



Growing Together: Stories of resilience in families of children with autism

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Growing Together: Stories of resilience in families of children with autism**ABSTRACT**

Caring for a child with autism has been shown to have adverse effects on the entire family (Greeff & Walt, 2010). However, whilst many families with children with autism have substantial difficulty in dealing with the challenges they face, some families cope exceptionally well. The theory of *family resilience* supports the latter notion by demonstrating that many families have the ability to withstand and bounce back from life's disruptive challenges (Walsh, 2012). The present study aimed to apply conceptual definitions of family resilience in a practical, narrative form by accurately illustrating the true experiences of families of children with autism. Qualitative methods, guided by the narrative tradition, were used to elicit stories of family resilience. Narrative analysis of the interview transcripts covered structural, thematic and wider socio-cultural components. The findings showed how a number of families of children with autism overcame different difficult challenges. These findings could be beneficial for strength-based interventions that focus on utilising families' strengths and build on the positives (Blundo, 2001). Narrating true stories of overcoming life's challenges could not only build the confidence that empowers families of children with autism, but disrupt the negative perceptions and expectations that society has on them.

KEY WORDS:

AUTISM

FAMILY RESILIENCE

NARRATIVE

STRENGTH-BASED

Introduction

Historical Context

In the late eighties, a growing body of research challenged the deterministic assumption that all difficult life experiences are inevitably damaging. Adversity was recognised as an event that could produce both positive and negative outcomes (Rutter, 1987). For example, early research theorised that children born from schizophrenic parents, often became particularly competent and successful individuals (Garmezy et al., 1984). Additionally, Kaufman & Ziegler's (1987) research found that most abused children did not become abusive parents themselves. This proposes the question: how was it possible for individuals to respond successfully to major challenges and to grow from the experience? The concept of *resilience*, or *hardiness*, was adopted by scholars to narrate how individuals thrived in the face of challenging circumstances (Price et al., 2010). Resilience was initially viewed as innate and reflected the dominant cultural ethos of the '*rugged individual*' (Anthony & Cohler, 1987; Luthar & Ziegler, 1991). However, the influences of Bronfenbrenner's ecological model (1979) encouraged the nature nurture debate by emphasising the role of families, communities and wider networks in promoting resilience. Families were seen as contributors to *risk* rather than resilience and were dismissed as providing any 'positive resources' to the hopelessly dysfunctional family (Wolin & Wolin, 1993). In a ground-breaking longitudinal study of resilience, Emmy Werner (1993; Werner & Smith, 1992) observed the lives of hundreds of children living in poverty on the Hawaiian island of Kauai. She found that despite the children's troubled upbringings, one third of the children grew up to become competent, caring, and confident young adults. Werner's research illuminated the significant influence of relationships with kin, intimate partners, and teachers – all of whom supported the children, believed in their potential, and encouraged them to make the most of their lives. Following Werner's profound research, research on resilience has expanded to include multiple adverse conditions such as parental mental illness, maltreatment, urban poverty and community violence, chronic illness, and catastrophic life events (Luthar et al., 2000). In fact, scholars are moving beyond viewing resiliency as an individual characteristic to providing a theoretical framework for viewing resiliency as a quality of families (Hawley & DeHaan, 1996; Price et al., 2010).

Family Resilience

Building on theory and research on family stress, coping, and adaptation (Walsh, 2003; Patterson, 2002) the concept of *family resilience* looks beyond the individual to understand how their families, as a unit, continually manage to successfully function during difficult periods of time. Walsh (2012) defines resilience as "...the ability to withstand and rebound from disruptive life challenges" (pp. 339). Dissimilar to the traditional approach in clinical and development psychology that focuses on factors of pathology (Antonovsky, 1987), the concept of family resilience forms part of a movement in positive psychology towards identifying factors of health (Bayat, 2007). Family resilience, once theorised as an interaction of risk and protective factors (Rutter, 1987), has been described as a flexible, dynamic process that encompasses positive adaption within the context of considerable adversity during the life cycle of a family (Luthar et al., 2000).

Froma Walsh is a frequent speaker and international consultant on resilience-oriented professional training, practice and research. She has made an exceptional contribution to the area of family resilience, producing a plethora of publications to aid resilience-based therapy and practice (1983, 1996, 1998, 2002, 2003, 2012). After three decades of clinical and social science research, Walsh (2012) presents a research-informed family resilience framework with the aim of engaging distressed families with respect and compassion for their struggles, affirming their reparative potential, and seeking out to bring out their best. This theoretical framework, grounded by family systems theory and the combination ecological and developmental perspectives (Walsh, 2002), serves as a valuable conceptual map to support and strengthen vulnerable and crisis-ridden families by guiding prevention and intervention efforts (Walsh, 2003). Walsh (2012) highlights nine key processes in family resilience, outlined in three domains: family belief systems; organisational patterns; and communication/problem solving. The domains and subdomains within the framework are presented in Figure 1.

