provide an interesting case study or be part of a wider analysis of parents of children with a diagnosis of ASC who also identify themselves as Jewish.

Other methods of analysis may also provide further information, for example, discourse analysis may reveal how parents write about their family and the type of language that is used, to further highlight the experiences of parents and how they relate to others. In terms of quantitative analysis for future research, it may be interesting to use questionnaires to examine reasons why parents blog, the type of people that read these blogs and the reasons for reading them. This may also enable investigation of any differences between fathers and mothers use of blogging, as well as investigating different roles and how they may relate to the child or treat the child differently. It may also allow exploration of any difference between mothers and fathers views regarding their understanding of ASC and understanding and managing the child.

Conclusions

The present study has examined themes that emerge from blogs written by parents of children diagnosed with an Autism Spectrum Condition (ASC), with a particular focus on themes regarding the self, the child and family relationships. Two stages of analysis were carried out. The first stage involved a surface thematic analysis of initial codes, which were collapsed into three themes; ‘coping’, ‘searching for an explanation - meaning making’ and ‘sense of belonging versus not belonging’. Two case studies, which differed on many aspects of these themes, were selected for full thematic analysis during a second stage of the study. This second stage of analysis revealed a superordinate theme of ‘searching for an explanation - meaning making’ with two subordinate themes of ‘relationship with ASC’ and ‘relationship with society’. There was much emphasis within the blogs of coping with the impact and dominance of ASC, often through making sense of the diagnosis and making sense of the child and using a variety of coping styles that include hope, avoidance, denial and positive reframing.

There was also an emphasis on stigma and feeling judged as well as feeling that other members of society, including family, friends, professionals and strangers, do not understand them, their situation, their child or ASC. These experiences appear to have led to feeling, at times, that they cannot trust others with their thoughts and feelings and that they are isolated due to a feeling of no longer belonging within society. The ASC community, particularly the online ASC community and blogging appears to help parents to have a sense of belonging and feeling understood by others, who may be having similar experiences and have similar views. These findings are significant for clinical work, by highlighting parent’s experiences and the ways in which they manage their thoughts and feelings regarding the diagnosis, some of which may be more helpful than others in the longer-term. The sense of not belonging and not being understood that emerged from the blogs appears to influence the parents relationship with members of society and include not trusting others and hiding thoughts and feelings from others, including professionals. This highlights the need for professionals to be aware of these potential barriers to accessing services, engaging with any help offered, building a therapeutic relationship and the development of a clear and thorough formulation.

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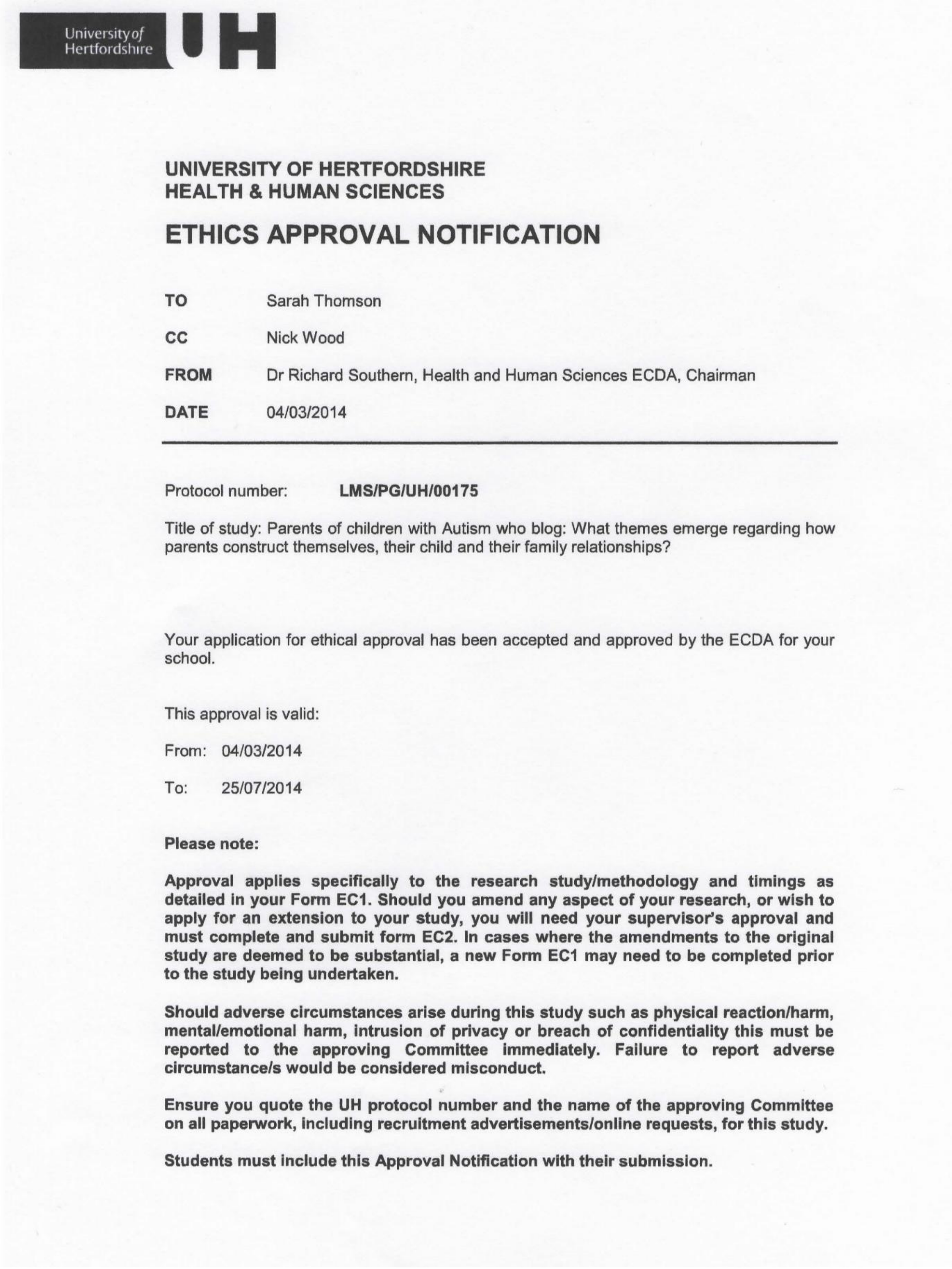
Appendix 1 – Ethical approval



University *of* Hertfordshire UH

UNIVERSITY OF HERTFORDSHIRE
HEALTH & HUMAN SCIENCES

ETHICS APPROVAL NOTIFICATION

TO Sarah Thomson

CC Nick Wood

FROM Dr Richard Southern, Health and Human Sciences ECDA, Chairman

DATE 04/03/2014

Protocol number: **LMS/PG/UH/00175**

Title of study: Parents of children with Autism who blog: What themes emerge regarding how parents construct themselves, their child and their family relationships?

Your application for ethical approval has been accepted and approved by the ECDA for your school.

This approval is valid:

From: 04/03/2014

To: 25/07/2014

Please note:

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1. Should you amend any aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit form EC2. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Students must include this Approval Notification with their submission.

Appendix 2 - Comparing first six months and second six months of Blog 1

List of codes and themes

Key
Black=present in both parts of blog 1
Green=Present in first six months of blog 1
Red=Present in second six months of blog 2
Number=Number of sentences in this blog that could be categorised with this code

Describing child

General
Physical appearance x3 x1
Positive personal attributes/personality characteristics x6 x5
Negative personal attributes/personality characteristics x1 x1
Skills/abilities x4 x11
Likes/loves/interests/favourites x11 x19
Obsessions x3
Dislikes/hates x1 x1
Fears/phobia x1 x2
Difficulties/symptoms related to ASC (general) x7 x4
Difficulties/symptoms related to ASC – language/speech x4 x8
Difficulties/symptoms related to ASC – stimming x2
Difficulties/symptoms related to ASC – echolalia x4 x5
Difficulties/symptoms related to ASC – scripting x3 x12
Difficulties/symptoms related to ASC – lack of TOM x9
Difficulties/symptoms related to ASC – interaction x4 x6
Other difficulties/symptoms x16 x8
Variable symptoms/skills x3
Diagnosis x2
Other diagnoses x1
Child helpless and alone/vulnerable/innocent x4 x4
Physical appearance - smile x1
Child age x1
Child as only child/no siblings x1 x1
Child understands x9
Child doesn't understand x2

Understanding child
Translating/interpreting child language x2 x6
Triggers to challenging behaviour x1 x1
Knowing/understanding the child x4 x10
Normalising x1
Empathising with child x1 x2
'Not even wrong' x2
Labelling/naming behaviours x2
Uncharacteristic behaviour/unexpected behaviour (also in child behaviours) x20 x6
Guessing child thought (also in guessing/mysteries) x5
Guessing child feelings (also in guessing/mysteries) x1
Guessing reason for child behaviour/symptoms (not cause of ASC) (also in guessing/mysteries) x19

Mysterious language (also in guessing/mysteries) x6 x1
Mysterious behaviour (also in guessing/mysteries)
Mysteries (not language or behaviour) (also in guessing/mysteries) x1
Trying to understand (also in coping) x11 x3
Gaining clarity/revelation (also in guessing/mysteries) x6 x12

