

THE UNIVERSITY OF HULL

Disabled Children in Families: Perspectives of Siblings and Adoptive
Parents

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Table of Contents

| | |
|--|----|
| Acknowledgements | 5 |
| Overview | 6 |
| PART ONE: | |
| Systematic Literature Review | |
| ‘The Impact on Children of Having a Disabled Sibling’ | 7 |
| Abstract | 8 |
| Introduction | 9 |
| Method | 13 |
| Results | 17 |
| Discussion | 37 |
| References | 43 |
| PART TWO: | |
| Empirical Paper | |
| ‘The Experience of Adopting a Child with a Disability’ | 47 |
| Abstract | 48 |
| Introduction | 49 |

| | |
|------------|----|
| Method | 52 |
| Results | 57 |
| Discussion | 73 |
| References | 81 |

PART THREE:

Appendices and Reflective Statement

| | |
|---|-----|
| Appendix A – Guidelines for Submission | 85 |
| Appendix B – Burke’s Model of Disability by Association | 90 |
| Appendix C – Data Extraction Form | 91 |
| Appendix D – Quality Assessment Tool | 94 |
| Appendix E – Quality Assessments | 97 |
| Appendix F – Criteria for identifying ‘Strong’ themes | 98 |
| Appendix G – Guidelines for Submission | 99 |
| Appendix H – Ethical Approval Letter 1 | 108 |
| Appendix I – Ethical Approval Letter 2 | 109 |
| Appendix J – Participant Information Sheet | 110 |
| Appendix K – Demographic Questionnaire | 114 |
| Appendix L – Consent Form | 115 |
| Appendix M – Interview Schedule | 117 |
| Appendix N – Sources of Support Sheet | 118 |
| Appendix O – Marked Transcript | 119 |
| Appendix P – Epistemological Statement | 121 |
| Appendix Q – Reflective Statement | 123 |

List of Tables and Figures

Part 1: Systematic Literature Review

Figure 1 – Search Strategy 18

Table 1 – Details of Reviewed Studies 20

Part 2: Empirical Study

Table 1 - Demographic information 54

Table 2 – Themes 57

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Overview

This thesis portfolio comprises three parts:

Part one is a systematic literature review that explores the impact of having a disabled sibling from a child's perspective.

Part two is a qualitative study using Interpretative Phenomenological Analysis (IPA) to understand the experiences of parents who adopt a child with a disability.

Part three is a complete set of appendices for parts one and two. This also includes an epistemological and a reflective statement.

The Impact on Children of Having a Disabled Sibling

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Abstract

The siblings of disabled children can experience public prejudice, and are vulnerable to loneliness and bullying. To date most research exploring the impact of having a disabled sibling has been based on the perspective of mothers.

This is the first review to examine the impact of growing up with a disabled sibling from a child's viewpoint. A systematic search identified eight studies which featured children who had siblings with a range of different disabilities. The five key components of Burke's model of Disability by Association were used to provide a theoretical framework to help organise the analysis of the papers. Any themes additional to this model were also identified. The review found that all five categories of Burke's model were represented to a greater or lesser extent. In addition, a further theme of anxiety was identified. Two of the strongest impacts on children were found to be social exclusion and isolation at home, with the theme of anxiety also evident in many of the papers. The combination of these challenges could have a negative impact on the children's psychological wellbeing.

Importantly, the theme of empowerment was also evident in many of the papers and could help transform children's outlook and life experience. This review highlighted the need for sufficient support for these vulnerable children and demonstrated the real difference this can make to their self-confidence and life experience.

Key words: Sibling, Disabled, Impact, Experience, Child

Introduction

There are over half a million siblings of disabled children and young people in the UK (Office for National Statistics, 2016). It is believed that these siblings experience more public prejudice, family breakdown, bereavement and poverty than siblings of non-disabled children (Dyke, Mulroy, & Leonard, 2008). As a consequence they are vulnerable to loneliness, bullying, lower mood and difficulties at school (Goudie, Havercamp, Jamieson, & Sahr, 2013). Disability of one family member affects the whole family and has a particular impact on siblings. As one parent explained 'we are a disabled family, we don't just have a disabled child' (Whiting, 2014).

The term 'disability' is often debated and may have different meanings for particular communities (Emens & Stein, 2016). The medical model focuses on disability as the result of one or more impairments of the individual body. In contrast, the social model of disability emphasises how barriers in society result in disability by limiting the participation of a particular group (World Health Organisation, 2007). Most published research in the area of children who have a disabled sibling has used the medical model to define disability with participants having a medically diagnosed disability (Burke, 2010).

There is a clear stigma associated with disability (Heary, Hennessy, & Swords, 2014). Members of the general public often erect a barrier between themselves and a disabled person as they fear that the stigma might be transmitted to them (Shakespeare, Watson, & Alghaib, 2016). A report by Scope showed that large sections

of the population hold negative attitudes towards disabled people and two thirds of the British public feel uncomfortable talking to a person with a disability (Scope, 2014).

The exclusion of disabled people by society often extends to family members and will therefore influence a sibling's self-concept and how they relate to others (Burke, 2010). Although attitudes are starting to become more positive, images of people with disabilities in popular culture still tend to be negative (Anastasiou, Kauffman, & Michail, 2016; Stoneman, 2005). Against this background there has been an assumption that to have a sibling with a disability must be damaging for children (Stoneman, 2005).

Burke (2010) introduced the 'Disability by Association' model which provides a theoretical framework to explore the experience of children who live with a disabled sibling. It describes their relationships with family and friends as well as their school and social life (see Appendix B). It also discusses how the non-disabled child's exposure to disability is an important influence on their development. Burke explained that living with disability in the family gives non-disabled siblings a disabled identity.

The Disability by Association model specifies that an association with a disabled sibling can cause stress in several social interactions. Importantly, once an 'associate disabled identity' is established by the sibling, there is the potential for positive as well as negative effects (Burke, 2010).

Much of the research exploring the impact of having a disabled sibling has concentrated on mothers' opinions rather than directly asking the child (Reichman, Corman, & Noonan, 2008). Mothers of disabled children experience more stress and depression than other family members (Feizi, Najmi, Salesi, Chorami, & Hoveidafar, 2014). Therefore, relying on mothers' reports only provides information that has already been filtered through a parent's perspective which may be influenced by their own tensions and strains (Dyke et al., 2008).

Interviews with parents have discussed both the positive and negative consequences for siblings who have a brother or sister with a disability (Dyke et al., 2008). Some of the positive effects described are connected to personality and include greater tolerance and awareness of difference; an increased capacity for caring and compassion; and a generally more mature attitude compared to their peers. Mothers have also described how siblings can have a heightened appreciation of their own abilities (Stoneman, 2005).

Dyke et al (2008) also described parents' reporting several disadvantages of having a sibling with a disability. These included having fewer opportunities for leisure activities and family outings. In addition, family holidays were more limited because of the financial burden of looking after a disabled child. Some described the embarrassment and ostracism that siblings could face when mixing with their peers (Reichman et al., 2008). There was also discussion of the additional responsibility placed on the healthy sibling to help in the care of their disabled brother or sister (Dyke et al., 2008).

The United Nations Convention on the Rights of the Child (1989) requires that rights apply to all children without discrimination and that children have the right to express an opinion on any matter relating to them (United Nations Children's Fund, 1989). This means that adults should seek the opinions of children in decisions that affect them and this should include the views of siblings of disabled children (Burke, 2010). It is important that children are consulted directly as 'experts on their own lives' (Malcolm, Gibson, Adams, Anderson, & Forbart, 2013).

There are currently no reviews of the research that explores the experience of growing up with a disabled sibling from a child's viewpoint. The objective of this systematic review is to identify and analyse papers that address the question of 'What is the impact of having a disabled sibling?' from the perspective of a child. It is hoped that this will give these vulnerable children a voice — highlighting both the positives and negatives of their experiences. It is anticipated that the findings of this review will help inform families, friends and professionals of how these disadvantaged children can be supported and helped to develop skills to manage the challenges they face.

Method

Search Strategy

A systematic search was conducted using the following predetermined search terms:

Disab* or handicap or retarded AND sibling or brother or sister AND effect* or impact* or consequence* or influence.

Searches were conducted in the following electronic databases: PsycINFO, Academic Search Premier, CINAHL Complete and MEDLINE. In addition, the reference section of articles meeting the inclusion criteria were searched for relevant studies. To achieve a comprehensive review of the literature, quantitative, qualitative and mixed method studies were included in the review. The search strategy is illustrated in Figure 1.

Inclusion Criteria

The study selection criteria were based on Cochrane's recommendations for conducting a systematic review to facilitate a comparison of the outcomes of the studies (Lefebvre, Manheimer, & Glanville, 2011).

Inclusion criteria included:

1. Peer reviewed journal article

2. Publication date between 1989 and 2016 – i.e. following the introduction in 1989 of the United Nations Convention on the Rights of the Child (United Nations Children’s Fund, 1989)
3. Written in the English Language
4. Study is qualitative, quantitative or mixed methods and includes measures or discussions around the impact for a child of having a disabled sibling
5. Study carried out in the UK (so that the results are context specific and can inform UK social services)
6. Study population to include children (aged 7-18 years) with a sibling with a disability (*not a mental health problem*) who is under the age of 18. The age of 7 was selected as the lower age bracket as this is when children are considered to be emotionally independent of adults to a great extent and is also the time when children enter Key Stage 2 of the UK educational system (UK Government, 2017) (Bjorkland & Causey, 2017). The disabled siblings could include those who have long-term physical, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others (United Nations, 2006)
7. Study information obtained directly from the child (and not via a parent or health care professional) so that the child’s perspective is explored

Data Extraction and Synthesis

An initial assessment of the data revealed that themes mainly grouped together according to the key components of Burke's model: Disability by Association (Burke, 2010). As this review aims to explore the impact of having a disabled sibling from the perspective of the child, themes were deductively derived from components of Burke's model (Appendix B) (Burke, 2010). In addition, to ensure that the review is comprehensive, any themes that did not fit into Burke's model were also identified and analysed.

Convergent thematic analysis (which involves sorting data into pre-determined themes rather than emergent themes) was used to synthesise the results of this review (Gough, 2015). Thematic analysis was considered an appropriate approach for reviewing this collection of studies as it captures common themes irrespective of study methodology (Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005; Feredy & Muir-Cochrane, 2006).