Figure 1. Key Processes in Family Resilience

Belief Systems

1. Making Meaning of Adversity
 - Relational view of resilience
 - Normalise, contextualise distress
 - Sense of coherence: View crisis as meaningful, comprehensible, manageable challenge
 - Facilitative appraisal: Causal/explanatory attributions; future expectations
2. Positive Outlook
 - Hope, optimistic bias; confidence in overcoming odds
 - Courage/encouragement; affirm strengths; focus on potential
 - Active initiative and perseverance (can-do spirit)
 - Master the possible; accept what can't be changed; tolerate uncertainty
3. Transcendence and Spirituality
 - Larger values, purpose
 - Spirituality: Faith, contemplative practices, community; connection with nature
 - Inspiration: Envision possibilities; life dreams; creative expression; social action
 - Transformation: Learning, change, and growth from adversity

Organisational Patterns

4. Flexibility
 - Open to change: Rebound, reorganise, adapt to new conditions
 - Stability to counter disruption: Continuity, dependability, predictability
 - Strong authoritative leadership: nurture, guide, protect
 - Varied family forms: Cooperative parenting/caregiving teams
 - Couple/coparent relationship: Mutual respect; equal partners
5. Connectedness
 - Mutual support, collaboration, and commitment
 - Respect individual needs, differences
 - Seek reconnection, repair cutoffs, grievances

6. Social and Economic Resources
 - Mobilise kin, social, and community networks; models and mentors
 - Build financial security; balance work/family strains
 - Larger systems: Institutional, structural supports
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Communication/Problem Solving

7. Clear, Consistent Messages
 - Clarify ambiguous information; truth seeking
 8. Open Emotional Expression
 - Share painful feelings; empathic response; tolerate differences
 - Pleasurable interactions, humour; respite
 9. Collaborative Problem Solving
 - Creative brainstorming; resourcefulness
 - Share decision making; repair conflicts; negotiation; fairness
 - Focus on goals, take concrete steps: build on success; learn from failure
 - Proactive stance: Preparedness, planning, prevention
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Source: Walsh, F. (2012). Family resilience: Strengths forged through adversity. In F. Walsh (Ed.), *Normal family processes: Growing diversity and complexity* (4th ed., pp. 399 – 427). New York: Guilford.

While some have questioned the contributions to the development of Walsh's family resilience framework (Lum, 2008), the strength-based concept of family resilience has become an important concept within mental health theory, research, and practice (Walsh, 2012). Taking a strength-based approach, Walsh's framework (2012) focuses on family strengths under stress, in midst of crisis and overcoming disruptive situations (Walsh, 2003). The shift from deficit-based approaches to strength-based approaches is becoming a far more prominent application within social work practices (Saleebey, 1996; Saleebey, 2006). Rather than focusing on client problems, strength-based practices and therapies begin by focusing on client strengths (Kisthard, 2006) whilst prioritising positive concepts such as resilience, adaptation and transformation (Summers et al., 2005; Bayat, 2007; Knight, 2012). Another strength of Walsh's family resilience framework (2012) is that, because family functioning is assessed in relation to the particular family being consulted, the model applies to all types of families and adverse situations. For example, Bishop & Greeff (2015) used Walsh's framework to explore resilience in families in which a member had been diagnosed with schizophrenia. Geldhof et al. (2014) identified and explored resilience factors associated with family adaption after their child had been diagnosed with cancer. However, although some families may be more vulnerable or face more challenges than others, the concept of family resilience views all families as having the potential to gain resilience in meeting their challenges and emerging out of experiences of adversity (Walsh, 2012).

Autism

As the number of children diagnosed with autism continues to rise UK, with more than 1 in 100 people in the UK with autism (Brugha et al., 2012), the need for a better understanding of autism and an efficient evidence-based practice has never been greater. Autism spectrum disorder (ASD) is characterised by limitations in