Comparisons
Comparing child with other ASC kids – similar x4 x2
Comparing child with other ASC kids – differences x1 x2
Comparing child with 'typical' kids – similar x1 x1
Comparing child with 'typical' kids – differences x2 x3
Comparing child with self – similar x1 x3
Comparing child with self – difference x1
Comparing child with partner – similar x1 x1
Comparing child with literature – similar x4 x9
Comparing child with literature – difference x1 x1

Child Behaviours
Describing behaviour/activities generally x4 x9
Coping x1 x7
Past behaviours x6
Expected/usual behaviour x5 x1
Odd behaviour x1
Uncharacteristic behaviour/unexpected behaviour (also in understanding the child) x20 x6
Repetitive behaviour x1 x2
Play x5 x9
Mysterious behaviour (also in guessing/mysteries) x2 x2
Displays of affection x4
Interaction with objects x1
Funny things child does x2 x3
Avoidance/resistance/reluctance x2 x4
Copying x1
Making friends x1 x3

Child feelings
Tired x1
Worry/anxiety x1
Grateful x1
Delight x1
Confused/bewildered x1
Dismay x1
Upset/distressed/sad x7 x3
Joy/enjoyment/happy x1 x1
Irritable x1
Child pride in self x3
Expresses difficult feelings best x1

Child language
Mysterious language (also in guessing/mysteries) x6 x1
Funny things child says x4 x7
Child use of language/describing speech/unusual use of language x7 x26

Responses/reactions
Reaction to therapy/treatments x1

Challenging behaviour
68) Challenging behaviour – aggression x1 x3
69) Challenging behaviour – meltdowns/tantrums x4 x5
70) Challenging behaviour – other x2 x3

Progress
Progress x19 x27
Lack of progress x3
Still a work in progress/some progress but not enough x3 x2
Things we're 'working on' x1 x1
Progress due to treatment x6 x3
Breakthrough x1
Nothing works (also in own thoughts & managing behaviour) x1 x1
Regression x3 x1
Hard to gauge results/questioning if progress is a coincidence x3
Goals (also in philosophy & own thoughts) x1
Mixed results x2
Things child has to learn x3 x1

Describing Self

View of self generally
Likes/loves/interests/favourites x12 x5
Strengths/abilities x3
Personality x3
Obsessions/addictions x1
Self in other roles x1 x9
Self as not an expert x1
Self as expert x1
Desires/wants x4 x4
Music as statement/identity x1

Own Weaknesses
Weaknesses x1 x1
Mistakes x4 x2
Blaming self (also in own thoughts) x1 x2
Difficulty managing (also in stress)

Own Feelings
Hidden feelings x3
Helplessness/powerlessness x1
Hopelessness/not hopeful x2 x1
Pride (generally not pride in child) x2
Irritation x2 x1
Worry x2
Hope/Faith (also in coping) x7 x8
Anger x1
Overwhelmed x2 x1
Panic/anxiety x2 x2
Anticipation x2
Frustration x1
Guilt (link with blaming self?) x1
Sadness/'down' x1
Grief x7
Disappointment x2

Excited x1 x2
Surprise/shock x4
Relief x1
Fear/dread x2
Tired/lack of stamina/exhausted x1
Emotional pain/heartbroken x1 x3
Desperate x1
Confused x2
Happy/delighted/pleased x5
Despair x5

Events and activities
Unexpected event x1
Usual day/expected events and activities x3
Good/amazing day/weekend/year x1 x3
'Autistic day' x1 x1
Predicting the future (also in own thoughts & guessing/mysteries) x1 x3
Anticipating difficulties (also in guessing/mysteries & own thoughts) x1 x3
Busy life/day/weekend x1
Recent events x6
Upsetting/difficult incidents x2 x2
Successful event x3
Favourite moment x2
Stressful day x1
Milestones x2
Transitions (not school) x3

Own Thoughts
Fascinated by child x1
Feeling blamed x1
Predicting the future (also in guessing/mysteries) x1 x3
Anticipating difficulties (also in guessing/mysteries & events and activities) x1 x3
Worries for future x3 x1
Worries about what others think x1
It will be worth it/it is worth it x1
Being lucky/could be worse (also in philosophy) x1
Goals (also in progress & philosophy) x1
Decisions/choices x7 x2
Dilemmas (also in own philosophy) x3
Uncertain of what to do x3 x3
Nothing works (also in child progress & managing behaviour) x1 x1
Inspired x1 x2
Sceptical (way of coping?) x1
Blaming self (also in own weaknesses) x1 x2
I was right/right decision x1 x1
Questioning own decisions/actions x1 x6
Questioning own thoughts x1
Questioning own understanding x1
Impact of child difficulties generally (also in parenting) x1 OVERARCHING?
Sacrifices/things they do/can't do due to child difficulties (also in parenting) x7
Preoccupation x2
Going on too long x1
Reason for only child x5
Fears x1 x2

Worse than I thought x1
Not his fault x1
Life as challenging x1
Child growing up x1
Comparing child pre and post diagnosis x1
Comparing self and article x1

Own Thoughts on ASC
Diagnosis queries/questions x1
Disagree with diagnosis (not ASC) x1
Comparing life pre/post diagnosis/way life is different x1
ASC as dominant x2
No one size fits all/individual differences (also in philosophy) x1
Normalising x1
Life with ASC x1 x3
Feelings about ASC x1
Reaction to diagnosis x1
Daily struggle/battle/fight x1 x1
Many ASC kids wouldn't have made it 20 years ago x1

Guessing/mysteries
Guessing others views of self (also in view of self & relationships/interactions) x1
Guessing stranger thoughts (also in community and society) x3 x1
Guessing stranger reactions (also in community and society) x2
Guessing stranger motivations (also in community and society) x4
Guessing child reaction/predicting behaviour (also in understanding child) x1 x3
Guessing child thought (also in understanding child) x5
Guessing child feelings (also in understanding child) x1
Guessing reason for child behaviour/symptoms (also in understanding child) x19
Mysterious language (also in understanding child) x6 x1
Mysterious behaviour (also in understanding child) x2 x2
Other mysteries related to child (also in understanding child) x1
Trying to understand (also in coping) x11 x3
Gaining clarity/revelation (also in understanding child) x6 x12
Looking for answers (also in coping & understanding child) x4 x1
Difficulty assessing child x4
Predicting the future (also in own thoughts & events and activities) x1 x3
Anticipating difficulties (also in events and activities & own thoughts) x1 x3

Own behaviours
Crying x2

Own history
Own past experience (also in view of self) x4
Pregnancy x1
Learning lessons from past x1
Diagnosis process x1
Past life events x3
Past thoughts x1
Past feelings x2
Past ambitions x1

Coping
Support x1

Distraction/escape/break x6 x2
Hiding feelings x3
Acceptance x1
Developing/changing/adjusting self (Maybe overarching theme?) x2
Finding meaning x9
Faith/hope (not religious faith) (also in own feelings) x7 x8
Helping others x2 x1
Research/reading x12 x18
Planning/preparing (also in managing behaviour) x1
Blaming others x1 x3
Normalising x1
Learning what works (Maybe overarching theme?) x5
Trying things/trial and error/taking a risk x1 x2
Not taking a risk/being cautious x1 x1
Humour x3
Educating others (also in community and society) x3
Problem solving (also in managing behaviour) x1
Looking for answers (also in guessing/mysteries) x4 x1
Telling others about ASC (also in managing behaviour & community and society) x3
Learning from others (also in ways of managing behaviour) x2
Not expecting miracles/no right answer x3
Trust professionals vs not trust professionals x5
Celebrate x1

Ways of managing challenging behaviour (maybe coping?)
Trying things/trial and error/taking a risk x1 x2
Problem solving (also in coping) x1
Planning/preparing (also in coping) x1
Preparing professionals (also in managing behaviour) x1
Gadgets/tools/equipment x1
Structure/routine x1
Negotiation (also in interaction with child) x2
Removing child x2 x1
Learning what works x3
Learning from others (also in ways of managing behaviour) x2
Positive reinforcement/reward x2
Praise (also in interaction with child) x1
Reassurance x1
Riding it out/letting it play out x1
Nothing works (also in own thoughts and child progress) x1 x1
Distraction/engagement in activities x2
Giving in/relenting x1
Slow pace x1
Declarative communication x1
Quiet x1
Early warnings x1

Own Philosophy
No one size fits all/individual differences (also in philosophy) x1
Normalising x1
Values x1
Being lucky/could be worse (also in thoughts) x1
Children need…
‘Normality’ (not related to child) x6 (overarching?) x2
Dilemmas (also in own philosophy) x3

Sceptical (way of coping?) x1
'The truth' vs what choose to present x3
Religious beliefs (not as coping) x1
Goals (also in progress & own thoughts) (merge with wants/desires) x1
What ifs x2

Parenting
Parenting role/responsibilities x13
Parenting beliefs x4
'Shoulds' in parenting x2
ASC parents & families generally x7
Identity as ASC parent x1
Using instinct/intuition x3 x3
Expectations of being a parent vs reality of being a parent x1
Comparing self and other parents/families x2 x5
Other ASC parent's views x3
Shared experience (also in relationships/interactions & community and society) x6
Respect for other parents x1
Other ASC parent's way of coping x1
Other parent's action x1