A data extraction form (Appendix C) was compiled with five section headings representing each of the key components of Burke's model: Potential for Social Exclusion; Potential for Isolation or Neglect; Sense of Difference; Family Normality; and Empowerment. In addition, a sixth heading was included for any additional themes that emerged during the data extraction that were not part of Burke's model. Each paper was analysed for data that fitted under each of these headings.

Quality Review

The Mixed Methods Appraisal Tool (MMAT) was used to assess the quality of studies (Appendix D) (Pluye, Gagnon, Griffith, & Johnson-Lafleur, 2009). This tool allows the simultaneous appraisal of qualitative and quantitative methodologies when different epistemological approaches may prevent the use of a single study quality checklist.

Using the MMAT, the methodological quality of each study was estimated, producing a score that could range from 0% (suggesting a study of low quality) to 100% (suggesting a study of high quality) (Appendix D).

Results

Study Characteristics

A summary of the papers included in this review can be found in Table 1. After applying the inclusion criteria eight original studies were identified (see Figure 1. These comprised five qualitative studies (Hames & Appleton, 2009; Malcolm et al., 2013; Petalas, Hastings, Nash, Dowey, & Reilly, 2009; Petalas, Hastings, Nash, Reilly, & Dowey, 2012; Read, Kinali, Muntoni, Weaver, & Garralda, 2011); two quantitative studies (Coleby, 1995; Lovell & Wetherell, 2016); and one mixed methods study (Velleman, Collin, Beasant, & Crawley, 2016). The papers were published between 1995 and 2016. The number of participants in the studies ranged from 8 to 726* and the age of participants ranged from 7 to 18. (*The mixed-method study had 692 children in the comparative group (Velleman et al., 2016)).

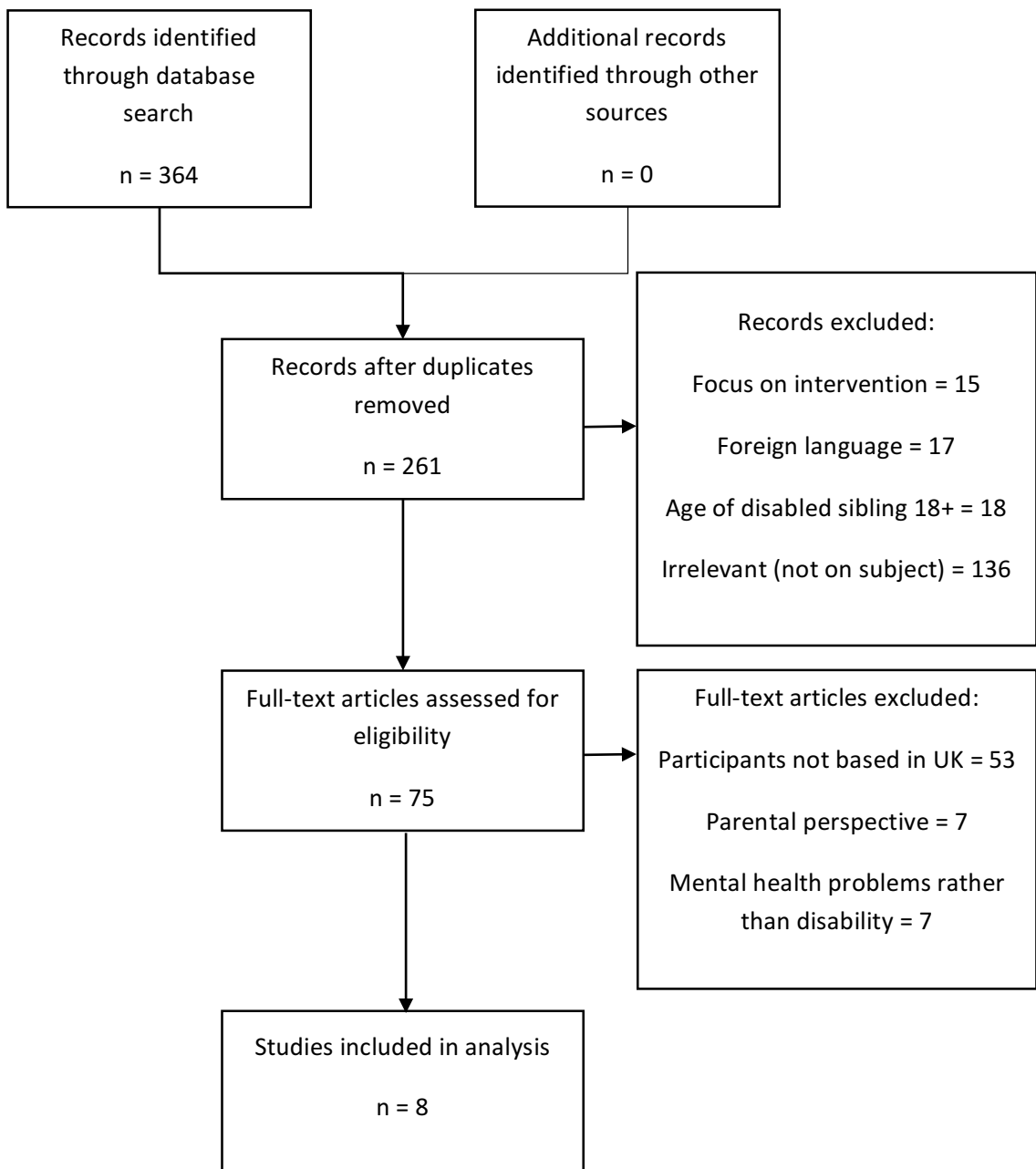


Figure 1. Search strategy - in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (Moher, Liberati, Tetzlaff, & Altman, 2009).

All five qualitative studies were based on semi-structured interviews followed by thematic analysis. The two quantitative studies used a range of questionnaires (Table 1) to assess the impact of having a disabled sibling and compared the scores with an index group. The one mixed method study used a combination of these two approaches.

There was a wide range of different disabilities featured in the studies both in terms of type and severity. These included neurodevelopmental disorders (e.g. autism) (Lovell & Wetherell, 2016; Petalas et al., 2009; Petalas et al., 2012); neurological (e.g. epilepsy) (Hames & Appleton, 2009); neurodegenerative disorders (e.g. Batten disease) (Malcolm et al., 2013); and life-limiting conditions (e.g. Duchenne muscular dystrophy) (Read et al., 2011).

To determine inter-rater reliability, an independent researcher evaluated a randomly selected subset of 4 papers (50% of the dataset). Any discrepancies between scores were discussed and a joint final decision was made (Appendix E). The average quality score of the 8 papers is 81.25% with a range of 50 -100%. No paper was excluded based on quality.

Table 1. Details of reviewed studies.

| Authors | Study Type | Disability | Measures | Participants | Data Analysis | Quality Score (%) |
|-----------------------|-------------------|---------------------------------------|----------------------------|-----------------------------------|----------------------|--------------------------|
| Hames et al (2010) | Qualitative | Epilepsy | Semi-structured interviews | 14 siblings (age range: 8-18) | Thematic analysis | 50 |
| Malcolm et al (2013). | Qualitative | Mucopolysaccharidoses /Batten disease | Semi-structured interviews | 8 siblings (age range: 7-12) | Thematic analysis | 50 |
| Petalas et al (2009) | Qualitative | Autism spectrum disorder | Semi-structured interviews | 8 siblings (age range: 9-12) | Thematic analysis | 100 |
| Petalas et al (2012) | Qualitative | Autism spectrum disorder | Semi-structured interviews | 12 siblings (age range: 14-17) | Thematic analysis | 100 |
| Read et al (2011) | Qualitative | Duchenne muscular dystrophy | Semi-structured interviews | 35 siblings (age range: 11-18) | Thematic analysis | 75 |

| Authors | Study Type | Disability | Measures | Participants | Data Analysis | Quality Score (%) |
|-----------------------|-------------------------------|--|---|---|--|-------------------|
| Coleby (1995) | Quantitative | Multiple disabilities | Questionnaires : Rutter's scale SBAS Voeltz Scale MAS | 41 siblings (age range: 7-17) and 41 matched siblings in comparison group | Comparison of scores on questionnaires between index and comparison siblings. | 100 |
| Lovell et al (2016) | Quantitative | Autism spectrum disorder | Questionnaires : CDI-2 SSSC SDQ | 25 siblings (age range: 7-17) and 20 matched siblings in comparison group. | Comparison of scores on questionnaires between index and comparison siblings | 100 |
| Velleman et al (2016) | Qualitative + Quantitative | Chronic fatigue syndrome/myalgic encephalomyelitis | Questionnaires : HADS SCAS EQ-5D-Y | Questionnaires: 34 siblings (age range: 12-17) and 692 matched siblings in comparison group Interviews: 9 siblings (age range: 12-17) | Comparison of scores on questionnaires between index and comparison siblings. | 75 |
| | | | Semi-structured interviews | | Thematic analysis | |

KEY 1

- CDI-2: Children's Depression Inventory-2 (Kovacs, 1985)
- SBAS: Social Behaviour Assessment Scale (Platt, Weyman, Hirsch, & Hewett, 1980)
- SSSC: Social Support Scale for Children (Malecki & Demaracy, 2002)
- SDQ: Strengths and Difficulties Questionnaire (Goodman, 1997)
- HADS: Hospital Anxiety and Depression Scale (Zigmond & Snaitth, 1983)
- MAS: Manifest Anxiety Scale (Taylor, 1953)
- SCAS: Spence Children's Anxiety Scale (Spence, 1998)
- EQ-5D-Y: European Quality-of-Life Youth (Wille et al., 2010)
- Voeltz scale: Measure of child's acceptance towards disabled peers (Voeltz, 1980)
- Rutter's scale: Measure of child's behaviour (Rutter, 1967)

Key 2

Mucopolysaccharidoses: group of progressive metabolic disorders affecting bone, connective tissue and organs

Batten disease: fatal autosomal recessive neurodegenerative disorder

Duchenne muscular dystrophy: severe type of muscular dystrophy

Myalgic encephalomyelitis: chronic fatigue syndrome

Themes

Each of the eight studies was analysed based on the five components from Burke's model of Disability by Association and any additional themes (Burke, 2010).