communication, social interaction, and a demonstration of restricted and repetitive behaviours (APA, 2000). Due to these characteristics, the presence of a child with autism could seriously impact the family system as a whole (Sivberg, 2002a; 2002b). Ludlow et al. (2011) explored the challenges faced by parents of children diagnosed with autism. They identified five core themes throughout the interviews: dealing with challenging behaviour; dealing with judgements from others; lack of support; impact upon the family; coping and the importance of appropriate support. However, although families with disabilities are at a higher risk of stress, financial disadvantage and family breakdown than other families (Muir and Strnadová, 2014), the majority of families of children with disabilities display positive adaptation in the face of such adversity (Breitkreuz et al., 2014). Not only have studies have shown that many parents may be positively transformed by the experiences of caring for their disabled child (Ryan & Runswick-Cole, 2009), but, at the family level, many families have 'pulled together' and established new rules and routines to integrate their child into their family, and their family into the community (Breitkreuz et al., 2014; Knestricht & Kuchey, 2009; Maul & Singer, 2009). Rather than focusing on 'normative' models of families and positioning families of children with disabilities in relation to their failure to match up to these norms (Goodley et al., 2015), current researchers are increasingly adopting 'corrective' strength-based approaches by focusing on positive concepts such as resilience, adaptation and transformation (Summers et al., 2005; Bayat, 2007; Knight, 2012).

Bayat (2007) examined many factors of family resilience within families of children with autism. Using both quantitative and qualitative methodologies, including quantitative analysis of survey responses and thematic analysis of open-ended questions, Bayat presented evidence that a considerable number of families of children with autism display factors of resilience. Although, DeHaan et al. (2002) argues that the operationalization of the concept of family resilience is problematic within quantitative research. Some suggest that qualitative methodologies should be employed where there are opportunities for in-depth face-to-face interviews to allow a deeper and richer meaning of analysis (Bayat, 2007). Consequently, capturing the true experiences of family resilience in a qualitative manner could increase others' understandings of how families of children with autism withstand difficult adversities. However, on the other hand, Dillenburger et al. (2004) suggests that teachers and other professionals still do not fully comprehend the impact that caring for a child with autism has on the families. Parents have argued that educational and social support services in the UK are not efficient – leading to families relying on support from their family and friends (Ludlow et al., 2011). Pellicano et al. (2014) sought to establish whether, in the UK, autism research makes a considerable difference to members of the autism community in their everyday lives. They suggested that current literature should particularly focus on research that would help people within the autism community, rather than focusing on a 'knowledge exchange' between them and researchers.

Research Aims & Questions

The present study adopts a narrative, strength-based approach to encapsulate stories of resilience within families of children with autism. Froma Walsh's (2012) theory of family resilience serves as the theoretical framework for the study, with the interview questions based on these key features of family resilience. By covering structural, thematic and wider socio-cultural analytical components, the study will capture stories that may help others understand *how* families with autism can bounce back from life's

challenges – thus, addressing the research question: *how* do families of children with autism overcome adversity? Consequently, the aim of the present study is to encapsulate stories of family resilience within families of children with autism and establish how they can withstand adversity and bounce back from disruptive situations, in the hope of demonstrating how transformative having a child with autism can be. Narrating these stories of resilience could build the confidence that empowers other families of children with autism, whilst disrupting the negative perceptions and expectations that society has on them.

Methodology

Study Design

Qualitative research has been described as “...an interpretive naturalistic approach to the world” (Denzin & Lincoln, 2005; pp. 3). To make sense of this ever changing and unorganised world, narratives or stories are constructed by telling stories about our lives to develop our sense of self and life. In recent decades, conceptual definitions of the ‘normal family’ have been redefined – with current literature revealing a variety of ways in which a ‘dysfunctional’ family can be well-functioning (Walsh, 1999). The concept of family resilience illuminates the ways in which families can overcome adversity and bounce back from difficult situations.

Rather than broadly exploring *what* family resilience is, the research adopted a social constructionist perspective to explore how certain families subjectively experience and make meaning of family resilience (Guba, 1990). The underpinnings of the research originate from Froma Walsh’s family resilience theory (2003). Walsh’s theoretical framework (2012), outlining 9 key processes in family resilience (see Figure 1), assisted the researcher in approaching and exploring the concept of family resilience to families of children with autism. Hence, the narrative process of the research enabled the researcher to comprehensively explore how families of children with autism have overcome adversity. Due to the social constructionist stance, no claims are made about the representativeness of the sample, the generalizability of the findings, nor the universality of the story-telling strategies described. Rather, this study seeks to illustrate some of the ways that family resilience might be found in the structures of stories, and demonstrate the insights that may be gained through a narrative approach to the study of resilience.

Participants

The participants required for this research had to meet the following criteria: the participant must be a parent of a child diagnosed with Autism Spectrum Disorder (including Asperger syndrome); and the participant must be over the age of 18. Due to the specific participant criteria, an opportunity sample was recruited from two Lancashire-based support groups for parents of children with ASD.