Describing other family members

Describing partner
Skills/abilities/strengths x1
Actions x1
Shared activities with child x1 x3
Shared action/activities between parents x1 x1
Shared thoughts/philosophies of parents x1 x1
Shared feelings of parents x1
Working together as parents x1 x2
Partner's diagnosis/difficulties x3
Assuming/guessing partner's feelings x2
Conversation with partner (also in own relationships/interactions) x1
Non-verbal interaction with partner(also in own relationships/interactions) x1 x1
Partner speech/words x1
Partner worry for child future x1
Partner reaction to child behaviour x1
Partner helpless x1
Partner hopeless/not hopeful x1
Partner interaction with child x2 x3
Child and partner affection x2
Child attachment to partner x2

Describing child's sibling
Reason for child having no sibling x5
Miscarriages/losses x3

Describing family relationships

Own Interaction with child
Interaction with child generally x2 x5
Explaining to child x3

Teaching/instructing/practicing/prompting/home therapy child x1 x12
Negotiation with child (also in managing behaviour) x2
Testing the child x1 x7
Encouraging child x1 x4
Praising child x1
Seeking opportunities for the child x1 x1
Shared activities x1 x8
Shared interest self and child x1 x2
Protecting child x2
Conversation with child x5 x16
Repetitive conversations x2
Favourite moments x2
Child understands mum x1
Child attachment x1 x2
Affection x3
Reassuring/calming child x2 x1
Child seeking mum support x1
Child trusts mum x1

Own Feelings towards child
Pride in child x4 x1
Love x1 x1
Dreams/desires/wants for child x4 x4
Impressed x1

Own Relationships/interactions partner
Conversation with partner (also in partner) x1
Non-verbal interaction with partner(also in partner) x1 x1
Shared activities with child x1 x3
Shared action/activities between parents x1 x1
Shared thoughts/philosophies of parents x1 x1
Shared feelings of parents x1
Working together as parents x1 x2
Partner as support
Shared family activity
Family joke x1

Own Relationships/interactions family & friends
Family/friends reaction to child behaviour x1
Family/friends description of child x1 x1
Own conversation with family member/friends x1

Child Interactions with family members
Child interaction with partner x2 x3
Child interaction with extended family x3 x3
Family/friends instructing the child x1

Child Interactions with others
Child interaction with other children x5 x8
Child interaction with strangers x2 x1
Child interaction with therapists/professionals x4

Partner Interactions with friends/family members
Partner working together with extended family x1

Extra codes and themes/misc

Describing wider relationships and society

Own Relationships/interactions with professionals
Preparing professionals (also in managing behaviour) x1
Agreeing with professionals x1
Disagreeing with professionals x2 x1
Working together with professionals x6
Professional advice/instruction x2
Professional description of child general x2 x2
Professional description of child – difficulties x2 x4
Professional - comparing child and other ASC children - different x1
Professional description of child - response to therapy/progress x2
Professional reaction to child behaviour x2
Trust professionals x1
Mistrust professionals x4
Professionals listen x1
Feelings about professionals x2
Guessing professionals thoughts/feelings x1 x2
Conversation with professionals x1
Professionals understand parents x2
Professionals understand child x1 x2
Professionals don't understand parents x1
Professionals don't understand child x2
Professionals don't know everything
Consulting professionals/seeking advice/seeking support x1 x2
Describing professional x4
Professionals uncertain/overwhelmed x1
Professional reaction to mum – shock/surprise x1
Professionals should understand x1
Feeling let down by professional x1
Professional competence x1
Professional incompetence x1
Grateful to professionals x1
Professionals go above and beyond x2
Giving advice/sharing articles/treatment plan with professionals x3
What mum expects of professionals x2
Professionals meet expectations x1

Community and society
Own Interaction with strangers (also in community and society) x2 x2
Guessing stranger thoughts (also in guessing/mysteries) x3 x1
Guessing stranger reactions (also in guessing/mysteries) x2
Guessing stranger motivations (also in guessing/mysteries) x4
Kindness of strangers x5 x2
Telling others about ASC (also in coping & managing behaviour) x3
Other children's reaction to child x3 x4
Others listen x1
Others don't understand x1 x1
Child being left out/excluded x1
Advice of others who don't understand x2
Conversation with other mums (known) x1 x2

Conversation with other mums (unknown) x2 x1
Guessing others views of self (also in view of self & guessing/mysteries) x1
Stigma (maybe overarching) x1 x3
Public vs private image x2
ASC in the news x2
Wishing others understood x2
Others helpful x3
Explaining situation to others x2
Describing other children x5 x3
Worries about what others think x1
Others are judgemental x2
Agreeing with author x1

Quotes from others
Other people's words (professionals) x1
Other people's words (authors/poets) x2 x5
Other people's words (researchers) x2
Other people's words (authors who are parents of children with ASC) x1 x1
Other people's words (newspaper article) x1
Other people's words (other bloggers) x1 x1
Other people's words/speech (partner) (also in describing partner) x1

Interaction with blog readers
Giving advice/recommendations/instructions x1
Asking for advice (merged with questions to readers) x1 x2
Asking for sharing of experience x1
Asking readers for donations/support to a cause/charity x1
Guessing readers thoughts/reactions/questions x1
Describing another blog x11
Link to other websites (non-ASC) x1
Link to petitions (non-ASC) x1
Describing past posts x3
Own comment on post x1
Blog set up/philosophy/description x2 x1
Addressing audience/readers x2

Own reactions
Reaction to article x2 x6

Debates
Cure/recovery vs acceptance x7
Causes of ASC x2 x11
Credibility x5
Morally questionable behaviour x5
Medication x3 x1
Thoughts on debates x6
'Parent wars' x2

Schooling
Describing school x3 x4

Community (general descriptions)
Local community x1
ASC community x1 x3
Online community x1 x1

Stigma x1 x3

Political issues
Politics generally x4 x3
News report x5 x4
Own reaction to news report x1 x1
Future research x1
Pharmaceutical companies x5
Blogging event x1

Misc codes/themes

Writing style/blogging generally
Humour x3
Sarcasm x1
Analogies/metaphors to explain x3 x8
Setting the scene x1 x2
Reason for blog/post x1 x2
Photos/Videos/Audio/Cartoons x1 x5
Stories of other people's lives x2 x1
Impact of blog on self x2
Impact of blog on others x2 x1

ASC generally
Describing ASC symptoms/difficulties generally x7 x6
Causes of ASC x2 x11
Research theories/literature x16

Treatment/therapies/assessments
Assessments generally (not ASC assessments) x6
OT x3
Chelation x1
ABA x4
Vitamins/supplements x2
Medication x16 x3
Equipment x2
Social stories x1 x1
Sensory diet x1
Craniosacral therapy x3
RDI x1 x4
Sensory Integration Therapy x1
SCERTS x5
Reward charts x2
Visual schedules x1
Early intervention x1
View of treatment x5
Treatments that didn't work x2
Treatment worked x1 x1
Treatment mixed results x1
No cure/no miracles/not perfect x4
Therapy intensive and hard work/complicated x1
Trying a few treatments at once/list of interventions x2
Side effects & negative side of therapy/treatments x5
Value of medication x1 x2
Remediation vs compensation therapies x5

Difficulties with treatments generally x1
Treatment choice/process overwhelming x2

Other
Describing organisation x2
Pop culture/cultural figure x3
Describing ASC book x5 x7
Describing ASC essay x1
Describing ASC documentary x1
Describing seminar/conference relevant to ASC x4
Describing non-ASC book x8 x7
List of books bought and read x3
Describing non-ASC dvd/film/TV show x3 x1
Describing music/songs x4 x6

Appendix 3 - Reason for choosing Blogs 2 and 3 as case studies – similarities and differences

	Demographics	**Blog 2**	**Blog 3**
	Gender of parent	Father	Mother
	Age of child	Child aged 8 (oldest of all blogs)	Child aged 5
	Time since diagnosis	6 ½ years (longest time of all blogs)	2 years (among the shortest time of all blogs)
Overarching themes	**Major themes**		
Coping	Finding value & purpose	Blog as 'venting'	Blog as 'venting'
		Very little advice giving and reports not wanting to give advice to others	Some advice/information giving regarding cause of ASC and treatments
	Humour	A lot of use of humour	Very little humour and lots of anger. A lot of sarcasm but appears to be due to anger rather than humour.
	Escape/avoidance	Much escape/avoidance and mention of hobbies and interests both inside and outside the house	Very little escape/avoidance. No mention of hobbies/interests.
	Hope	Hope for improvement but not 'cure'	Hope for complete 'recovery'
Searching for an explanation - Meaning making	Making sense of diagnosis	Does not believe that vaccines caused ASC	Strong beliefs in vaccines and subsequent toxic overload as cause of ASC
		Similar treatments tried to blog 3. However, now seeking 'traditional therapies' only. Previously tried 'bio-medical' treatments but felt they made his child 'regress'	Similar treatments tried to blog 2. Seeking change and recovery through any means including 'traditional' and 'biomedical'/ 'alternative' treatments
	Trying to understand child	Evidence of trying to understand child idiosyncrasies, comparing child with others and learning what works	Evidence of trying to understand child idiosyncrasies, comparing child with others and learning what works
		Little mention of reading and research	More mention of reading and research
		When comparing the child with others and feeling things could be better there is a sense of acceptance	When comparing the child with others and feeling things could be better there is a sense of seeking further change and improvement
Sense of belonging	Stigma	Reports feeling different to others	Reports feeling different to others
		Feels society does not understand his situation	Feels society does not understand her situation
		Trusts professionals	Mistrusts most professionals