1. Potential for Social Exclusion (social experience)

Social exclusion can make siblings feel isolated and different from those around them (Burke, 2010). Often their lives seem very unlike their peers. In particular, it may be hard for them to talk to friends about their disabled brother or sister, as they think friends will not understand. This was a key theme in the reviewed literature, and featured in four of the eight papers.

There was evidence in some studies of children reporting feelings of being different resulting in a sense of isolation. Hames and Appleton (2009) reported that approximately half of the 14 siblings in their study described:

'feeling lonely, anxious or just different' (p. 700)

Social exclusion can also happen when children choose not to mix with their peers as they feel they do not fit in. One participant explained:

'I just try and keep my distance from most people' (Petalas et al, 2009, p. 386)

This feeling was echoed by a child who felt excluded as a result of negative peer reactions:

'It's like they don't really like me anymore, because they see [*sibling's name*] as someone they don't really want to know' (Petalas et al., 2009, p. 388)

The perception of being alone was confirmed in an interview by Malcolm et al. (2013) where a child described a strong feeling of isolation and reported the limited time he has with friends.

The sense of being different was reinforced for some children by unkind behaviours towards them or their sibling. Two children whose siblings had Batten disease talked about being teased by peers at school (Malcolm et al., 2013). One of these children reported being upset by how unkind people could be:

'you've got a disabled brother, ha, ha, ha, ha' (p. 7)

Another child described:

'whenever you're walking down the street with [*sibling's name*], they look at him and then just go like that (*demonstrates turning his back away*)' (p.7)

The two qualitative studies that scored highest for quality (100%), Petalas et al (2009) and Petalas et al (2012), both provided strong evidence of social exclusion of children. However, it should be noted that these two studies have been carried out by the same group of researchers and both explore the experience of having a sibling with autism with participants of different ages (9-12 and 14-17 respectively). One boy commented:

‘once in primary and they started to make fun of my brother so I didn’t want this to happen again’ (Petalas et al., 2009, p. 388)

Children with autistic siblings often felt embarrassed in public. The brother of a child with autism described the awkwardness of social situations:

‘it can be embarrassing because everyone is watching’ (Petalas et al., 2012, p. 307)

These children can feel excluded as they do not think that they are wanted and do not want to take the risk of peers making fun of them. One child talked about being mocked because of his autistic brother and fearing that he would be an outcast within his peer group:

‘I feel that people are going to point and laugh because people always take the mickey out of disabled people’ (Petalas et al., 2012, p. 307)

2. Potential for Isolation and Neglect (home experience)

Children may experience neglect and isolation at home due to the overwhelming parental needs of a disabled brother or sister (Burke, 2010). Siblings often receive less care and attention from their parents due to the limited time available rather than deliberate neglect. The issue of lack of parental interest was a very strong theme in the reviewed papers and was the main focus of the interviews in four of the qualitative

and the one mixed methods paper. The only qualitative paper that did not feature it as a central issue was Petalas et al, (2012). This may have been because the participants in this study were adolescents (14-17 years old) and are therefore less likely to seek parental attention.

The papers reported that sometimes siblings thought their feelings did not matter to their parents as they perceived the needs of a disabled brother or sister as being more important. Some children talked about the negative impact their sibling had on the whole family. For example, one child confided:

‘sometimes I’d quite happily swap him for a quieter brother who didn’t need so much of mummy’s time and attention’ (Hames & Appleton, 2009, p. 700)

Children also commented on how they felt their parents did not often think about their needs:

‘exhausted.....couldn’t think of anything else but his fits’ (Hames & Appleton, 2009, p. 700)

Read et al (2011) also found that siblings perceived an inequality in parental attention and availability. This qualitative study had the highest number of participants (35) and most of them discussed this issue in their interview. For example, when talking about their parents, siblings in their late teens mentioned lack of attention and feeling excluded. They expressed feelings of jealousy, neglect and isolation:

‘so he takes the attention away from everybody and puts it on himself.....I’m here too, I feel left out and I do like a bit of attention too’ (Read et al., 2011, p. 24)

Some children discussed the stress of balancing their own needs with those of their disabled sibling (Read et al., 2011). Similarly, children who had a sibling with Myalgic Encephalomyelitis (ME) often felt that the focus of their parent’s attention had shifted from being shared to being on their sibling:

‘so, family life changed quite a bit. It’s become more focussed on [*sibling’s name*]’ (Velleman et al., 2016, p. 626)

The needs of a disabled child may be too unpredictable for parents to be able to commit to regular activities such as sports or music lessons. For example, in Velleman et al (2016) all of the nine children with a sibling with ME talked about the impact and restrictions on family life which excluded them from activities because of their brother or sister’s condition (Velleman et al., 2016). One child described how:

‘we can’t plan too far ahead because we don’t know if she will be ok’ (p. 625)

Some children discussed how lack of communication had an impact on family life and described feelings of being left out (Velleman et al., 2016). In addition, in Malcolm et al (2013) – a study which interviewed slightly younger children (aged 7-12) – one child described being unable to talk to their parents about how they felt:

'you cry in yourself you know.....when I go to my bedroom I have a big cry' (p. 7)

This feeling was also described in Petalas et al (2009). One child in the study explained that they had resigned themselves to having very little attention from their parents because of their autistic brother's needs:

'I've pretty much taken to staying in my room most of the time - he wants a lot of attention' (p. 386)

Some of the children felt alone and lacking in support:

'I felt quite annoyed, because there's no one really to talk to about when I feel angry with [*sibling's name*], and when he always gets his own way, and stuff about that' (Petalas et al., 2009, p. 392)

3. *Sense of Difference (as family)*

Burke (2010) describes how children's lives are affected by the fact that the public view disabled people as different, which leads to stigma not only for those with a disability but also for their families. This can result in negative interactions with both strangers and friends and can cause children to feel angry and embarrassed when they are with their disabled brother or sister in public (Petalas et al., 2009). This was the least strong theme in the review and was only mentioned briefly in three of the

papers. Moreover, some of the limited evidence for Sense of Difference would also fit under the themes of Social Exclusion or Isolation discussed earlier.

There are many ways in which family life with a disabled child can be different from other families. Children who had a brother or sister with Batten's disease talked about the limitations on their family's social experiences due to the demands of caring for a disabled child (Malcolm et al., 2013). Some mentioned a lack of family togetherness because of the need to organise independent leisure activities due to different physical abilities. In addition, holidays tend to revolve around the needs of the disabled child (Read et al., 2011). Children often wished that their sibling was not disabled:

'It would be nice to have a nice, normal brother' (Petalas et al., 2009, p. 390)

Petalas et al (2012) highlighted that, in contrast to younger siblings, adolescents tended to compare their personal situation with their peers and with other families. One teenager described the disruption that his brother's behaviour often caused to family life:

'I feel quite angry because he has spoiled a day, which we were all enjoying at that point' (Petalas et al., 2009, p. 387)

4. Family Normality

Burke (2010) commented that growing up with a disabled sibling instils an acceptance of disability as a feature of normal family experience. In four of the qualitative papers children described how having a disabled brother or sister was a normal part of family

life for them. However, this was not a major theme in any of the papers as participants did not think of it as anything remarkable.

Some children reported that the situation was usual for them as it had gradually developed since early childhood (Read et al., 2011). A number of families became closer because of the understanding they share. In Hames and Appleton (2009) siblings accepted their siblings for who they were, and commented that they:

‘wouldn’t change him for anything’ (p. 700)

The sense of normality was conveyed in Petalas et al (2009) when a child described his acceptance of his brother:

‘he’s just like my normal brother, I never even think about it I just recognise him as just another human’ (p. 389)

Some participants went further than just accepting their disabled sibling as a normal part of family life and spoke about the advantages of their particular family:

‘that’s what a strong family is all about, being there for one another and getting through what life throws at you together. You have to make the best of any situation and look at the positive things in life rather than the negative’ (Hames & Hamelton, 2009, p. 700)

An example of focussing on positive experiences and family normality was provided by a participant who recalled happy family holidays with her autistic brother:

‘we went on a few holidays in the summer and they were fun because, like in Greece, we had to share a room and stuff, so we had a lot of time to ourselves and we could sit and watch these videos, and get sweets and stuff.....Yes, the holiday was good’ (Petalas et al., 2012, p. 310)

5. Empowerment (including professional Intervention)

Burke (2010) described how, once a sibling develops an ‘associate disabled identity’, there is the potential for positive as well as negative effects. If these children are supported they can become more resilient and able to cope with difficult experiences. Empowerment enables siblings to build a positive identity in relationships and to develop valuable qualities such as maturity and tolerance. This was one of the strongest themes in this review with six out of the eight papers providing evidence to support it. Moreover, the papers had multiple examples of how empowerment could feature in siblings’ lives.

Read et al (2011) found that some siblings with disabled brothers and sisters had increased family cohesion. The children in this study developed coping techniques such as using humour and controlling negative emotions. Some children spoke with pride about the caring role they took within their family and the sense of responsibility they felt for their brother or sister with Duchenne muscular dystrophy. Participants also

reported feeling more mature than their peers and this had been noticed by their teachers (Read et al, 2011).

In Petalas et al (2012) some siblings of children with autism had increased social ability and a more positive self-concept compared to siblings of children with no disability.

They commented on how much they had been taught by their brother or sister:

‘I always think to sort of learn from that, and take after him.....I obviously feel comfortable around other handicapped people. I know how to react because of being with [*sibling's name*]' (p. 310)

Another child in the same study remarked:

‘it makes me appreciate stuff, like you shouldn't judge people on what they are and what condition they have, or anything like that' (Petalas et al., 2012, p. 310)

One child felt that his brother's disability had allowed him to increase in confidence:

‘Because in a way I've found my own voice I suppose' (Velleman et al., 2016, p. 626)

Some children felt they had developed skills from their sibling:

‘I’ve learnt about caring well for people... We get to understand more about other people. Because if I didn’t have [*sibling’s name*] then I wouldn’t know what autism means’ (Petalas et al., 2012, p. 391)

For many of the children support groups provided a valuable opportunity to overcome isolation (Malcolm et al., 2013). In Petalas (2009) participants explained that it was helpful to talk openly about their feelings and share their experiences with other children in similar circumstances. Autism support groups, which allow siblings to come together, make friends and share experiences, were linked with positive psychological changes including fewer depressive symptoms (Lovell & Wetherell, 2016). Unfortunately, these groups were limited in number and difficult to access.