The researcher made initial contact with two support group leaders (Appendix 4), who then introduced the researcher to their support group members. The use of a gatekeeper potentially ensured an ethical, clear practice between the researcher and the participants as the gatekeepers are likely to be trusted by the participants (Namageyo-Funa et al., 2014). In order to make the participant feel comfortable and enhance the quality of the data (Braun & Clarke, 2013), upon permission from the

gatekeeper, the researcher contacted the parents prior to the interview stage to build rapport. Once they had received the invitation letter (Appendix 5), read through all the briefing information (Appendix 6) and signed the informed consent form (Appendix 7), the researcher contacted them to arrange an appropriate time and location for the interview.

A total of five parents of children with autism participated in the research. All five of the participants were mothers who had sons diagnosed with ASD. Whilst this may be a small and unrepresentative sample, Kim (2015) suggested that if the focus of the research is on collecting life stories, the sample of the participants may be small as the interviewing process is considerably lengthy. The sample was manageable yet adequate for the researcher to sufficiently address the research aims and question. The biographical details of the parents are displayed in Figure 2.

Figure 2. Demographics of Participants

Participant*	Age	Marital Status	Family Size	Age of ASD Child	Age of ASD Diagnosis
Jen	57	Married	4	21	3
Wendy	38	Married	4	9	7
Harriet	42	Married	4	10	3
Susan	52	Married	5	14	14
Bridget	55	Widowed	3	21	3
Average (mean)	48.8	–	4	15	6

* the participants were assigned pseudonyms to ensure anonymity

Data Collection

In order to encapsulate stories of family resilience, qualitative methods guided by the narrative tradition were used. According to Lietz & Strength (2011), the narrative tradition asserts that we naturally communicate about our lives through the stories we share (Mishler, 1986; Riessman, 2008). Thus, as stories are commonly used to describe transitions in our lives, some have proposed that narrative inquiry could be particularly useful when examining resilience (Hauser et al., 2006).

To encapsulate first-hand human experiences in a narrative form, semi-structured interviews were used to explore family resilience within families of children with autism. The in-depth interviews lasted from 45 minutes to one hour, with one parent representing each family. To ensure that the parents represented their family as well as themselves, the interview questions (Appendix 8) were posed in a way that would encourage them to discuss how their family unit had overcome adversity, rather than on an individual basis. The interview questions (Appendix 8) stem from Froma Walsh's (2003; 2012) extensive theory of family resilience.

Upon completion of the transcripts (Appendix 1), the audio recordings were destroyed and each participant (and their family members) was allocated with a pseudonym to

ensure anonymity. Narrative analysis of the data could then begin. Additionally, the family members that they mentioned were also given pseudonyms to ensure that anonymity was achieved.

Data Analysis

Narrative analysis was selected as the most appropriate approach to analyse the data. Riessman (2005) refers to narrative analysis as a collection of approaches to diverse kinds of text, which all have a storied form. Moreover, narrative analysis is known to be suitable for exploring the lives of those whose experiences have departed from normative expectations (Hines et al., 2012). Thus, it was an appropriate method of analysis to explore how families of children with autism have overcome adversity.

Similar to Brooks et al. (2014), the narrative analysis of the interview transcripts (Appendix 1) covered structural, thematic, and wider socio-cultural elements. Firstly, a 'micro' level analysis reflected on the structural components of the stories - this was accomplished through application of Labov & Waletzky's (1967) framework of the structural components of narratives. The identified stories were parsed into six constituent elements: abstract (what the story is about), orientation (sets the scene of the story), complication (describing the action or event that occurred), evaluation (the attitude of the narrator towards the story), resolution (the outcome), and coda (the return to the present moment or the moral of the story) (Labov & Waletzky, 1967). Subsequently, the elements of the stories of resilience were reviewed by the researcher to elucidate the stories' meanings (Montgomery et al., 2012) – refer to Appendix 2 for an example of how this analysis was conducted. Secondly, a content level analysis explored overarching themes expressed within the narratives (Brooks et al., 2014). Thirdly, a 'macro' level analysis addressed wider socio-cultural contexts about issues around support services and specialist schools. To demonstrate the transparency and interpretive credibility of the analytical process (Bailey, 1996; Riessman, 2008), all of the analytic steps are presented sequentially in Figure 3.