Appendix 4 – List of codes from Stage 2 of analysis

Key
Black=present in both blogs
Green=Present in blog 2
Red=Present in blog 3
Number=Number of sentences in this blog that could be categorised with this code

Describing child

General

Nicknames x2 x5
Physical appearance x10
 -smile/laugh x9 x3
Skills/abilities x2
 -fast x1
 -learns quickly x2
Likes/loves/interests/favourites x8 x7
Fears/phobia x1
Difficulties/symptoms related to ASC (general) x3 x21
Difficulties/symptoms related to ASC – language/speech x10 x13
Difficulties/symptoms related to ASC – stimming x25 x9
Difficulties/symptoms related to ASC – echolalia x2
Difficulties/symptoms related to ASC – scripting x4
Difficulties/symptoms related to ASC – lack of social awareness x6
Difficulties/symptoms related to ASC – interaction x2 x1
Other difficulties/symptoms x15 x43
Not interested x2
Past difficulties x4
Diagnosis x5 x18
Other diagnoses (potential) x1 x8
Personality – stubborn/insistent x3
 Impatient x3
 friendly x1
 cute x7
 amazing x1
 sweet x1
Child helpless and alone/vulnerable/innocent x6 x4
'Small'/'little'/'little boy' x5
Child not that bad x2
Angel x1
Child age x3 x4
Child as only child/no siblings x5
Severity of ASC x3 x14
'Back to normal' x1
Child as dominant x4

Understanding child

Translating/interpreting child language x2
Normalising child difficulties x1
Guessing child reaction/predicting behaviour (also in guessing/mysteries) x4 x30
Guessing child thought (also in guessing/mysteries) x1
Guessing child feelings (also in guessing/mysteries) x1
Guessing child expectations x1

Guessing reason for child behaviour (also in guessing/mysteries) x16 x1
Mysterious behaviour (also in guessing/mysteries) x9
Mysteries (also in guessing/mysteries) x7
Trying to understand (also in coping) x2 x4
Gaining clarity/revelation (also in guessing/mysteries) x4 x4

Comparisons
Comparing child with other ASC kids – similar x1 x2
Comparing child with other ASC kids – differences x1 x9
Comparing child with 'typical' kids – similar x2
Comparing child with 'typical' kids – differences x5
Comparing child with self – similar x2
Comparing child with self – difference x1
Comparing child with partner – similar x1
Comparing child pre and post ASC diagnosis – things that are different x4 x3
Comparing child and other disability x1 x1
Comparing child with dog x1
Would be better if child was high functioning x1
Would be worse if child was high functioning x1

Child Behaviours
Describing behaviour/action generally x43 x19
Coping x3
Past behaviours x6 x3
Worse in the past x1
Expected/usual behaviour x14 x3
Odd behaviour x1
Unexpected behaviour x16 x7
Repetitive behaviour x6 x5
Unpredictable/inconsistent behaviour x1
Dangerous x1
Play x1
Displays of affection x1
Avoidance/resistance x6 x4
Copying x1
'Didn't mean it' x1
Behaviour not pleasant x1
Behaviour not devilish x1
Child as curious x1
Child crying x5
Madness/crazy x1

Child feelings
Tired x1
Excitement x4
Confused/bewildered x2
Upset/distressed x3
Joy/enjoyment x4
Happy/cheerful/'good mood' x9 x2
Overwhelmed x1

Child language
Child use of language/describing speech x29
Wants/requests x1

Challenging behaviour
Challenging behaviour – aggression/'fighting' x8 x1
Challenging behaviour – meltdowns/tantrums x12 x9
Challenging behaviour - 'going insane' x2
-'fussing' x1
-'lost it' x1
– other x9 x4
No meltdowns x3 x1

Progress
Progress x69 x20
Lack of progress x3 x12
Reason for progress x1 x2
Trying to work out reason for progress x1
Still a work in progress/some progress but not enough x14 x2
Progress due to treatment x4 x11
Regression x4 x15
Guessing reason for regression x1 x1
Questioning if progress is a coincidence x9
Hard to gauge results x1
Expect progress x4 x1
Still not 'recovered' x1
Cool/amazing to see progress x2
Previous progress x1
Nothing works x2
Past skills x1
Things child has to learn x1
Happiness vs progress x2
Does better in school x1
Short-term progress x1

Describing Self

View of self generally
Likes/loves/interests/favourites x2 x12
Dislikes/hates x3 x2
Strengths/abilities x3
Personality -determined/stubborn x5
-organised x2
-accepting x1
-understanding x1
-resilient x1
-'a crier' x1
-negative x3
-not mushy x1
Obsessions/addictions x3
Self in other roles x8
Self as not an expert x2
Feeling different/comparing self and others x1
Comparing others perception of self with own x1
Age x3
Medical issue x1
Desires/wants/wishes x18 x12
Dreams/desires/wants for child x11

Comparing self with children and after x3
Comparing self and children with ASC – similar x1
Comparing self and book – similar x1
Mum speech x26
Things he doesn't want x1

Own Weaknesses
Weaknesses x1 x12
Mistakes/'I was wrong' x10 x7
Difficulties/diagnoses x1
Madness/Crazy (also in child reaction/responses) x2 x5
Hang ups/irritations x5
Not perfect x5
Not worried about weaknesses/failings x1

Own Feelings
Hidden feelings x5 x3
Helplessness/powerlessness x2 x1
Hopelessness/not hopeful x2 x3
Pride (generally not pride in child) x1 x1
Regret x4
Embarrassment x2 x2
Not embarrassed x1
Irritation x2 x5
Worry x8 x9
Hope/Faith (also in coping) x23 x15
Dashed hope x4
Anger x25 x5
Panic/anxiety x2 x3
Frustration x11 x14
Sadness/'down'/upset x12 x4
Grief x2 x4
Disappointment x10
Excited x9
Surprise/shock x15 x6
Relief x1 x1
Fear/scared x4
Feeling trapped x3
Tired/lack of stamina/exhausted x5 x3
Resignation x1
Emotional pain x1
Envy x5
Nervous x1 x1
Desperate x1 x2
Incredulous/disbelief x21 x7
Paranoid x1
Happy/pleased/joy/ecstatic x9
Confused x4
Depressed x2
Fed up x1
Admiration x3
'Sigh'/'deep breath' x9
Unexpected feelings x1
Heartbreaking x1
Past feelings x5

Rollercoaster of emotion x1
Reluctance x2
Impact of own feelings on family life x2

Stress
Everyday stress/stress generally x5
Stress related to child difficulties x3
Stress with professionals x3
No pressure/stress x1

Events and activities
Unusual day/event x1
Usual day/expected events and activities/typical day x7 x52
‘Bad day’/week x1 x1
Good day/week/times x6 x1
Glorious event/day x3
Bad news x1
‘Autistic day’/’autism moment’ x1
Waiting x9
Predicting the future (also in own thoughts & guessing/mysteries) x2
Anticipating difficulties (also in guessing/mysteries & own thoughts) x7
Recent events x6
Humorous incidents x1
Successful event x2 x2
‘Drama’ x1 x1
‘Insane’/’crazy’ x2 x4
‘Nice experience’ x13 x2
Upcoming event x7
Lucky event/circumstance (could have been worse) x12
Beautiful day x1
Perfect day x1
Heaven x2
Unplanned/just happened (not event) x4
Had some fun despite difficulties x2
No fun/not fun/not funny x3
Amazing evening x1
‘Circus’ x1
Going well x1
Event could have been better x1
Worse than expected x1
Rollercoaster year x1
Event ‘miserable’ x1
‘Tough’ day/year x2
Not exciting x1
Some good mainly bad x2
Plenty of bad days x1

Own Thoughts
Predicting the future (also in guessing/mysteries) x2
Anticipating difficulties (also in guessing/mysteries & events and activities) x7 x2
Worries for future x4 x1
It will be worth it/it is worth it x1
Being lucky/could be worse (also in philosophy) x1 x8
Expectations x2

Goals (also in progress & philosophy) x2
Decisions/choices x2 x25
Having no choice x4 x2
Dilemmas (also in own philosophy) x8
Uncertain of what to do x4 x6
Nothing works (also in child progress and managing behaviour) x2
Sceptical (way of coping?) x2
It's just how it is/deal the hand you're dealt x3 x1
Unexpectedly easy x2 x4
Don't care what other people think x1 x1
I was right/right decision x1
Self talk/questions to self x4 x6
Questioning own decisions/actions x3 x1
Questioning own thoughts x2
Questioning own understanding x1
Impact of child difficulties generally (also in parenting) x1 x14
Sacrifices/things they can't do due to child difficulties (also in parenting) x2 x6
Feeling different/comparing self & life with others (also in view of self) x2
Grass is always greener x3
Preoccupation x1 x4
Not wanting to rock the boat/quit while ahead x3
Not that positive/negative x3 x4
Falling into trap x1
Thoughts on thoughts x1
Miracle x1
Repetitive thoughts x1
Waste of time x4 x1
Going on too long/something has to change x1 x1
Going on too long/felt like a long time x5
Nothing I can do x1
Fears x4 x1
How life may have been different x1
Glutton for punishment x1
Hard to see good times x2
Need for precision x3
Needing to give 'perfect' answers x1
'Can't help how I feel' x1
Angry at self x1
Not angry with child x1
Do everything I can/everything in my power x2
'Who knows x1
Pick your battles x1
Thwarted plans x1
Never a dull moment x1
'Sad what you come to admire' x1
Excitement overshadowed by child difficulties x1
Not perfect x1
Hard to rebound from frustration x1
Feel sorry for disabled children x1
Past hopes x1
Will take 30 steps forward and 2 steps back ANY TIME! x1
Stupidly hopeful x1
Feeling stupid x2
Want to escape/disappear x3
No price on health of child x2