Children also reported that they used a variety of other sources of support. For example, they would seek help from friends, parents and professionals (Petalas et al., 2009). It was found that support from parents and close friends reduced depressive symptoms (Lovell & Wetherell, 2016). The presence of social support explained a significant portion of the variance in children’s total scores on the Children’s Depression Inventory-2 (CDI-2).

For some children, also having a non-disabled sibling acted as a comfort:

‘We just talk, it’s called our huddle.’ (Petalas et al., 2009, p. 391)

Some participants reported talking to their parents to get a greater understanding of their sibling’s disorder and seeking their support when they were upset:

'I speak to herwhen it's actually affecting me, about what happens in the house, like if I've got upset.' (Petalas et al., 2009, p. 391)

6. Anxiety (worry)

The review of the eight studies revealed the additional theme of anxiety (or worry) which is not featured in Burke's model. The theme of anxiety was present in five of the eight reviewed papers, with all three of the studies with a quantitative component highlighting this as an issue.

Malcolm et al (2013) found that worry about their brother or sister who had Batten Disease was present throughout siblings' lives. Some children described difficulties concentrating at school because of a worry. One of the themes that Petalas et al (2012) identified in their interviews was anxiety about the future. For several siblings concerns about the future and their sibling were at the front of their minds:

'am I going to have to look after him, which I wouldn't mind doing, but is he going to be able to look after himself? That's what worries me' (p. 310)

Similarly, several children who had siblings with autism expressed anxiety about what the future holds and what their role may be:

'the first thing I've got to worry about is when he gets to high school, he might get bullied....' (Petalas et al., 2012, p. 310)

Worry was not just confined to components of Burke's model. Some of the worry concerned uncertainty regarding the future. Children may find unanswered questions more distressing than knowing the truth. A big concern for siblings is what will happen when their parents die, even for young children (Petalas et al., 2012).

High levels of anxiety were apparent in both the interviews with siblings and in the questionnaires that they completed. The quantitative papers particularly focussed on the psychological impact for participants particularly anxiety and depression (Coleby, 1995; Lovell & Wetherell, 2016; Velleman et al., 2016).

For example, children who had siblings with ME had a high level of anxiety with 25% scoring above the 90th percentile on the Spence Children's Anxiety Scale described feeling hopeless and worrying about their brother or sister (Velleman et al., 2016). Similarly, the study by Coleby (1995) found that siblings had reduced contact with friends and higher scores on the Rutter Antisocial Scale and Manifest Anxiety Scale when compared with children who did not have a disabled brother or sister.

In Lovell and Wetherell (2016), children with siblings who had autism scored higher for emotional problems than those without a disabled sibling.

Discussion

This is the first systematic review aimed at exploring the impact on children of having a disabled sibling from a child's perspective. The fact that, even with broad inclusion criteria, only eight studies were identified shows how limited research has been in this area. However, the quality of the studies was reassuringly high with four given the top score on MMAT (100%) (Coleby, 1995; Lovell & Wetherell, 2016; Petalas et al., 2009; Petalas et al., 2012). It is also noteworthy that the two lowest scoring papers (each scoring 50%), received a high mark for the relevance of their research question and the process of data analysis (Hames & Appleton, 2009; Read et al., 2011). Moreover, these two studies had the highest number of participants (35, 14) of all the qualitative studies reviewed. Until recently much of the research in this field has concentrated on mothers' opinions rather than directly asking the affected children. Indeed siblings are still often forgotten in the attempt to meet the needs of disabled children (Dyke et al., 2008; Reichman et al., 2008).

Disability by Association

Burke (2010) explained that living with disability in the family gives non-disabled siblings a disabled identity. The 'Disability by Association' model specifies that an association with a disabled sibling can cause stress in social interactions both within the family and in the wider community. All the five categories of Burke's model were represented to a greater or lesser extent in the papers examined for this review. In addition, a further theme of anxiety was identified which could also contribute to the development of a disabled identity. When a theme was identified an assessment of

whether it could be classified as a 'strong' themes was made in accordance with pre-defined criteria (Appendix F).

Challenges

When analysing the papers to explore the impact on children, two of the strongest themes to emerge were the challenges of social exclusion and isolation at home which featured in Burke's model (Burke, 2010).

Importantly the additional theme of anxiety or worry was also evident in many of the papers. The anxiety experienced by children was sometimes related to themes within Burke's model but could also be linked to their brother or sister's health status; their additional responsibilities; or the future in general.

The combination of these challenges (social exclusion, isolation at home and anxiety) could have a negative impact on the children's psychological wellbeing. This was demonstrated by the findings of the quantitative studies which showed higher levels of psychological distress particularly anxiety as measured by anxiety scales (Coleby, 1995; Velleman et al., 2016).

The Biopsychosocial Model of anxiety in childhood explains how social factors such as discouraging interactions with others can contribute to the development of anxiety (Chavira, Stein, Bailey, & Stein, 2004). There is evidence that childhood anxiety may be predictive of pathology at later development stages of an individual's life (Walkup et al., 2008). Fortunately, anxiety in children can be effectively treated with psychological therapy (In-Albion & Schneider, 2007).

Compared to previous research based on interviews with mothers, the papers considered in this review accessed children's views directly and have shown how children may interpret situations differently from their parents due to their immaturity. For example, children tended to interpret the lack of parental attention as an indication that they were less important whereas in previous studies parents viewed it as an indication of extreme time pressure (Dyke et al., 2008; Hames & Appleton, 2009; Read et al., 2011).

Empowerment

Burke's model highlights empowerment as a positive consequence of having a sibling with a disability. Empowerment was a strong theme in the papers and could help to transform siblings' outlook and life experience. The studies emphasised the need for support for siblings and highlighted the difference that sufficient help makes to children's self-confidence (Petalas et al., 2009). Effective support could be provided by sibling groups or families (including extended family such as grandparents) (Lovell & Wetherell, 2016).

The amount of professional help made available to siblings is greatly influenced by local and national policies. For example, the UK Children and Families Act 2014 has added new sections to the original Children Act 1989 to obligate social services to 'assess whether a young carer within their area has needs for support and, if so, what those needs are' (UK Government, 2014). Most siblings with a disabled brother or sister would be considered a young carer. There is clearly a real need for interventions

to help these children. Organised groups that allow siblings to come together to have fun and share their experiences can be a valuable form of support (Hartling et al., 2014). In addition, helping children develop skills to manage other people's reactions to their disabled sibling can increase their confidence (Petalas et al., 2012).

Information for siblings that will help them understand how disability affects their brother or sister is also important (Dyke et al., 2008; Hames & Appleton, 2009).

Limitations

Burke's Disability by Association model was a valuable tool in organising this review (Burke, 2010). Importantly all five categories of the model were represented to a greater or lesser extent in the reviewed papers. However, there may be limitations of using an existing model such as Burke's as the basis for data extraction and synthesis. For example, although the model helped to connect the data to an existing understanding of siblings' experience of disability, it was not constructed to allow possible new themes to be explored. Therefore, to ensure that this review was systematic and comprehensive, the data extraction and analysis process was designed to also accommodate themes not part of Burke's model.

It should also be remembered that Burke's model was not originally designed for use in a child population (as it is based on data derived from interviews with adults).

Considering this, it has adapted well to the child population and could be further improved by including the additional theme of Anxiety.

Importantly, this review features studies that involved children with a wide range of disabilities in terms of type, severity and long-term prognosis. This broad approach to

the inclusion criteria for participants was appropriate as there are so few papers published in this area. However, this review is not able to address the possibility that the impact on a child may be dependent on the exact nature of their sibling's disability. There are currently not enough studies published to make such a review feasible. Interestingly, the quantitative study by Coleby (1995) which featured participants with a range of disabilities, found that there was no direct relationship between a child's social adjustment and an objective assessment of the severity of their sibling's disability.

It is also worth considering if the participants in the studies are representative of most children who have a disabled sibling. It is possible that only those who had positive views agreed to share their experiences (Hames & Appleton, 2009). For example, siblings whose views were more negative may have felt uncomfortable or embarrassed to share them and therefore their voices may not have been heard. Children need to be able to express both their positive and negative feelings regarding their disabled sibling and feel comfortable with this complex mixture of emotions. In particular, it is important that siblings who may be vulnerable to distress are identified so that additional support can be offered (Read et al., 2011).

Opportunities

Future research in this area should be aimed at increasing our understanding of the best way to support children with disabled siblings to enable them to become self-assured adults (Stoneman, 2005). This review has shown these children often grow up in a stressful family environment with parents who may be struggling to meet the many demands on their time (Hames & Appleton, 2009). They also face the stigma

associated with disability which may make them feel excluded by peers and the community (Burke, 2010; Petalas et al., 2012). These children often do not have the maturity to deal with these challenges and the associated complex emotions. Without the opportunity to express their feelings, a child's self-esteem can suffer (Velleman et al., 2016). However, studies have shown that if siblings are well supported by their families, friends and professionals their confidence can increase and they can become empowered and may develop positive qualities such as compassion, tolerance and maturity (Lovell & Wetherell, 2016; Malcolm et al., 2013; Petalas et al., 2009). It is therefore of great importance that the challenges these siblings face are recognised by their families and professionals and that they are not forgotten when services for disabled children are being planned.

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The Experience of Adopting a Child with a Disability

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Abstract

Adoption agencies have difficulty finding adoptive homes for disabled children. Despite these challenges, very little research has been carried out into disabled adoption. This study aims to explore the experience of parents who have adopted a child knowing that they have a disability - asking them to reflect on their lives before, during and after the adoption. Interviews with five mothers were audio-recorded and the transcripts were analysed according to the principles of Interpretative Phenomenological Analysis (IPA). This generated 12 themes that clustered into 4 subordinate themes. These included: 'Expectations of life after adoption'; 'The Reality'; 'Getting help' and 'Finding positives'.