Figure 3. Stages of Narrative Analysis

	Process	Function
Stage 1	<ul style="list-style-type: none"> Data transcription Text familiarisation Margin notes made Extraction of narratives <p style="text-align: right;"><small>Crossley (2000)</small></p>	<ul style="list-style-type: none"> Written representation of verbal discourse Identifying narratives for analysis
Stage 2 'micro' level analysis	<ul style="list-style-type: none"> Labovian structure identified within each narrative Story elements reviewed Reflected on each narrator and the stories they told Interpreted the story structure and their meanings <p style="text-align: right;"><small>(Labov & Waletzky, 1967).</small></p>	<ul style="list-style-type: none"> Closer reading Examine narrative structure, highlighting meaning in the evaluative device Demonstrates how each narrator <i>storied</i> their experiences Differentiates the uniqueness of how each narrator <i>experienced</i> family resilience
Stage 3 content level analysis	<ul style="list-style-type: none"> Transcripts examined and additional margin notes made 	<ul style="list-style-type: none"> Emphasis on the content of the narrative

	<ul style="list-style-type: none"> • Focus on topics and themes described within each narrative • Prominent themes identified across participants • Themes are interpreted and discussed 	<ul style="list-style-type: none"> • Facilitates contextual meanings in text through the development of emergent themes (Bryman, 2001) • Elicits meaning from narratives
Stage 4 'macro' level analysis	<ul style="list-style-type: none"> • Focus on narrator's experiences and reflections on societal and historical issues • Prominent issues identified, interpreted, and critically discussed 	<ul style="list-style-type: none"> • Addresses wider socio-cultural and historical contexts.

Analysis method taken from: Brooks, A., Farquharson, L., Burnell, K. & Charlesworth, G. (2014) 'A Narrative Enquiry of Experienced Family Carers of People with Dementia Volunteering in a Carer Supporter Programme'. *Journal of Community and Applied Social Psychology*, 24(6): pp. 491-502.

Ethical Considerations

The primary responsibility of psychological research is to protect participants from any psychological or physical harm (Langdridge, 2004). Subsequently, this study was subject to ethical guidelines outlined by the British Psychological Society (BPS, 2009) and the internal ethics committee at Manchester Metropolitan University (MMU). After the Application for Ethical Approval Form (Appendix 2) was accepted and approved by the university, contact could be made between the researcher, gatekeeper, and any potential participants.

Before the interviews concluded, the participants were fully debriefed (Appendix 9) and they were made fully aware of the aims and nature of study throughout. Overall, the Data Protection Act (GB, 1998) was abided by and the data was used in a limited and specific purpose, and kept no longer than necessary.

To avoid unfair, prejudiced or discriminatory practices, each participant was valued and respected both individually and culturally. If the gatekeeper and participants required any further information about the research, they were able to contact the researcher or their research supervisor at any time.

Analysis & Discussion

Micro (structural) level

The parents told many stories of family resilience, despite the extraordinary challenges that they faced. Although these stories collectively demonstrated how the families overcame adverse situations, all of the different scenarios expressed were unique in structure, meaning and function. Therefore, to ensure that these stories could be adequately discussed within the word confines of this paper, three stories of resilience were analysed and discussed. This differentiated the uniqueness of how each family overcame different challenges in their lives.

Jen's story of support

Following a summer holiday that Jen found '*a bit of a nightmare*' (Jen, line 181), she decided to contact a local support group that she was referred to when her son received his diagnosis of autism. According to Banach et al. (2010) autism support groups can provide families with the knowledge, understanding, and acceptance they seek. Jen enjoyed attending the support group:

'That was brilliant... all we would do was talk, but we kind of laughed about the situations we were in, in a way that you wouldn't laugh with other people' (Jen, lines 186-188)

The support group allowed Jen's family to connect with other families in similar situations. Although parents of autism often experience a lack of understanding from others (Woodgate et al., 2008), connecting families with other families in similar situations could make them feel more understood and accepted within their communities. Additionally, joining a support group could give families an increased sense of power in their ability to come together and advocate on behalf of their family member with autism (Banach et al., 2010).

'It kind of put things into perspective. We were all coming through it. Also, I think you realize that there was other people who actually had far worse situations than yourself to deal with...' (Jen, lines 192-195)

The support group offered Jen's family a sense of belonging, that they were all going through it together. Barnett et al. (2003) suggests that having this sense of belonging may help families process their feelings about the autism diagnosis. Moreover, the parents within support groups can exchange knowledge and different skills in dealing with different behaviour issues and other day-to-day concerns. Discovering how other families overcame their difficult challenges could have helped Jen's family to reflect on their own challenges and how they could deal with them in the future.

Harriet's story of adaption

Harriet believes that the main difficulty in their house is the '*clash*' that her and her husband John have. (Harriet, line 84). They both use different coping strategies when dealing with their son's behavioural issues, and John believes that Harriet's methods just aren't '*strong enough*' (Harriet, line 97). According to Hastings et al. (2005), mothers and fathers are likely to report different ways of coping with behavioural issues and parenting stress. Moreover, they could interpret their child's autism in very different ways (Gray, 2003).