Don’t understand world x1

Own Thoughts on ASC

Coming to terms with diagnosis x1 x4
Comparing life pre/post diagnosis/way life is different x4 x6
Hardest part of having a child with ASC x10
ASC as dominant x4 x71
Normalising ASC symptoms/difficulties (also in philosophy) x1
Life with ASC x4 x73
Feelings about ASC x1 x7
ASC awareness (also in coping) x2
Cause of ASC x25 x12
Impact on finances x14 x13
Impact on professional life x1
Reaction to diagnosis x6 x5
Still having a hard time/still dealing with it x1 x2
ASC as unfair x3 x2
Daily struggle x1
ASC a bad/dark side x2
Religion and ASC x2 x4
Rollercoaster/ups and downs x3
Thought it would get easier/doesn’t get easier x2
Impact on self – ugly version of self x1
Stimming as reminder of ASC x1
Frustration makes mum cry x1
Happy for other ASC parents whose kids recover x1
ASC as mysterious x1
ASC as difficult/hard x2
ASC makes mum cry x1
Angry at ASC x1
Describing ASC kids – all it takes is a second x1

- Comparing thoughts to song lyrics x1

‘Autism daze’ x1
‘Autism world’ x3
ASC sucks x1
Tired of explaining ASC x1

Guessing/mysteries

Guessing stranger thoughts (also in community and society) x1
Guessing child reaction/predicting behaviour (also in understanding child) x6
Guessing child thought (also in understanding child) x8
Mystery thoughts x2
Guessing child feelings (also in understanding child) x1
Guessing child understanding x14
Guessing child expectations x1
Guessing reason for child behaviour/symptoms (also in understanding child) x16 x7
Mysterious behaviour (also in understanding child) x9 x7
Mysteries (also in understanding child) x7
Trying to understand (also in coping) x2 x4
Gaining clarity/revelation (also in understanding child) x4 x4
Looking for answers (also in coping & understanding child) x11
Predicting the future (also in own thoughts & events and activities) x2
Guessing reason for behaviour of others (also in community and society) x2
Anticipating difficulties (also in events and activities & own thoughts) x7 x2

Own behaviours
Own actions/activity x11 x5
Over exaggerating/Overanalysing x1
Crying x9
Giving up (also in coping) x2 x6
'Usual' behaviour x1
Thing she wouldn't do x1

Own history
Own past experience/life events (also in view of self) x6 x10
Childhood/upbringing/family history x2 x3
Learning lessons from past x1
Diagnosis process x3 x1
Past routine/activity x1
Past behaviour/action x3 x2
Past skills x2
Past ambitions x2
Past thoughts x1 x2
Past feelings x5 x6
Past upsetting/difficult incidents x4
Comparing current and past event – similar x1
Embrace experiences x1
Being negative x3
Child happiness gets her through negative stuff x1
Belief in recovery x14
Stay firm despite mainstream beliefs x1

Coping
Support x12 x5
Distraction/escape/break x7 x7
Showing feelings x9
Hiding feelings x5 x5
Acceptance x4 x4
Developing/changing/adjusting self x1
Seeking advice of others/research/reading x11 x9
Finding meaning x2
Religious faith x1 x2
Faith/hope (not religious faith) (also in own feelings) x23 x15
Avoidance (not about behaviour) x1 x2
Planning/preparing (also in managing behaviour) x26 x6
Blaming others x6 x1
Normalising x1
Learning what works/finding what works x5 x1
Trying things/trial and error/taking a risk x2 x6
Not taking a risk x1 x1
Humour x5 x18
Sarcasm x32
Sceptical x2
Educating others (also in community and society) x1
Raising awareness/campaigning/supporting organisations (also in community and society) x1
Helpful books x1 x1
Looking for answers (also in guessing/mysteries) x11
Telling others about ASC (also in managing behaviour & community and society) x3
Service dog x1
Cleaning woman x1

Antidepressants x4
Exercise x1
Blog as coping x3 x2
Care less x2
Less expectation x1 x1
Giving up x2 x6
Seeing similarities in book x1 x1
Not expecting miracles x1 x4
Trying to move forward x1
Fighting for child x1
Trust professionals x1 x1
Anger x25 x5
Leave it to partner x1

Ways of managing challenging behaviour
Ignoring x1
Reassurance x1
Explaining x4
Reasoning x1
Telling others about ASC (also in coping & community and society) x3
Preparing professionals (also in managing behaviour) x2
Physical intervention x9
Removing child x3
Rescuing child x3
Riding it out/letting it play out x3 x1
Nothing works (also in own thoughts and child progress) x2
Tending wounds x1
Distraction/engagement in activities/redirecting x5 x4
Stay calm x2
Making child apologise x1
Finding cause x1
Giving in x2
Not giving in/not giving up x2
Service dog x1

Own Philosophy
Normalising ASC symptoms/difficulties (also in thoughts on ASC) x1
Being lucky/could be worse (also in thoughts) x1 x8
'Normality' (not related to child) x1 x6
Dilemmas (also in own thoughts) x8
Sceptical (also in own thoughts) x2
'The truth' vs what choose to present x13 x1
Religious beliefs (not as coping) x2 x4
It's just how it is/deal the hand you're dealt (also in own thoughts) x3 x1
Live each moment x1
What ifs x1 x2
If only x1
Pick your battles (also in own thoughts) x1

Parenting
Parenting role/responsibilities x1 x54
'Shoulds' in parenting x3
ASC parents & families generally x9 x5
Typical vs ASC families x1 x1
Identity as ASC parent x3

Comparing self and other parents/families x10 x19
Other ASC parent's views/feelings x6 x4
Shared experience (also in relationships/interaction & community and society) x1
Disagreeing with other parents x5 x3
Understand other parent's views x1 x1
Impact of child difficulties generally (also in own thoughts) x15
Don't understand other parent views x1
Guessing motivation of ASC parents x1
Sacrifices/things they can't do due to child difficulties (also in own thoughts) x2 x6
'Parent wars' x1
Need to work together x4 x2
Resisting inappropriate school x1
Complying with inappropriate school x1
Doing his best/ordinary dad x1

Describing other family members

Describing partner
Partner positive qualities x3
Partner personality x1
Likes/loves/interests x7
Dislikes/hates x1
Roles/responsibilities as a parent x58
Partner professional role x3
Partner proactive/goes above and beyond x4
Behaviours/actions x9 x7
Shared activities with child x3
Shared action/activities between parents x12
Shared feelings of parents x2
Working together as parents x2 x55
Disagreement x1 x5
Fighting for child x3
Partner views on child x1
Partner diagnoses/difficulties x1
Conversation with partner (also in own relationships/interactions) x3 x70
Partner speech/words x3 x54
Partner stress x2
Partner thoughts/philosophies x2 x3
Partner past feelings x1
Partner anger x1 x1
Partner embarrassed x1
Partner frustration x1
Partner sadness x1
Partner excited x1
Partner reaction to child behaviour x1 x2
Partner was right x1
Partner wanting to be anonymous x1
Partner not wanting others to know about child difficulties x1
Out of her mind x1
Partner description of the day x3
Partner advice x1
Partner reaction to blog x1
Partner view on debates x1
Partner suggestion x1
Partner mocking mum's views x1

Partner coping – escape x1
Partner support x9
Partner mistakes x1

Describing child's sibling
Reason for child having no sibling x2

Describing extended family
Describing own sister x2
Describing own dad x1
Describing own parents x1

Describing family relationships

Own Interaction with child
Interacting with child generally x1
Physical interaction x1
Observing the child x1 x1
Talking to child (not about behaviour) x1
Explaining to child (not about behaviour) x6
Teaching/instructing child x13 x13
Making child apologise x2
'Nagging' child x1
Scolding child x1
Testing the child x3
Encouraging child x4
Praising child x1 x2
Comforting child x1
Day-to-day activities x1
Special moments x1
Shared activities x3
Protecting child x2
Conversation with child x6 x7
Child understands mum x1
Child attachment x5
Affection x1 x1
Child seeking reassurance/help from mum x8
Rescue child x1
Rebuilding child trust x1
Mum helping child x2
Child copying mum (also in child behaviour) x1
Dancing with child x1
Co-sleeping x1

Own Feelings towards child
Pride in child x8
Love x2 x4
Dreams/desires/wants for child x11
Fascinated by child x1
Amused by child x2
Have confidence/faith in child x1
'Want to squeeze' x1
'He's my guy' x1

Own Thoughts about child

Feel sorry for the child x1

Own Relationships/interactions partner

Conversation with partner (also in describing partner) x3 x70
Shared action/activities with partner (also in partner) x12
Own addiction affecting marriage x1
Comparing self and partner – differences x1 x6
Comparing self and partner – similarities x2 x2
Love for partner x1
Partner as support (also in describing partner) x9 x3
Past with partner x1 x1
Partner notices dad’s mood x1
Shared family activity x3 x3