One of the main themes to emerge centred around the expectations participants had for how their lives would change following the adoption. For all interviewees, life after the adoption was much harder than they had anticipated. This discrepancy may be due to a combination of 'wishful thinking' by the adopters; an overly positive description of the child's disabilities by social workers or, in some cases, the withholding of important information about the child, their condition or background. Another important theme were factors that could help to make the reality of the participants' lives more tolerable including access to suitable respite; more help from social services; and being part of support networks of other adoptive parents or parents of children with similar disabilities. It is hoped that the findings of this study can help social services and adoption agencies to better support similar families leading up to an adoption and in the years that follow.

Keywords: Adoption, disabled, experience, parent, interviews

Introduction

Disabled children are nine times more likely to become looked after than non-disabled children. In fact, it is estimated that approximately 25% of all looked after children are disabled (Gordon, Parker, Loughran, & Heslop, 2000; Grant, 2013). These children are regarded as 'hard to place' for adoption and those with a learning disability are the most difficult to place in permanent homes (Baker, 2007; Bunt, 2016).

As a child with a disability does not represent the idealised notion of a perfect childhood, they are more likely to be considered unadoptable (Cousins, 2006). Until the mid 1970s the file of an infant with even a slight disability was stamped as 'unfit for adoption' (Argent, 1996). In fact it was only following the emergence of effective contraception, legalised abortion and increased acceptance of children born out of wedlock that adoption agencies started putting disabled children forward for adoption (Macaskill, 1985). Today discriminatory views towards disabled people are so culturally embedded that they are almost unavoidable (Munyi, 2012). A report by SCOPE showed that large sections of the population hold negative attitudes towards disabled people (Scope, 2014). In fact, it found that two thirds of the British public feel uncomfortable talking to a person with a disability.

Collecting evidence on disabled children and adoption is difficult due to the variety of ways in which this group is defined. Surprisingly, the annual looked after statistics do not include data on whether a child is disabled (Grant, 2013). The lack of basic demographic information on disability in childhood has been described as 'scandalous' (Bunt, 2014; Gordon et al., 2000). One of the reasons for this lack of data is the

uncertainty over the definition of disability. There are a number of separate definitions used by different communities and organisations (Altman, 2011). For this empirical study, the definition of disability from the most recent UN Convention on the Rights of Persons with Disabilities was used (United Nations, 2006). This describes disabled people as ‘those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’.

The introduction of the Children and Families Bill 2013 was intended to reform adoption services and provision for children with special educational needs (Children and Families Bill, 2013). Government debates linked to this bill have highlighted the inadequacy of currently available statistics and other data needed to understand more about adoption and disabled children (Bunt, 2014). In the July 2015 budget statement, the UK Chancellor pledged an extra £30 million pounds of funding to enable children to have a wider range of potential adopters (UK Government, 2015a). In response to this announcement, the British Association for Adoption and Fostering (BAAF) released a statement which emphasised the continued challenges surrounding the adoption of difficult to place children such as those with disabilities (British Association for Adoption and Fostering, 2015).

The process of finding families can be a struggle as adoption agencies have to balance giving a favourable impression of a disabled child while also ensuring that they are providing an accurate representation of the child’s particular needs (Cousins, 2006). In

particular, adoption services find it difficult to find adopters who are interested in adopting a child with a health or learning disability (Bunt, 2016)

The challenge faced by adoption agencies is reflected in research that found that prospective adoptive families are much less likely to want disabled children (Ivaldi, 2000). It showed that, whereas 69% and 83% of people who were interested in adopting stated that they would take a child who had been sexually abused and physically abused respectively, only 13% and 21% would consider children with mental or physical disabilities.

Against this background, it is clear that when someone chooses to adopt a disabled child, they are making a decision that is in opposition to the prevailing discourse that such children are of less value as they do not fit with the idolised notion of a perfect child (Lord, 2013). Unfortunately, this is an area where very little research has been carried out. In fact, Bunt (2014) describes a 'dearth of literature' on the adoption of disabled children within the UK.

Considering the difficulties adoption agencies have in finding adoptive homes for disabled children and the surprising lack of research in this area, it would be helpful to explore the stories of parents who have adopted a child knowing that they have a disability. This research asked the question: 'What is the experience of people who have adopted a disabled child?' The study explored parents' reflections on their lives before, during and after the adoption. In this way, it provides valuable insight into the

factors that supported or undermined the adoption process. This information could help social services and adoption agencies to better support similar families leading up to an adoption and in the years following it.

Method

Recruitment

Parents who had adopted a child knowing that they had a disability (physical, health, intellectual or sensory) were recruited to take part in the study. This wide inclusion criteria reflected the fact that there is currently very little literature in the field of disability and adoption, and therefore a more exploratory approach is required.

Moreover, the research is primarily interested in the stories of parents who have had the experience of adopting a child who has been classified as 'hard to place', rather than focussing on any particular disability. Following ethical permission from the Faculty of Health and Social Care Research Ethics Committee, University of Hull (Appendices H and I), participants were identified through on-line social media groups. Interested potential participants were sent a Participant Information Sheet giving them more details about the study and inviting them to take part (Appendix J).

Participants

Five parents (all mothers) consented to take part in the study. At the time of the interviews, the participants' ages ranged from 42 to 61 and at the time of the adoption their ages ranged from 33 to 48. Four participants were married and one was single.

Demographic information regarding the adopted child and their siblings is summarised in Table 1.

Table 1. Demographic information relating to adopted children and their siblings¹

| Adopted Child | | Siblings | |
|-------------------------|--|---------------------------|-----------------------------|
| Age when adopted | Disability | Adopted or biological | Disability |
| 3 months | Global developmental delay Learning disabilities | 1 Adopted | 1 Learning disability |
| From birth ² | Chronic lung disease Global developmental delay Curvature of spine | 4 Biological 1 Adopted | None |
| 1 year | Autism Drug dependency at birth Vision problems | 1 Adopted | None |
| 3.5 years | Attention deficit hyperactivity disorder (severe neglect) | None | n/a |
| 3.5 years ³ | Cerebral palsy Epilepsy | 3 Biological | 1 TAR syndrome ⁴ |

¹Participants' pseudonyms have not been included in this table in order to maintain anonymity

²Fostered from birth, officially adopted aged 2

³lived with family from age 3.5 years old with the intention to adopt. Adoption finalised when aged 9

⁴TAR = thrombocytopenia with absent radius

Procedure

The research is based on audio-recorded interviews (Pistrang & Barker, 2010).

Interviews took place in participants' homes. Prior to the interview all participants completed a demographic questionnaire (Appendix K) and signed a consent form (Appendix L). Interviews were recorded on a digital Dictaphone and lasted between 60 and 90 minutes. The aim of the interview was to allow participants to tell their own stories, in their own words (Brocki & Weardon, 2006). To this end, the interviewer asked a core interview question at the start of each interview:

“I'd like to ask you about your experience of adopting a child with a disability.

Please think of the entire experience as a story from when you first considered adopting to the present day with as much detail as you can remember.”

An interview schedule was prepared (Appendix M) and was used when appropriate to guide the researcher in asking further exploratory questions on themes that had been raised (Smith, Flowers, & Larkin, 2009). An initial draft of the interview schedule was tested on a colleague and changes made to ensure that the questions were broad and general so that, as far as possible, the researcher did not impose their views on the participant. At the end of the interview process, each participant was given a list of useful contacts in case they needed support (Appendix N).

Analysis

Following the interviews, the recordings were fully transcribed. Examination of the data was conducted according to the principles of Interpretative Phenomenological Analysis (IPA) (Smith, 2004). The primary focus of IPA is people's lived experience and

the meaning which people place on that lived experience (Brocki & Weardon, 2006; Smith et al., 2009). An IPA approach involves the inductive process of a detailed case by case analysis of individual transcripts to identify emergent themes, followed by the organisation of these themes across participants (Finlay, 2014). To ensure that the themes were well represented, a colleague also reviewed the transcripts (Smith et al., 2009; Smith & Osborn, 2007). In addition, the analysis includes an interpretation of the themes during which the researcher makes sense of the participant making sense of their experience (Smith et al., 2009) . The process of interpretation involves going beyond the participant's own words and critically examining the account in order to gain further insights and understanding (Finlay, 2014). Moreover, as the researcher is central to IPA process, it is important that they are aware of how their own values and interests can influence the interpretative process. For example, the researcher in this study is the mother of three biological children (all teenagers). It is important, therefore that the researcher is aware of how her own life experiences may influence the interpretation of the data. A section of marked transcript can be found in Appendix O.

Results

The IPA analysis generated 12 themes which cluster into 4 sub-ordinate themes. These include: 'Expectations of life after adoption'; 'The Reality'; 'Getting help' and 'Finding positives.' The results are presented in Table 2. In the presentation of the results, pseudonyms have been used and other identifying information removed to maintain participants' anonymity.

Table 2. Themes

| Super-ordinate Themes | Themes |
|--|--|
| 1. Expectations of life after adoption | 1.1 Wearing rose-tinted specs 1.2 Feeling cheated 1.3 Acceptance |
| 2. The Reality | 2.1 Parental struggle 2.2 Exclusion and bullying 2.3 Attachment issues |
| 3. Getting help | 3.1 Need for respite 3.2 Fighting for support 3.3 The right school |
| 4. Finding positives | 4.1 Pride in child 4.2 Impact on siblings 4.3 Support network |

Superordinate theme 1: Expectations of life after adoption

This superordinate theme comprises participants' anticipation of how their life will be following the adoption. The picture they had created in their mind of their future life with their adopted child was key to their decision to adopt. Interestingly, in the interviews participants explained that they had focussed on the positives and may have only taken notice of the information from agencies or social services that supported this optimistic position. Consequently, the reality of post-adoption life was an overwhelming experience for which they didn't feel prepared.

Theme 1.1 Wearing rose-tinted specs

Participants commented on their overly optimistic outlook in the time leading up to their decision to adopt and their expectations for how the adoption would affect them and their family. For example, Rachel described that:

'you have this picture in your head, I suppose you look through rose coloured glasses really.....I didn't expect it to be as difficult as it was.'