Harriet mentioned that she was '*the one who does the [autism] courses*', whereas John just '*leaves it*' to her (Harriet, lines 85-86). While considerable efforts are made to offer "family-centered" health, educational and social supports, family-centered practices have been criticised for not being typically oriented toward fathers (Cheuk & Lashewicz, 2016). Some have argued that even in the 21st century, mothers are still treated as their children's exclusive care providers (Cassano et al., 2006). Perhaps the reason behind why John does not go on any autism courses is that he doesn't feel like that is his 'role' as the father – on the other hand, he could just feel that they would not benefit him as a parent.

Harriet says that John has *'come round a lot now'* (Harriet, lines 99). John *'agrees'* with her now he can *'see what things work for Alex'* (Harriet, lines 100-101).

'He has learnt to do this ten second rule with him, because usually he'd just say 'Alex are you listening to me? Alex?' which frustrates him. But now, John has come around' (Harriet, lines 108-111)

According to Hastings et al. (2005), many families of children with autism adapt successfully through the development of individual and family coping strategies. As both parents learn what strategies work for their families, they can begin to adopt more adaptive coping strategies and take positive steps towards a well-balanced home (Rodrigue et al., 1993).

Susan's story of togetherness

Susan recalls of a time when her son with autism, Sam, was admitted into hospital. According to Susan, he just *'wanted to die really'* and he really *'needed some help'* (Susan, line 112). So she took him down to casualty and stayed with him.

'It was at this difficult stage where [his other siblings] found him annoying... he just wanted his big brother to like him, he really looked up to him' (Susan, lines 115-117)

Dillon (1995) noted that siblings of a child with autism will undoubtedly receive a disproportionate share of their parents' attention. Perhaps Susan's other children suffered social embarrassment caused by Sam's negative behaviour (Dillon, 1995), or maybe they were fearful or anxious about how to interact with him (Powell, 1985). Regardless, Sam's siblings came to visit him in the hospital, even his big brother. Susan said that *'it was great when [his brother] did come in to hospital, and he just treated [Sam] like a lad'* (Susan, Lines 117-118).

'It was just so nice that all of the family came together really. Well, particularly the last time which was really bad, and that brought us all together' (Susan, lines 147-149)

Bristol (1984) postulated that families who are committed to supporting one another are more likely to adapt successfully to the present of a child with autism. According to Susan, they have the *'tools to keep [Sam] on an even keel'* (Susan, lines 135-136). Families with supportive environments such as Susan's, have the ability to adapt to stressors through the reorganisation of patterns of family interactions to meet the new demands faced by the family (Walsh, 2003).

Content Level

Through analysing the interview transcripts, three overarching themes emerged through the parents' narratives: (a) acceptance, (b) positivity, and (c) perceptions of normality. Each theme will be described and particular quotes from the transcripts will be included to support the theme.

Acceptance

Generally, it appeared that most of the families were accepting of their child with autism. For Susan, it was faith that helped her family accept things.

'I personally felt, being a Christian, what would Jesus have said? We knew underneath that we weren't bad people, and he wasn't a bad person... so we kind of kept that and sort of went with that really. So that was us, all standing up against it all I suppose' (Susan, 196-200)

According to Greeff & Walt (2010), faith in God is an important factor contributing to adaptation within families of children with autism. Susan's Christian family ethos may mediate their family challenges by giving them a meaning and a purpose to the sacrifices they make to care for their family member with autism. Bridget's family mentioned that their Christian faith has helped them *'immensely to keep going, just keep living, and keep growing'* (Bridget, lines 8-9). Shared, facilitative beliefs that increase the options for problem resolution, healing and growth may foster family resilience within a family that has a strong belief system (Walsh, 2003)

Bridget discussed how she accepts her son for who he is and tries to do *'more and more to understand where he's coming from, and to appreciate him more'* (Bridget, lines 200-201)

I think we need to accept them as they are. You have to reach a point of acceptance... that they're not going to be perhaps what you'd hope they would be' (Bridget, lines 189-191)

For Wendy, accepting her son's diagnosis of autism may be something that comes with time. Wendy spoke about how she struggles to watch videos of her son before he was diagnosed with autism.

'It just makes me really sad... because that was a time where we didn't know what the future held and, as much as it was a surprise to us when he started failing at school, I can see it when I look back in the videos. It's as plan as day now.' (Wendy, lines 88-90)

Beyond the personal changes associated of being in a family of children with a disability, 'losses' occur for the family too. According to Hartley & Stuntzner (2015), these changes may be experienced due to the family's loss of the previously held hopes or dreams for the future. Sometimes, Wendy *'hit by this wave of sadness'* (Wendy, line 97), and this may be due to her loss or alteration of life dreams because of her son's autism (Stuntzner, 2012). Perhaps when Wendy's family can accept the full meanings and implications of their child's autism, they can adapt themselves to it and become more resilient to future challenges (Blacher, 1984).