Own Relationships/interactions family & friends

Relationship with extended family x15
Family don’t listen x2 x1
Family/friends reaction to child behaviour x2
Family/friends view of child x2 x3
Guessing family/friends thoughts on child x2
Guessing thoughts x1
Family/friends reaction to diagnosis x2 x15
Understanding x1
Lack of understanding x3 x5
Kindness x1
Comments x6
Advice/recommendation/suggestion x2 x3
Support x3 x3
Own conversation with family member/friends x4 x14
Explaining to extended family x1
Not wanting to be a burden x1
Wider family difficulties x1
Caring for wider family x1
Comparing self and family (differences) x1
Being let down by family x9
Expectations of family x2
Family arguments/disagreements x1 x3
Shared family activity (including extended family member) x1
Family didn’t accept child difficulties x2

Child Interactions with family members

Child interaction with partner x5 x5
Child interaction generally smile x2 x1
affectionate x1 x1
connected x1
Child feelings about dad x1
Child feelings about mum x1

Child Interactions with others

Child interaction with other children x9
Child interaction with strangers x7
Child interaction with therapists/professionals x3

Partner Interactions with friends/family members
Partner relationship with friends/family x3
Partner conversation with extended family x3
Partner conversation with other ASC mums x1
Partner shared activities with friends x1

Partner Interactions with others
Partner interaction with professionals x1 x4
'3 head' treatment (also in community and society) x6
Partner wanting to be more involved with school x7

Extra codes and themes/misc

Describing wider relationships and society

Own Relationships/interactions with professionals
Preparing professionals (also in managing behaviour) x2
Agreeing with professionals x1
Disagreeing with professionals x1 x1
Professional was right x1
Instructing professional x2
Working together with professionals x1
Professional advice/instruction/recommendation x16 x14
Professional description of child - response to therapy/progress/lack of progress x5
Professional description of child-difficulties x2
Professional view of/reaction to child behaviour x1 x5
Trust professionals x1 x2
Mistrust professionals x2
Ignoring professional advice/instruction x2
Following professional advice against own judgement x1
Professionals listen x2
Professionals listen to other professionals x1
Professionals don't listen x2
Lecture from professional x1
Feelings about professionals –like/love x2
Guessing professionals thoughts/feelings/reactions x7 x1
Conversation with professionals x42 x1
Professionals understand parents x1
Professionals don't understand parents x6 x4
Professionals don't understand child x4
Professionals doesn't know everything/ inexperienced/not knowledgeable x7
Consulting professionals/seeking professional advice x7 x4
Describing professional as -nice x1
-angel x1
-amazing x4
Professionals agree x1
Comparing different professionals (differences) x2 x1
Professionals uncertain/overwhelmed x2 x2
Professional reaction to parents – shock/surprise x3
-support x1
Professionals should understand x4 x1
Professional questions x2
Not expecting much from professionals x2
Professional disorganised x2

Feeling let down by professionals x2
Keeping secrets from professionals/not telling them everything x5
Explaining child to professionals x3
Explaining situation to professional x2
Professional as impersonal x1
Professional as not thorough x1
Professional competence x1
Professional as incompetent x17
Professional dismissive x1
Professionals care x1
Professionals don't care x2
Professional goes above and beyond x3
Professional as unprofessional x2
Professional action x2
Grateful to professionals x2
Guessing reason for professional behaviour x1
Mum 'testing' professionals x1
Feeling singled out by professionals x1
Professional apology/explanation x1
Professional view on debates x1
Glad professional saw behaviour x1
Arguing with professional x9
Professional physical intervention x3

Community and society
Strangers/others - interaction
Own Interaction with -strangers (also in community and society) x14 x2
-Other children x3
Conversation with others x1
Questions of others x2
Apologising to stranger x1
Making child apologise to stranger x2
Stranger words x1
Stranger's reaction to child behaviour x5 x1
Others reaction to child x1
Others reaction to diagnosis x3
Other children's reaction to child x7
Strangers describing child x3 x1
Telling others about ASC (also in coping & managing behaviour) x3
Explaining situation to others x4 x1
Other ASC child's behaviour x8 x4
Describing another child x2

Thoughts about strangers/others
Other people are the problem x2
Blaming others x6 x1
Other ASC mum's should be more understanding x1
Thoughts about stranger x2
Pick your battles x1
Managing the reactions of others x4
Kindness of strangers/others helpful x1 x2
Others take advantage x3
Feeling let down x3
Others don't listen x1
Others should understand x4 x2

Others understand x2 x4
Others don’t understand x3 x12
Wishing others understood x4
Comments/advice of others x1
‘3 head’ treatment (also in partner interaction with others) x6
Advice of others who don’t understand x6 x2
Guessing stranger thoughts (also in guessing/mysteries) x1 x3
Guessing stranger reactions (also in guessing/mysteries) x1
Guessing stranger motivations/reason for others behaviour (also in guessing/mysteries) x3
Agree with stranger/understand stranger’s reaction x3
Don’t understand stranger’s reaction x1
Making child desirable to strangers x2

Community/Society
Society as cruel x1
Public vs private image x8 x1
ASC in the news/online x1 x8
Feel good stories x2
‘Typical’ vs ASC families x1 x1
Blaming others x6 x1
Society view of gender roles x2
ASC community should be working together x9 x2
Public need to see dark side of ASC x1
ASC community/Autism world x14
Describing ASC symptoms/difficulties generally x6
Progress in ASC community x1
ASC community should be working together x9 x2

Quotes from others
Other people’s words (professionals) x1
Other people’s words (newspaper article) x13
Other people’s words/speech (partner) (also in describing partner) x3 x54

Interaction with blog readers
Giving advice/recommendations/instructions x11 x7
Asking for advice (merged with questions to readers) x3 x1
Asking for comments/questions x4
Questions to readers x6 x10
Asking for donations/clicking links for parent to get money x14
Guessing readers can identify/agree/guessing shared experience x7 x2
Guessing readers thoughts/reactions/questions x4 x17
Reader’s questions/readers frequently asked questions x2 x45
Reaction to reader’s questions/comments x4
Describing blog readers x5
Reader’s advice x1
Addressing audience x23 x41
Shock at blog popularity x2
Describing/linking to past posts x2 x30
Describing/planning future posts x2 x15
Linking with other blogs/research x1
Link to other websites x9
Own comment on post x4
Review of ASC friendly show x1
Blog set up/philosophy/description x2 x26

Own reactions
Reaction to article x2
Reaction to news report x4

Debates
Cure/recovery vs acceptance x14
Causes of ASC x12
    – vaccines x10
    - toxicity/toxins x14
    - God teaching a lesson x1
    - gift from God x1
Autism epidemic x2 x2
View on epidemic x1 x1
Therapies/treatments x2
Biomedical treatment x1 x3
Medication x2
'Autism speaks' x2 x1
Thoughts on debates x28 x2
Supporting organisations x2

Schooling
Describing school x8 x2
Choosing school x5

Political issues
Political issues – funding x1 x2
Political issues – school system x5
Political issues – local issues x4
Political issues – services x2
Other political issues (related to child) x5
Health insurance x1 x2
Making local events/venues autism friendly x1

Misc codes/themes

Writing style/blogging generally
Humour x5 x15
Sarcasm x32
Rhetorical questions x16 x9
Building suspense x3
Analogies/metaphors to explain x2
Cultural reference x2
Setting the scene x51 x45
Reason for blog x3 x25
Reason for post x4 x19
Writing on behalf of partner x2
Impact of blog on self x7
Impact of blog on readers x2
Photos/Videos/Audio/Cartoons/pictures/graphics x20 x9
Staying anonymous x4
Stages of grief generally x2
Literary device 'let me rewind' x1

Treatment/therapies/assessments
Assessments generally (not ASC assessments)/investigations x19 x10

Difficulty assessing child x19
Process of getting help x2
GFCF diet x7 x3
Diet (not GFCF) x3
OT x3 x3
SLT x14
Chelation x9
Toxin free house x8
ABA x2 x4
Music therapy x1 x5
Auditory integration therapy x1
Vitamins/supplements x11 x5
Biomedical x2 x3
HBOT x1 x3
Antifungals/probiotics x3 x1
Secretin x1
Medication x12
Equipment x1
Service dog x44
Social stories x1
PECS x1
Early intervention x1
Treatments that didn't work x2 x4
Treatment worked x1 x2
Treatment/therapy could be better x2
Expectations of treatment x1 x2
No cure/no miracles/not perfect x8
Non ASC treatments x4 x1
Future treatments x3 x5
Justification x7
Waiting for the right time x5
Don't want to waste time and money x1
Therapy intensive and hard work x3
Tried everything x1 x1
Lots of interventions/list of treatments tried x2
Positive effects of therapy/treatment generally x10
Side effects & negative side of therapy/treatments x2 x10
Difficulties with treatments generally x2
Paperwork x6
Appointments/IEP meetings x22
Distance to appointment x1
Test results x9
Results make sense x1
View of treatment/those that are most effective/favourites x4 x3

Misc
Song lyrics x41
Describing a play x6
Describing an organisation x29
Thanking public figure x1