Some participants could reflect on how they might have discounted information that did not support their optimistic outlook:

'I don't think it's been any different to what they said it was going to be, it's just that you're never listeningyou just think, oh, it doesn't matter, it will be fine.' (Emma)

This selective attention could be explained by the overwhelming desire some participants had to become parents:

'Your want and desire to have a family is so great that it's really hard to honestly say, yes, I know it's going to be difficult, and I know we're going to have challenges, because you actually don't.....The facts were there in the file, but we chose to sort of focus on other facts in the file..... you hear what you want to hearall of us have been a little unrealistic.'

Following these unrealistic expectations, it is not surprising that the reality often came as a shock:

'they are different.....and I think it's always been hard for us to accept that.....our expectations sometimes are too high.' (Alice)

People also continue to wear rose-tinted glasses and do not think about what the future might hold for them and their disabled child. For example, parents tend not to consider the challenges that will come with adulthood:

'You don't really sort of think about what are they going to do when they leave school at 16 with no qualifications. You know, what are they going to do if they wet the bed every night aged 40. You sort of, you don't think about these things.' (Alice)

Theme 1.2 'Feeling Cheated'

Several participants reported that following the adoption they went on training courses and met other people who had disabled children and found out information that would have affected their decision to adopt:

'there was a time when we did feel a bit sorted of cheated.....we felt that should be the course [*a post-adoption education course*] that people

should go on when they first sign up to adopt. Probably half of them would drop out..... for years we thought, God, if we'd known then what we know now.' (Alice)

Others felt that they had been misled by the way information was presented to them by social services:

'They're so desperate to get these children adopted, that they often just make out the best-case scenario.' (Sally)

Emma echoed this opinion and described, how, even if social workers are honest about a child's disability:

'they couch it in very positive ways'

As participants had a sense of responsibility and commitment to the child who had joined their family, they felt that even though they had been misled by social services, there was no longer the option to change their minds. They believed that it was too late to re-evaluate their decision to adopt considering the new information now available to them:

'we should have just said it's not going to work, it's just awful.....we probably wouldn't recommend adoption at all.' (Emma)

Some participants felt anger that they had been deliberately misled and that information had been intentionally kept from them. Some described the impact of not being fully informed before making the decision to adopt a child:

'When we asked to see his files, the files had mysteriously got lost.....we weren't told the full extent of what was wrong with our son by a long way.....the difference between what we were told and what the reality

turned out to be has been quite hard.....I am now going to lose my career to look after him.’ (Sally)

Others described how they had to fight to gain access to key documents:

‘It took years to get the notes from the hospital..... because they wouldn’t let us have them. But now I understand why.’ (Emma)

Theme 1.3 ‘Acceptance’

With time, adopters started to accept the ongoing reality of their situation – even if it was not what they had expected or wished for:

‘... we might have felt a bit more bitter and angry and disappointed about things, but I think that was all part of us going through this process of accepting that actually, it is what it is.’ (Alice)

For some, there was a sense of resignation that the only option was to do what had to be done:

‘coming to terms with your lot, and once you have, which took quite a while, then you just start getting on with it.’ (Viv)

This was confirmed by Rachel who commented that:

‘I stuck at it. Well, you’ve got to. I’m not like somebody that could just throw the towel in.’

Despite the difficulties and challenges following the adoption, there was a sense that participants had to make the most of the situation they were in:

‘we’ve kind of made it work.’ (Sally)

However, some people often found it difficult to accept their situation as they deeply wished that things were different. The ongoing, daily challenges were described by

Emma:

‘the quiet superheroes that are adoptive parents.....we’re doing extraordinary things every single day.’

Superordinate theme 2: The Reality

All interviews included a discussion of how hard parents had found life since the adoption. People talked about the impact of stress and exhaustion on their day to day lives.

Theme 2.1 ‘Parental struggle’

All participants spoke with emotion about how they had struggled as a parent:

‘it’s been tough, it’s been extremely challenging..... I feel like a prisoner in my own home, I don’t know what to do.’ (Alice)

For some these challenges are often extreme and can occur daily:

‘to be perfectly honest, he has sent us to hell and back and does so every day.’
(Emma)

‘he’s been hard work, I’m not going to say he’s been easy, he’s been hard work.’ (Viv)

‘he just took every ounce of energy to cope.’ (Rachel)

Participants discussed that the adoption had not only affected them but had also had a negative impact on their relationships:

‘how we stayed together sometimes, I think God, it’s a miracle, because it was extremely stressful on us.’ (Alice)

‘It has an impact on your relationship with your spouse.’ (Sally)

Some parents experienced times of absolute despair. For example Emma described:

‘I’ve fallen down to this world that sometimes I don’t even know that I can cope in it, to be honest.....I got fairly suicidal about it.’

This extreme level of hopelessness was also experienced by Rachel who reported:

‘I remember so many times sitting here and I’m like.....just cry my eyes out and thinking I cannot do this, I just cannot do this.’

Several participants discussed how they had considered asking for their child to be taken back in to care as they felt that they could no longer cope:

‘I probably picked up the phone three or four times in the last five years intending on ringing the social worker to say I just can’t do it anymore, you’ll have to have him back.’ (Emma)

Others felt that the constant stress had an impact on their physical as well as mental health:

‘it took quite a toll, my husband ended up having [*serious medical condition*], so and I think a lot of that came from the stress of it all.....it’s just the accumulative effect of the stress, really over the years.’ (Sally)

Theme 2.2 'Exclusion and bullying'

The interviews revealed that the adopted children often struggled to be accepted.

Participants talked about the exclusion of their child by peers; by school teachers and by the public. All the parents felt distressed and upset that their child had been treated in this way.

For example, Alice described how she came to realise how much her son struggled to fit in with his peers at school:

'he slowly stood out more and more like a sore thumb because he was so very different from the other children his age.'

A consequence of children being perceived as different was exclusion from activities.

Emma was angry as she explained the extent to which other parents and children did not include her child:

'never got invited to one single party from first year right through to year five, so that's tough.....and we've invited people here to play and never got an invitation back.....and when you go to school nobody wants to know you or nobody wants to know your child either.'

Viv described how they also experienced rejection from people in the street due to her son's disability:

'when we used to take him outand people used to like shy away from him, walk away from him.'

Some parents were angry that their child was excluded because of the attitude of teachers. For example, Rachel described how teachers often left out her child from group activities in school:

‘they just left him with a teacher in another room, they totally isolated him.’

Some of the children found it so hard to be accepted by their peers that they excluded themselves from playground activities:

‘and he especially struggled in the playgroundand so he decided that it’s probably better if he stays in.’ (Emma)

For some children their school experience was spoilt by bullying, Alice reported that her child:

‘was in the wrong place, he was being bulliedthe school didn’t know where to put him.’

Theme 2.3 ‘Attachment issues’

All participants discussed attachment issues as an important aspect of their experience of adoption. They had all learnt much more about the consequence of poor attachment since adopting. Participants reported that this was an ongoing problem and Viv remarked that even after many years her son still had difficulty forming attachments. Parents were also able to reflect on why their children had difficulty forming attachments:

‘[child’s name]’s got attachment disorder, because she’s mourning the loss of her mum, she’s mourning the loss of her foster mum.....attachment issues have been a major thing and people don’t really understand it.’ (Alice)

This was echoed by Rachel who commented that her child:

‘has got real attachment issues and obviously because he’s moved from his mum to foster carer and then to another foster carer and then to

me.he's not had that nurturing or that contact with his mum that he should have had.'

These attachment difficulties continued to affect the quality of the relationships between parents and their adopted child:

'It took a long time for him to trust, it took years for him to trust.' (Sally)

In fact, attachment problems have such an impact on children and families that it led Emma to suggest:

'the best thing for them would have been to be with their own families, not to be with an adoptive family.'

Superordinate theme 3: Getting help

Considering the challenges that participants all faced in caring for their adopted disabled children, it is not surprising that they spent time talking about the things that could potentially make their lives easier.

Theme 3.1: 'Need for respite'

A key issue for all participants was accessing respite care for their child:

'we all want to have respite; I'd love to have some respite because I just need a rest I have never had a break.' (Emma)

There was also discussion of the fact that the issues that made looking after their child exhausting and stressful also made it harder to find people to help so that they could have a break:

‘We didn’t feel we could leave [*child’s name*] with the grandparents for a whole day. You know, fine to do a couple of hours, but not a day.’ (Alice)

Similarly, Emma described how unlike most parents who might have friends or family who could look after their children on occasions, she was not able to have a break as looking after her child was just too hard for others:

‘we don’t want to leave these children with members of the family because we don’t want them to have to suffer the stuff that we put up with.’

Rachel also highlighted the importance of having some respite:

‘My mum and dad looked after [*child’s name*] for a couple of hours or whatever – because obviously, I was there all the time, you know 24/7 because I wasn’t at work for a year.’

Sally recognized the difficulty of accessing respite care despite her child’s needs:

‘respite provision and everything has all been cut for everybody.....my son needs one to one care and can’t be left alone at all.....we got just the local package of respite, which wasn’t a great deal.’

Theme 3.2 ‘Fighting for support’

Parents often had to challenge services to try and get the help their child needed:

‘we did just shout and bang the doors down and ask for help.’ (Alice)

‘wrangling really, to get some support.’ (Sally)

Some participants had problems with practical support issues that were hard to resolve and could feel exhausting:

‘I have regular arguments with transport because once a year they change the bus company.’ (Viv)

There was a consensus that support from social services was hard to access once the adoption was finalised:

‘at certain points in the process you feel quite at a low, and you don’t feel so well supported.’ (Alice)

‘but in terms of making sure we were okay as a family, it was very much, “well you’ve signed on the dotted line.”’ (Sally)

Even when help was successfully accessed it could then be removed having a devastating impact on families:

‘It’s just awful, so you get the money and then it’s just cut off and you think, oh my God, what are we going to do?’ (Emma)

Overall participants did not think they were well supported by social services following the adoption which often made them feel isolated:

‘in the end, you’re on your own’ (Alice)

‘we pretty much battled through it on our own.’ (Sally)

Theme 3.3 ‘The right school’

Finding a school that met the needs of their child and where they would be happy was of great concern to parents. Several participants had a negative experience with their child’s first school:

'so many examples of why [*child's name*] was in the wrong place, [*child's name*] was being bullied, homework was inappropriate.so we sort of got to the right place for [*child's name*] in the end.' (Alice)

Parents often felt unsupported by the school:

'He was previously at another school who couldn't deal with his behaviour.....they said "we don't think he can be here anymore because of his behaviour" so that first school really let him down.' (Emma)

The negative experience of school was so bad that one participant removed her child from school completely:

'school wasn't able to manage him.....so I took him out of school and he went back to pre-school'. (Rachel)

Parents spent a lot of time researching and trying to find the right school for their child. Parents who moved their children to a new school, talked with passion about the difference this had made:

'so she moved to a special school - once the parent accepts, actually, it's the right place to be for their kids, it's just an inspirational school'. (Alice)

Participants were enthusiastic about the importance of their child being at the right school:

'The school that I am at now is just stunning, just amazing. In fact, I want them to win an award. So, any child could go to that school who's adopted, who has problems, they will know what to do.' (Emma)

After much searching, Rachel eventually found a suitable school for her child and commented:

‘It was a very warm school, the teacher was really nice and they didn’t seem overwhelmed by it. And I thought, he has to go to that school.....and now he’s at the school he loves it, he’s doing really well’.