Positivity

A predominant theme throughout the analysis was the positive ideologies that all of the families learned to adopt over time. When Jen was at her *'lowest ebb'*, one thing that helped her *'get over those hurdles'* was the positive outlook that her father had on her son's future (Jen, lines 252-255).

'He would say 'Oscar will find his niche in life, you need to hold onto that because it's going to happen... everyone has a niche in life and he will find it' (Jen, lines 259-261)

High-functioning families have been found to hold more optimistic views of life than low-functioning families (Beavers & Hampson, 1990). In relation to Seligman's (1990) concept of *'learned optimism'*, Jen could have adopted a lot of the optimism that she has today from her father. Jen's father's words could have affirmed Jen's family's strengths to counter their feelings of helplessness and failure when it came to Oscar not finding his 'niche' yet.

Bridget reflected on the past, acknowledging that she hadn't been as positive as she had wished to be.

'I think that I've not always done that... appreciated what he can do and his good points. I've realised that I should do more of that' (Bridget, lines 203-204)

According to Aponte (1994), many families who feel lonely or trapped within their communities lose hope, suffering a deprivation of a 'can-do' spirit. Walsh (2003) claims that this may rob families of their purpose and sense of future possibilities. While Bridget's family may have been in that position before, Bridget spoke very highly of her son, saying how *'amusing'* and *'fascinating'* he is (Bridget, lines 260-261). Attending to the positives and emphasising growth and development may restore the balance between the family's needs and capabilities, whilst maximising their abilities to bounce back from stress (Gupta & Singhal, 2004).

Perceptions of Normality

Throughout the interviews, the analysis demonstrated that many families' perceptions of normality changed since they received the diagnosis. For example, Susan admits that 'your expectations of normality change, I suppose' (Susan, lines 56-57).

'That's our normal. And it's just coming to terms with that. It's not what we had in our head of what we would be like as a family... but it works. If we try to enforce 'the normal', it just makes for the most horrific time' (Wendy, lines 70-73).

Goodley et al. (2015) present the theoretical notion of the *'DisFamily'* in which, not only is disability celebrated for its productive potential, but normative ways of being and living in families are invoked. Gray (1997) argues that parents of children with autism suffer the pressure of having a 'normal family life'. 'Normal family life' is linked to factors such as: their ability to socialise; the emotional equality of their interactions among family members; and the routines and rituals that comprises their perceptions of what 'normal' families do (Gray, 1997).

Bridget mentions that her daughter Sarah *'struggled'* particularly in her early teens with the fact that she didn't have a *'normal'* brother (Bridget, lines 189-191). Perhaps openness and communication between them enabled Sarah to adjust, understand more about her sibling's impairment (McHale et al., 1986) and establish her own perception of what normality is.

Macro (socio-cultural) level

The parents often reflected on how people with autism and their families of children with autism are currently supported in society. These beliefs were very mixed.

For Jen, the support she received from social services was really positive. Their family social worker was *'on the ball from the start'* (Jen, line 61) and she turned her son's statement of educational needs into a *'very positive thing'* (Jen, line 64) that would not only support him, but her family too. According to Anderson et al. (2005), the employment of paraprofessionals such as educational support workers is becoming a common strategy for providing support for children with special educational needs (SEN). Bridget's family however, only found social services helpful until her son turned 16. When her son was between the ages of 16 and 18, they found themselves in a *'a bit of a hole'* (Bridget, line 108) when it came to accessing support.

'Not a lot happens because in school you automatically get that support if you have a statement of educational needs... but after that, you have that gap before their 18 and under adult services' (Bridget, lines 108-111)

According to Kogan et al. (2008), families of children with autism have more problems accessing family support services than families of children with other special health care needs. Not meeting the needs of families of children with autism has been found to negatively correlate with the autistic child's functional independence (Brown et al., 2012). As the prevalence of autism continues to rise (Brugha et al., 2012), social services must adapt and offer accessible services that will meet the needs of all families, regardless of the age of the person with autism.

Harriet had many positives things to say about the mainstream school that her son attends. *'They're always just that one step ahead'* (Harriet, lines 134) and they frequently cooperate with services such as The Information, Advice and Support Services Network (IASS) who provide advice and support to families and schools with children with SEN. Blair et al. (2011) emphasizes how beneficial it is for families and schools to establish and maintain family-school collaborations. Harriet brings IASS along with her when she attends reviews at her son's school, and she spoke about the confidence it gave her that someone's *'there with you'* (Harriet, line 131)

Wendy compares the feeling of when her son got into a specialist school to *'winning the lottery'* (Wendy, Lines 261). Specialist schools are known to meet the educational and social needs of children diagnosed with autism (Starr & Foy, 2012). After Susan's son was expelled from his mainstream school, short stay school that he transferred to was an *'immense support for [them] as a family'* (Susan, line 191).