Appendix 5 – Collapsing codes and creating themes for Stage 2 of analysis

Key
Black=present in both blogs
Green=Present in blog 2 (father)
Red=Present in blog 3 (mother)
Number=Number of sentences in this blog that could be categorised with this code

Searching for an explanation - Meaning making

Understanding the child

- ***Do understand child***

Translating/interpreting child language x2
Gaining clarity/revelation x4 x4
Child is predictable x21 x55
Usual day/expected events and activities/typical day x7 x52

- ***Don't understand child***

Child is unpredictable x17 x8
Unable to understand motivation/reason for child behaviours x19 x7

- ***Trying to understand child***

Trying to understand x2 x4
Trying to predict child behaviour x4 x30
Guessing child thought/feelings/expectations/understanding x17
Guessing motivation/reason for child behaviour/symptoms (not cause of ASC) x16 x7
Looking for answers x11

- ***Describing child generally***

1) *Describing child behaviour/action* generally x45 x19

Past behaviours x6 x3
Repetitive behaviour x6 x5
Play x1
Copying x1
Child crying x5
Madness/crazy x1
Not interested x2
Avoidance/resistance x6 x4

2) *Demographics/general introductions*

Child age x3 x4
Physical appearance x10
Nicknames x2 x5
Positive personal qualities x5 x7
Negative personal qualities x6 x3
Physical appearance x10
    -smile/laugh x9 x3
Skills/abilities x2 x3
Likes/loves/interests/favourites x8 x7

3) *Child feelings*

Tired x1

Excitement x4
Confused/bewildered x2
Upset/distressed x3
Joy/enjoyment x4
Overwhelmed x1
Fears/phobia x4
Happy/cheerful/good mood x9 x1

4) *Child language*
Child use of language/describing speech x29
Wants/requests x1

Making sense of diagnosis
Trying to work out/guess reason for progress/regression x12 x3
ASC as mysterious x2
Coming to terms with diagnosis x8 x11
Cause of ASC x25 x13
Blaming others x6 x1
Religion and ASC x2 x4
Acceptance x4 x4
Finding meaning x2
Seeking advice of others/research/reading x11 x9

- *Assessments/investigations/interaction with professionals*

Assessment/investigation (not ASC assessment) x19 x10
Difficulty assessing child x19
Process of getting help x2
Professional advice/instruction/recommendation x16 x14
Conversation with professionals x42 x1
Professional description of child - response to therapy/progress/lack of progress x5
Professional description of child-difficulties x2
Professional view of/reaction to child behaviour x1 x5
Professionals listen to other professionals x1
Guessing professionals thoughts/feelings/reactions x7 x1
Comparing different professionals (differences) x2 x1
Professional questions x2
Professional action x2
Guessing reason for professional behaviour x1
Professional physical intervention x3
Partner interaction with professionals x1 x4

- *Investigating types of treatment/therapies*

Alternative therapies – x44 x16
Traditional therapies x20 x28
Other/unsure if alternative or traditional x1 x44

- *Effects of treatment/therapies*

Treatments that didn’t work x2 x4
Treatment worked x1 x2
Future treatments x3 x5
Positive effects of therapy/treatment generally x10
Side effects & negative side of therapy/treatments x2 x10
Test results x9
Results make sense x1

- *Political issues*

Funding x1 x2
School system x5
Local issues x4
Services x2
Other political issues (related to child) x5
Health insurance x1 x2
Making local events/venues autism friendly x1
Choosing school x5
Appointments/IEP meetings x22
Distance to appointment x1
Paperwork x6

Feeling hopeless/powerless vs hopeful/in control

Hopeless/powerless
Hopelessness/not hopeful x8 x5
Lacking hope in progress x26 x38
Helplessness/powerlessness x2 x2
Worry/panic/anxiety x14 x13
Disappointment/frustration x21 x14
Fear/scared x8 x1
Fed up x1
Nothing works x2
Sceptical x2
Uncertain of what to do x4 x6
Having no choice x4 x2
Feeling negative x3 x4
Excitement overshadowed by child difficulties x1
Not perfect x1
Hard to rebound from frustration x1
Giving up x2 x6
Caring less x2
Lowering expectations x2 x5
Not taking a risk x1 x6
Treatment/therapy could be better x2
No cure/no miracles/not perfect x8
Waiting for the right time x5
Don't want to waste time and money x1
Therapy intensive and hard work x3
Tried everything x1 x1
Lots of interventions/list of treatments tried x2
Difficulties with treatments generally x2

- ***Child has many difficulties***

1) *Difficulties/symptoms/diagnoses*

Difficulties/symptoms related to ASC x55 x44
Other difficulties/symptoms x15 x43
ASC Diagnosis x5 x18
Other diagnoses x1 x8
Fears/phobia x1

Challenging behaviour – x33 x14
Dangerous x1

2) *More difficulties than others*

Comparing child with other ASC kids – differences x1 x9
Comparing child with 'typical' kids – differences x5
Comparing child and other disability x1 x1
Would be better if child was high functioning x1
Severity of ASC x3 x14
Child helpless/alone/vulnerable/innocent/small x12 x4
No price on health of child x2

Hopeful
Hope/Faith x23 x15
Hoping for further progress x4 x1
'Back to normal' x1
Times when expected meltdowns didn't happen x3 x1
Progress x77 x32
Cool/amazing to see progress x2
Previous progress x1
Excited x9
Happy/pleased/joy/ecstatic x9
Goals x2
Expectations x2
Unexpectedly easy x2 x4
Belief in recovery x14
Have confidence/faith in child x1
Expectations of treatment x1 x2
Justification x7
View of treatment/those that are most effective/favourites x4 x3

Wanting to take control/determination vs wanting to escape
Self as determined/stubborn/persistent/resilient x6
Self as organised x2
Desperate x1 x2
Fighting/battling x1 x3
Distraction/escape/break x7 x7
Hobbies/interests x10
Feeling trapped x3
Want to escape/disappear x3
Don't want to be reminded of ASC x1 x2
Avoidance (not about behaviour) x1 x2
Planning/preparing x26 x6
Learning what works/finding what works x5 x1
Trying things/trial and error/taking a risk x2 x6
Trying to move forward x1
Leave it to partner x1
Finding things that help you cope x7
Blog as coping x3 x2
Working together as parents x2 x55
Partner determination x7
Partner coping – escape x1

Self-doubt vs self-belief

I was right/right decision x1
Self-talk/questions to self x4 x7
Self-doubt x7 x1
Rumination x1 x5
Stupidly hopeful - mistake x1
Over exaggerating/Overanalysing x1
Dilemmas x8
Not perfect x2
Positive self-talk - It will be worth it/it is worth it x1
 -Going on too long/something has to change x1 x1
 - It's just how it is/deal the hand you're dealt x3 x1
 - Do everything I can/everything in my power x2
 - I was right/right decision x1

Relationship with ASC

Impact of ASC

1) Things that are different

Comparing child pre and post ASC diagnosis – things that are different x4 x3
Comparing life pre/post diagnosis/way life is different x7 x6
Sacrifices/things they can't do due to child difficulties x2 x6
Impact on self – ugly version of self x1
Impact on finances x14 x13
Impact on professional life x1

2) Loss

Choosing not to have another child x7
Regret x4
Sadness/'down'/upset x12 x4
Grief x2 x4
Emotional pain x1
Depressed x2
Heart breaking x1
How life may have been different/what ifs/if only x2 x3

3) ASC/child as dominant/life with ASC

Impact on day to day life x3 x17
ASC/child as dominant x15 x53
Feelings about ASC x5 x7
Tired/lack of stamina/exhausted x5 x3
Stress related to child difficulties x3
Bad times/days/events x17 x7
ASC as difficult/hard x5 x2
ASC as bad/dark/unfair x3 x4
Rollercoaster/ups and downs x3
Managing Challenging Behaviour x27 x13
Parenting role/responsibilities x1 x54
Partner sharing parenting responsibilities x58
Dominance of ASC/child for partner x10
Finding time to spend with partner x12
Partner relationship with others x7
Partner hobbies/interests x1

Decisions/choices x2 x25
Dilemmas (also in own philosophy) x8

Cognitive processing

- *Positive reframing*

Normalising child difficulties x8
Would be worse if child was high functioning x1
'not that bad'/positive aspects/positive times x49 x36
Relationship with child as loving, caring and supportive x27 x11
Lucky event/circumstance (could have been worse) x12
Being lucky/could be worse x1 x8
Finding the humour in situations x8 x18
Will take 30 steps forward and 2 steps back ANY TIME! x1
Embrace experiences x1
Child happiness gets her through negative stuff x1
Live each moment x1

Emotional processing

- *Sharing vs hiding feelings*

Showing feelings vs hiding feelings x15 x5
The truth' vs what choose to present x13 x1

- *Variety of emotional experiences*

Hidden feelings x5 x3
Helplessness/powerlessness x2 x1
Hopelessness/not hopeful x2 x3
Pride (generally not pride in child) x1 x1
Pride in child x8
Love for child x2 x4
Amused by child x2
Regret x4
Embarrassment x2 x2
Not embarrassed x1
Irritation x2 x5
Worry x8 x9
Hope/Faith x23 x15
Dashed hope x4
Anger x25 x5
Panic/anxiety x2 x3
Frustration x11 x14
Sadness/'down'/upset x12 x4
Grief x2 x4
Disappointment x10
Excited x9
Surprise/shock x15 x6
Relief x1 x1
Fear/scared x4
Feeling trapped x3
Tired/lack of stamina/exhausted x5 x3
Resignation x1
Emotional pain x1
Envy x5
Nervous x1 x1
Desperate x1 x2