Superordinate theme 4: Finding positives

Despite the many challenges and stresses associated with caring for their child, all participants talked about the positive aspects of the adoption.

Theme 4.1 ‘Pride in child’

Every participant spoke with pride about their child. Often their tone of voice and facial expression changed as they tried to convey how special their child was and how proud they were of them. This pride often focused on their child’s personality:

‘the kindest, loveliest boy ever imaginable.....He’s quite a sweetheart’. (Alice)

‘he’s such a really nice polite little boy he’s so sociable, he’s so loving and sociable’. (Rachel)

‘is lovely, he fits in with the children’. (Sally)

Other parents focussed on their child’s ambitions and achievements:

‘he’s funny. He is, and he’s got a great sense of humour, and he beats most people on general knowledge.....he wants to be a scientist, because he wants to cure cancer and cure dementia’. (Emma)

‘just been voted on the school council, bless himhe’s a diamond,
absolute diamond’. (Viv)

Theme 4.2 ‘Impact on siblings’

Although for those families with more than one child, there was often concern regarding the possible negative impact of having an adopted disabled sibling, parents were still able to identify some positives (Burke, 2010):

“because she’s [*the sibling*] very empathic when it comes to people, so I suppose it’s [*having a disabled brother*] helped her in a way’. (Emma)

Some participants thought that having a disabled brother or sister could sometimes have a positive impact on their siblings:

‘it actually had a real balancing effect on the familythey’ve [*siblings*] turned out lovely human beings because of the extra empathy and understanding they have’. (Sally)

Theme 4.3 ‘Support network’

Nearly all participants could identify individuals or groups who had made a big difference to how they coped and how supported they felt. They were all very appreciative of any help that they received. For example, Alice identified several people who had encouraged her:

‘we fell on good luck, because the lady that ran the nursery was just fantasticour social worker stayed involved with us, and we were really lucky we had the same one’.

Spending time with other parents living in similar circumstances could be a big help:

‘the biggest support I get is from other adoptive parents and other parents of children with [*child’s condition*]. Those two groups of people who I probably get most from because they’re all dealing with the same issues and I don’t need to tell them anything because they understand instinctively’. (Emma)

Similarly, despite feeling let down during some parts of the process, Rachel could recognize that there were lots of people who had supported her:

‘it’s not just me, it’s a lot of other people, my family and friends have been fantastic, social workers, the OT, everybody, teachers, it’s been a team effort’.

Some participants could also identify key people who had made a big difference to the life of their child:

‘He still sees the same paediatrician from the day that he was born – he is a brilliant man’. (Viv)

Unfortunately, Sally felt that she had missed out on opportunities for support:

‘I think I would have valued being able to chat with someone who’d had a fairly similar journey.....there were times when I felt quite alone’.

Discussion

Choosing to adopt a child with a disability is a life-changing decision. The interviews in this study represent highly personal accounts that give insight into the experience of people who make such decisions. The participants told their stories in their own words, without the need for the researcher to ask many questions from the interview schedule. The issues that were discussed are therefore important to these parents and to their lived experience of adoption. Analysis of the data using an IPA approach has identified key shared themes that reveal the challenges and rewards associated with adopting a disabled child. This data is particularly interesting as there has been very little research in the field of adoption of disabled children in the UK (Bunt, 2014). If these findings are acted upon, they may help improve the experience of future adopters.

Summary of main findings

One of the main themes to emerge centred around the expectations participants had for how their lives would change following the adoption. For all interviewees, life after the adoption was much harder than they had anticipated. Studies have shown that adoptive parents may be especially vulnerable to stress as they usually become parents suddenly and the children may have a history of problems (Goldberg & Smith, 2014). In addition, it is known that biological parents of children with disabilities have increased demands on their time compared with other parents, which may lead to greater levels of anxiety (Green, 2007; Woodman, 2014). Studies have shown that biological parents of disabled children face a number of challenges including unpredictable childcare requirements, financial hardships and the threat of negative

social judgement (Algood, Harris, & Hong, 2013; McConnell, Savage, Sobsey, & Uditsky, 2015). In addition, many of these parents describe their experience as a continuous fight to receive support. However, literature has also reported that although it is culturally embedded to presume that having a disabled child is a totally negative experience, biological parents often report a number of benefits including increasing the strength of emotional bonds within the family, personal growth and closer social relationships (Godley & Tregaskis, 2006) (Green, 2007).

From the interviews in this study, it appears the discrepancy between the expectations and the reality of adoption may be due to a combination of 'wishful thinking' by the adopters; an overly positive description of the child's disabilities by social workers or, in some cases, the withholding of important information about the child, their condition or background.

This is generally in contrast to the experience of biological parents of disabled children where their child's disability is not a consequence of a decision they made or a result of incomplete information that was given to them. This may make it easier for these parents to accept the ongoing challenges that they face. It appears that, in contrast to adoptive parents, biological parents of disabled children are not burdened by the same feelings of regret or anger that they have been misled (Green, 2007; McConnell et al., 2015).

The decision to adopt a certain child is inevitably based on predictions of what a life parenting that child could be like. These predictions are influenced by the hope that is invested in the adoption and may follow the distress of infertility; the intensity of a home study assessment; the disappointment of not being selected as a match for other children and the fear that this might be the best or only chance of parenting a child (Eriksson, 2016). Understandably, against this background, prospective adopters may view the profile of a child through a lens of optimism and wishful thinking – always focussing on the positives and discounting the negatives (Krizan & Windschitl, 2009; Oettingen & Mayer, 2002). This type of cognitive bias, called confirmation bias, can be seen in the way participants selected evidence that supported what they already believed i.e. that their love and determination would overcome any challenge (Nickerson, 1998). This approach to making life changing decisions is not unusual as studies have shown that in social decision making, the crucial point of choice is often influenced by emotion (Bechara, 2004).

Social workers therefore have the difficult task of presenting the profile of a child in a realistic way without downplaying the child's impairments, while still giving these already disadvantaged children the best chance of finding a family (Bunt, 2016). When families adopt children without knowing or fully understanding all the details of the child's profile, it can result in extreme distress and resentment in the parents. For the families in this research the reality of life following adoption often involved a level of struggle that had not been anticipated. Although these placements may be considered a success by social services as the children are all still living with their adoptive families, the day to day reality for the parents is very different.

While some of the parents may regret the adoption, they cannot bring themselves to return the child to social services due to the overwhelming feelings of guilt associated with placement disruption and their concern for the welfare of the child (Coakley & Berrick, 2008). Research into adoption disruption has found that breakdown is more likely when services have not helped parents to adjust their expectations to a child's abilities and they do not have sufficient accurate information to understand the challenges posed by a child (Farmer & Dance, 2016).

A balance must therefore be struck between the needs and aspirations of adoptive parents, the child, and social services. For example, it is important to ensure that potential adopters are not just focussing on the best-case scenario but are also accepting that a worst-case scenario is also a real possibility. To this end, it may be useful for parents to be given the opportunity before they commit to the adoption to speak to parents who have children with similar disabilities (particularly those with older children – so they can see what potentially lies ahead) (Algood et al., 2013; McGlone, Santos, Kazama, Fong, & Mueller, 2002).

It would also be helpful for adopters to know that they can turn down a child they are matched with if they think they may not be suitable, without this risking their future chances of being shown other children's profiles. This would prevent adopters going ahead with an adoption when they may have reservations right from the start. It would also encourage other potential adopters to consider the possibility of parenting a disabled child without fearing they will be immediately committed.

Another important theme that emerged from the data in this study were factors that could help to make the reality of the participants' lives more tolerable. These comprised: access to suitable respite so that they could have a break; receiving more help from social services including access to child therapies; and being part of support networks of other adoptive parents or parents of children with similar disabilities.

Breakdown in an adoption is more likely when support has not been provided post adoption (Farmer & Dance, 2016; Schweiger & O'Brien, 2005). Despite the power of local authorities to offer financial support for complex adoptions such as those involving disabled children, this is discretionary and packages are often minimal and insecure (Bunt, 2016). Adoption UK, a leading charity providing support to adoptive parents, has campaigned and lobbied parliament during the Education and Adoption Bill debate to get more post-adoption support for parents (Adoption UK, 2013; UK Government, 2015b) . Currently parents must fight to get the help they need. Indeed, it has been suggested that having the confidence and tenacity to challenge services should be a quality looked for in potential adopters (Bunt, 2016). Parents of disabled children have previously described their relationship with professional staff as a 'battleground' (Whiting, 2012).

Strengths and Limitations

Given the lack of published research reporting the experience of parents who have adopted a disabled child, a key strength of the current paper is that it enables these

parents to have their stories heard. The lack of existing research may be due to the difficulty recruiting from this group because of the deeply personal and often troubling experiences they are being asked to share.

It is also interesting to reflect on why only mothers were recruited to this study. Participants were identified through on-line social media groups which may have introduced a bias as women are more likely to use social media (Kimbrough, Guadagno, Muscanell, & Dill, 2013). In addition, studies that have looked at the reasons why participants agree to take part in research, identified altruism and the desire to help others as a main incentive (Thornton, Batterham, Fassnacht, Callear, & Hunt, 2016). Participants also need to believe that the research is worthwhile and that there will be some benefit to themselves. Perhaps women are more likely to want to help future adopters and to see the value of someone listening to and acknowledging their story (Newington & Metcalfe, 2014) (Espinosa & Kovarik, 2015).