'The short stay school was great with him. I guess they had that experience of working with other children who needed extra support' (Susan lines 193-195)

Specialist schools tend to employ highly experienced educators who, based from their knowledge of autism, can provide a flexible learning environment that is sufficient to meet the needs of a child with autism (Whitaker, 2007). However, the battle to get a placement in a specialist school is a tough one, with the number of children with autism (~90,000) far exceeding the number of available specialist places (~7,500) (Batten &

Daly, 2006). As some argue that this is due to local authorities' significant lack of funding (McNerny, 2015), perhaps local authorities could overcome this shortfall by reviewing and reallocating funds for families and children special educational needs.

'Society has a long way to go, but I think they're getting there... autism is such a broad thing. But obviously some people are struggling to get care at the right stage' (Susan, lines 370-372)

Limitations

This study has some limitations. Firstly, Walsh's resilience theory (2012) served as the theoretical framework for the study – this carried a number of presumptions as to what family resilience was. Additionally, the theoretical model may have provided too much guidance to the interview questions, thus preventing other aspects of family resilience to be explored. The second limitation of this study is the limited demographic profile of the sample. All of the participants were females from white middle-class families who attended support groups. This is not representative of the population of families of children with autism, therefore the sample cannot be generalised. Thirdly, the study looked at individual reports regarding the family as a unit. In this study, the parent of the family was used to represent the opinion of the family as a unit so their perceptions of events could have potentially been very different had the study used reports from all family members. While the interview questions directed the questions towards particular events that the whole family experienced, data was still gathered at an individual level and extrapolated to the family level. DeHaan et al. (2002) argues that 'while such data obviously can be helpful, useful, and appropriate for a number of research questions ... they are limited in their usefulness for the operationalisation of family resilience' (pp. 20).

Conclusion

This study offers a window into the ways in which families of children with autism overcome adversity. The findings of this study serve a dual role in terms of their utility in facilitating family resilience. Firstly, this research confirms that factors such as support, togetherness, adaptation, acceptance, positivity and perceptions of normality are all important resilience factors. As such, they could be beneficial for strength-based interventions that focus on utilising families' strengths and build on the positives (Blundo, 2001). Secondly, they enhance our knowledge and understanding of how families of children with autism respond with strength and resilience, despite the extraordinary challenges that life throws at them. Narrating stories of resilience may empower other families of children with autism to acknowledge their strengths, utilise their resources and recognise their own capacities for resilience.

Future Recommendations

Although there were some methodological and sample limitations, this study could be recognised as a small step towards encouraging further resilience research with other families of children with other developmental disabilities. For example, families of children with Down syndrome could be investigated to identify the factors that enable them to be resilient. Additionally, future research could explore how individual resilience factors may contribute to (and strengthen) family resilience.

Reflexive Analysis

According to Mauther & Doucet (2003), reflexivity is essential within qualitative research as it allows the researcher to justify their assumptions based on their positionality. The entire conceptualisation of this project arose from my own experience of being in a family of someone with autism - my twin brother has Asperger's syndrome. These experiences enabled me to have some pre-established knowledge and awareness of what similar families go through - this will have sensitised me to the topic areas that were being discussed, thus influencing my interpretations within the analysis.

It can be argued that the interview started before the tape-recorder was switched on. Before the 'formal' interview took place, the participants and I had a conversation about ourselves and our families. The disclosure of personal information by the researcher can create an atmosphere that encourages a more 'conversational' interview style (Holstein & Gubrium, 1997). Additionally, the power can shift towards the participant, allowing them to set the agenda and speak a lot more freely and naturally (Finch, 1993). Also, because I could relate to their experiences of being in a family of someone with autism, I felt like it really enabled them to open out for me. Having that commonality provided me with a powerful tool that gave the participants the confidence to talk about specific challenges in their lives that perhaps they wouldn't have disclosed with someone who didn't have the same experiences as myself.

Overall, I thoroughly enjoyed the project and I feel like I have gained new insights into the experiences and lifestyles of other families of children with autism. While many of the participants were startled at the idea of talking about something positive about their families, every participant said that they enjoyed the experience. The process was almost transformative as many said that it encouraged them reflect on the positive outcomes of negative situations, which not many had done before. I referred each parent to proactive academics such as Katherine Runswick-Cole to enable them to connect with other people within the autistic community in the hope of it being a source of strength for them. Taking a positive approach had amazing results – instead of buying into the negative psychopathological perspectives, we introduced a new way of thinking about resilience and positivity.

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