Incredulous/disbelief x21 x7
Paranoid x1
Happy/pleased/joy/ecstatic x9
Confused x4
Depressed x2
Fed up x1
Admiration x3
‘Sigh’/’deep breath’ x9
Unexpected feelings x1
Heartbreaking x1
Past feelings x5
Rollercoaster of emotion x1
Reluctance x2
Impact of own feelings on family life x2

Sense of belonging vs not belonging
Sense of belonging x4 x2

Stigma/Community/Society
Blaming others x6 x1
Society view of gender roles x2
Guessing stranger thoughts (also in guessing/mysteries) x1 x3
Guessing stranger reactions (also in guessing/mysteries) x1
Guessing stranger motivations/reason for others behaviour (also in guessing/mysteries) x3
Don’t understand stranger’s reaction x1
Thoughts about stranger x2
Managing the reactions of others x4
Comments/advice of others x1
Don’t understand world x1
Own Interaction with -strangers (also in community and society) x14 x2
-Other children x3
Conversation with others x1
Questions of others x2
Apologising to stranger x1
Making child apologise to stranger x2
Strangers reaction to child behaviour x5 x1
Others reaction to child x1
Others reaction to diagnosis x3
Other children’s reaction to child x7
Strangers describing child x3 x1
Explaining situation to others x4 x1

- *ASC community*

Happy for other ASC parents whose kids recover x1
ASC parents & families generally x9 x5
Typical vs ASC families x1 x1
Other ASC parent’s views/feelings x6 x4
Disagreeing with other parents x5 x3
Guessing motivation of ASC parents x1
Choosing a side on debates/controversies x29 x3

Feeling different vs finding similarity
Comparing self and others – similar x15 x2
Comparing self and others – different x18 x22

Shared experience with others x7 x3
Expecting blog readers have shared experience/can understand x7 x2
Envy others x1 x8
'Normality' (not related to child) x1 x6
'Typical' vs ASC families x1 x1
Other ASC child's behaviour x8 x4
Describing another child x2
Understand other parent's views x1 x1

People who understand vs don't understand
Other people are the problem x2
Stress with professionals x3
Sarcasm x32
Support x12 x5
Tired of explaining ASC x1
Telling others about ASC x3
People who understand x4 x4
People who don't understand x30 x23
People who should understand but don't x5 x4
Wishing others understood x4
Advice of others who don't understand x6 x2
People who listen x2
People who don't listen x4 x1
People who are kind/people who care x2 x1
People who are unkind/judgemental/don't care x1 x9
Feeling let down by others x2 x9
Trust others x12 x11
Mistrust others x17
Professionals uncertain/overwhelmed/disorganised/incompetent x25
Public need to see dark side of ASC x1

Trust vs mistrust others
Trust others x12 x11
Mistrust others x17
Don't care what other people think x1 x3
Needing to give 'perfect' answers x1
Feeling stupid x2
Showing feelings vs hiding feelings x15 x5
'The truth' vs what choose to present x13 x1
Embarrassment x2 x2
Partner not wanting others to know about child difficulties x2
Not wanting to be a burden x1
Public need to see dark side of ASC x1
Society as cruel x1
Making child desirable to strangers x2

Finding value/a role
Educating others x8
Giving advice x3 x1
Raising awareness/campaigning/supporting organisations x2
Identity as ASC parent x3
Helping the child learn, progress and develop x33 x15
Self in other roles x8
Partner wanting to be more involved with school x7
Working together with professionals x1

ASC community should be working together x9 x2
Being part of online community/interacting with readers x56 x175

Blogging

Quotes from others
Other people's words (professionals) x1
Other people's words (newspaper article) x13
Other people's words/speech (partner) (also in describing partner) x3 x54
Describing song lyrics x41
Stranger words x1

Writing style/blogging generally
Humour x5 x15
Sarcasm x32
Rhetorical questions x16 x9
Building suspense x3
Analogies/metaphors to explain x2
Cultural reference x2
Setting the scene x51 x45
Reason for blog x3 x25
Reason for post x4 x19
Writing on behalf of partner x2
Impact of blog on self x7
Impact of blog on readers x2
Photos/Videos/Audio/Cartoons/pictures/graphics x20 x9
Staying anonymous x4
Literary device 'let me rewind' x1
Describing/linking to past posts x2 x30
Describing/planning future posts x2 x15
Blog set up/philosophy/description x2 x26
Shock at blog popularity x2
Describing a play x6
Describing an organisation x29

Appendix 6 - Reflections

As during the self-reflexivity statement outlined at the end of the method section, the tense used in this section will now change from third person to first person, in order to share some of my reflection and demonstrate some of the self-reflexivity crucial for this type of analysis.

Before the analysis I wrote in my reflective journal what I was expecting to see in the eight blogs. I was expecting mainly white, middle-class, fairly well-educated stay-at-home mothers living in the USA. I was hoping for at least one father but I was not expecting this. I was therefore surprised and pleased to find two fathers within the sample, as I felt that they may present a different aspect of the experience and slightly different themes and reflections. It was not possible to ascertain the ethnicity of the parents but they mainly resided within the USA and I assumed that they were all white and they appeared to be well-educated. They were mainly stay-at-home mothers, as expected but I was pleased to find some that were in employment, again I felt that they may provide a different viewpoint.

I expected many blogs to contain a religious element due to my assumptions about American culture being more religious on the whole than the United Kingdom. I must admit that I expected the religion to be Christian and was therefore pleased to find a different religion and culture presented within Blog 5. However my interest in this blog was quickly diminished as it was much more difficult to read, due to cultural references and Jewish words that I did not understand and the fact that it was by far the longest blog at around 136,000 words. My relationship with this blog, may therefore have affected the way in which it was interpreted. I attempted to counteract this through use of a reflective journal and through having the codes and themes checked by two other researchers.

Before starting the analysis I wrote in my reflective journal that I was expecting parents to mention difficulties, stresses and attempts to cope with this through meaning making but I also expected there to be many mentions of positive aspects of parenting and personal and familial transformations the parents had undergone. The difficult aspects were present, as was coping and meaning making but positive aspects of parenting and transformations were much less present than I expected. This may have been due to using the first six months of entries of newly established blogs, which may have been more related to difficulties than in other parts of the blog. Other parts of my expectations were also unexpectedly absent from the analysis, for example, I was expecting emotional responses to be mainly guilt and sadness balanced with pride and joy, as is detailed within the research literature. There were elements of sadness and pride, however, joy and guilt were much less prevalent than expected.

I was worried when coping and meaning making emerged as overarching themes within the first stage of analysis, as I wondered if they had only emerged as they were in some way expected, therefore I read and reviewed the codes associated with these themes carefully in order to make sure that I did not just find what I had been looking for.

I was expecting description of difficulties within family relationships, such as difficulty bonding with the child, marital discord and perhaps separation or divorce, however I was surprised to find that all of the parents who blogged, reported still being in a relationship with the partner whom they had the child with. There was, however, surprisingly little written about relationships with their partner and sometimes only a few sentences about their partner at all, littered sporadically throughout hundreds of pages of text. There was also little mention of difficulty bonding with the child, beyond attempts to understand them. This may be because these aspects were not present in the lives of these parents, or they may have chosen not to mention them due to shame, embarrassment, or fear of being judged by others. I was particularly struck by the dominance of themes around how having a child diagnosed with ASC impacted on wider relationships outside the family. The three research questions that I outlined in the introduction, did not include relationships outside the family, which I feel was quite a narrow and naïve view of the process, thinking that parents would confine their blogs to their views of self, child and their family.

I had a much more emotional response to the blogs than I was expecting. For example, I was struck by the view of some of the parents, that people with a diagnosis of ASC can be ‘cured’ or ‘recover’. I was shocked and slightly appalled at this idea, as I felt that it meant that parents had not accepted the diagnosis and I felt that some of the parents were pushing their children into many therapies, some of which could be quite dangerous, such as chelation. For some parents this search for ‘recovery’ appeared to be all consuming and impacted every aspect of their life, including the sense of self, the thoughts and feelings about the child and the parent’s relationships with society in general. My thoughts and feelings about this debate made me reflect on my views that acceptance of the permanence of the child’s difficulties is a necessary part of the experience of coming to terms with the ‘diagnosis’, in order to bond with the child and how these views may have influenced the way I interpreted the data and the reasons for selecting the two case studies, due to differing views on this debate.

In my clinical and personal experiences, I have not encountered parents that have expressed a view that their child could ‘recover’ from ASC. This may be due to the fact that these blogs were mainly written by people residing in the USA and that those views may be more prevalent there than here. It may also be because people that believe in ‘recovery’ are in the minority. This does not appear to be true of this sample, but it is a small sample and it may be that people who have this view are more likely to blog. Another reason that I have not encountered these views previously may be due to only having a few years of experience in this field and as my career progresses I may encounter others with this view. Finally, many parents write about hiding their feelings from others, particularly professionals, therefore parents I have encountered may have hidden these thoughts and feelings from me, due to fear that I will not understand or will judge them.