As with most qualitative research, this study was based on a small number of participants which limits the transferability of the findings. Furthermore, it is possible that the participants may not be entirely representative of adoptive parents of disabled children. For example, there may have been selection bias in that those who chose to take part are likely to have strong opinions or views that they wished to share (Cuddeback, Wilson, Orme, & Combs-Orme, 2004). To attain 'subtle realism' in the interpretation of the data, emerging themes were discussed with peers and a supervisor (Mays & Pope, 2000). Ideally validation from participants would also have been sought but logistical considerations meant that this was not possible. It is worth

noting that this study has given the parents of adopted disabled children the rare and valuable opportunity to articulate their expert perspective on their own experiences. This will hopefully act as a base from which further research in this neglected area can be considered.

Future research

There has been very little research done in the field of adoption and disabled children. This study is therefore very much a preliminary study and could act as a platform to explore the experiences of parents with different parenting experiences. For example, interviews could be carried out with groups of parents who have children who are:

- disabled but not adopted
- adopted but not disabled
- neither adopted nor disabled

It would also be interesting to conduct a longitudinal study, interviewing one group of parents who have adopted a disabled child after 1 year, 3 years, 5 years, and 10 years to explore how their experience and perspectives change over time.

Finally, as the interviews in this study often discussed the role of social workers and social services, it would be interesting to conduct a study that interviewed social workers to find out about their experiences of finding families for children with a disability.

Opportunities

There are several ways in which parents could be helped with the psychological challenges of adopting a child with a disability. As it is known that these parents are under considerable stress (Goldberg & Smith, 2014), it would be useful for regular checks to be made by social services of how they are coping and to identify those who may be particularly struggling so that they can be offered access to individual psychological support. This may not only help relieve their distress but may also prevent placement breakdown. All adoptive parents could benefit from being given the opportunity of joining a support group with other parents in similar situations – importantly, childcare should be provided to enable parents to attend such groups. It would also help these parents if sufficient provision was made for psychological support for their adopted children who often have traumatic backgrounds and significant attachment issues. In addition, the interviews reveal that adopted disabled children are frequently subjected to bullying and exclusion by peers which may have a negative impact on their psychological wellbeing. These children could therefore benefit from psychological therapies (Russel, 2003).

In recent years the government has placed growing importance on adoption with the introduction of the 2014 Children and Families Act which aimed to increase the number of adoptions and also to help children with disabilities (UK Government, 2014). For the government to achieve these aims and if more children with complex needs are to be adopted, the important issues raised by this research including unrealistic expectations of adopters and lack of post-adoptive support need to be addressed urgently (Baker, 2007; UK Government, 2014).

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Appendix A – Guidelines for submission

Journal of Child and Family Studies – instructions to authors

General

In general, the journal follows the recommendations of the 2010 Publication Manual of the American Psychological Association (Sixth Edition), and it is suggested that contributors refer to this publication. The research described in the manuscripts should be consistent with generally accepted standards of ethical practice. The anonymity of subjects and participants must be protected and identifying information omitted from the manuscript.

Manuscript Submission

The Journal uses Editorial Manager™ as its submission and peer review tracking system. All authors are required to register as a new user with Editorial Manager the first time they login in to the system. Straightforward login, registration procedures and step-by-step instructions for submitting manuscripts can be found on the website. Authors can use the Editorial Manager to track the review of their manuscripts in real time.

All authors should submit their manuscripts online. Manuscript submissions to the Journal should be prepared electronically and submitted in a standard word processing format. Microsoft Word® is preferred. Electronic submission substantially reduces the editorial processing and reviewing times, and shortens overall publication times. Please connect directly to the site: <http://jcfs.edmgr.com> and upload all of your manuscript files following the instructions given on the screen.

Suggested Reviewers

Authors of research and review papers, excluding editorial and book review submissions, are allowed to provide the names and contact information for, maximum, 4 to 6 possible reviewers of their paper.

When uploading a paper to the Editorial Manager site, authors must provide complete contact information for each recommended reviewer, along with a specific reason for your suggestion in the comments box for each person. The journal will consider reviewers recommended by the authors only if the reviewers' institutional email is provided. A minimum of two suggested reviewers should be from a university or research institute in the United States. You may not suggest the Editor or Associate Editors of the journal as potential reviewers. Although there is no guarantee that the editorial office will use

your suggested reviewers, your help is appreciated and may speed up the selection of appropriate reviewers.

Authors should note that it is inappropriate to list as preferred reviewers researchers from the same institution as any of the authors, collaborators and co-authors from the past five years as well as anyone whose relationship with one of the authors may present a conflict of interest. The journal will not tolerate this practice and reserves the right to reject submissions on this basis.

- <http://jcfs.edmgr.com>

Publication Policies

The Journal considers manuscripts for publication with the understanding that they represent original material and have not been published, submitted or accepted elsewhere, either in whole or in any substantial part. Each manuscript should report sufficient new data that makes a significant contribution to its field of research; thus, the submission of small amounts of data from a larger study or research project for divided publications would be inappropriate. A statement transferring copyright from the authors (or their employers, if they hold the copyright) to Springer Science+Business Media, Inc. will be required before the manuscript can be accepted for publication. Such a written transfer of copyright, which previously was assumed to be implicit in the act of submitting a manuscript, is necessary under the U.S. Copyright Law in order for the publisher to carry through the dissemination of research results and reviews as widely and effectively as possible.

Authors can expect a decision usually within 8 to 10 weeks. Reviewers comments are sent with the decision. Accepted papers are subject to editorial revisions and copyediting. However, the contents of the paper remain the responsibility of the author.

Double-Blind Peer Review

All submissions are subject to double-blind peer review. In general, experimental/research studies are judged in terms of the following criteria: originality, contribution to the existing research literature, methodological soundness, and readability.

When you are ready to submit a manuscript to JCFS, please be sure to upload these 2 separate files to the Editorial Manager site to ensure timely processing and review of your paper:

- A title page with no running head, manuscript title, and complete author information. Followed by the Abstract page with keywords and the corresponding author e-mail information.

- The blinded manuscript containing no author information (no name, no affiliation, and so forth).

Manuscript Style

All manuscripts should be formatted to print out double-spaced at standard 8" x 11" paper dimensions, using a 10 pt. font size and a default typeface (recommended fonts are Times, Times New Roman, Calibri and Arial). Set all margins at one inch, and do not justify the right margin. Double-space the entire manuscript, including title page, abstract, list of references, tables, and figure captions. After the title page, number pages consecutively throughout including the reference pages, tables, and figure legends. The average article length is approximately 30 manuscript pages. For manuscripts exceeding the standard 30 pages, authors should contact the Editor in Chief, Nirbhay N. Singh directly at nirbsingh52@aol.com.

The Journal encourages the publication of research that is virtually jargon-free and easy to read. Thus, a personalized manuscript, written in active tense, is preferred. For example, "This study examined . . ." could be stated as, "We examined . . ." The Journal encourages a conversational rather than an impersonal tone in the manuscripts. Hypotheses should be written as a part of the last paragraph of the Introduction and not in bullet form. All reference to the study being reported should be consolidated in the last (or, if necessary, the last and penultimate) paragraph of the Introduction and not scattered throughout the introductory section.

Title Page

A title page is to be provided and should include: (1) the title (maximum of 15 words); (2) full names of the authors (without degree), with a bullet between the names of the authors; (3) brief running head; and, at the bottom of the title page, (4) the corresponding author's initials and last name (without degree), affiliation, mailing address, and e-mail address. The initials and last name of all authors should be listed as well. All authors from the same institution should be listed together, with a bullet separating the names. For all, but the corresponding author, list the affiliation, city and state only.

Abstract

The abstract should be between 200 and 250 words. It should be concise and complete in itself without reference to the body of the paper. In addition to a general statement about the field of research as the first sentence, abstracts of experimental/research papers should contain a brief summary of the paper's purpose, method (design of the study, main outcome measures, and age range of subjects), results

(major findings), and clinical significance. Abstracts of review papers should include a general statement about research area being reviewed as the first sentence, it should contain a brief summary of the review's purpose, method (data sources, study selection process), results (methods of data synthesis and key findings), and conclusions (summary statement of what is known, including potential applications and research needs). Do not use sub-headings and do not cite data or references in the abstract.

Key Words

A list of 5 key words is to be provided directly below the abstract. Key words should express the precise content of the manuscript, as they are used for indexing purposes.

Text

Text should begin on the second numbered page. Authors are advised to spell out all abbreviations (other than units of measure) the first time they are used. Do not use footnotes to the text. When using direct quotations from another publication, cite the page number for the quotation in the text, immediately after the quotation. When reporting statistically significant results, include the statistical test used, the value of the test statistic, degrees of freedom, and p values. In the discussion include an evaluation of implications (clinical, policy, training or otherwise) of the study when appropriate. Also, discuss limitations in study design or execution that may limit interpretation of the data and generalizability of the findings. Do not use any sub-headings in the Introduction or Discussion sections.

Footnotes

No footnotes are to be used.

References Cited Within the Text

Cite references in alphabetical order within the text.

References

The accuracy of the references is the responsibility of the authors.

List references alphabetically at the end of the paper and refer to them in the text by name and year in parentheses. References should include (in this order):

- last names and initials of all authors,

year published (in brackets)

title of article

name of publication

volume number

and inclusive pages

Do not include issue numbers of journals unless each issue begins with page 1. For book chapters, include volume number (if applicable) and page numbers, as shown below.

Consult the Publication Manual of the American Psychological Association, 6th Edition (Chapter 7) for formatting references. The style and punctuation of the references should conform to strict APA style – illustrated by the following examples:

• Journal Article:

Roelofs, J., Meesters, C., & Muris, P. (2008). Correlates of self-reported attachment (in)security in children: The role of parental romantic attachment status and rearing behaviors. *Journal of Child and Family Studies*, 17, 555-566.

Book:

McBee, L. (2008). *Mindfulness-based elder care: A CAM model for frail elders and their caregivers*. New York: Springer.

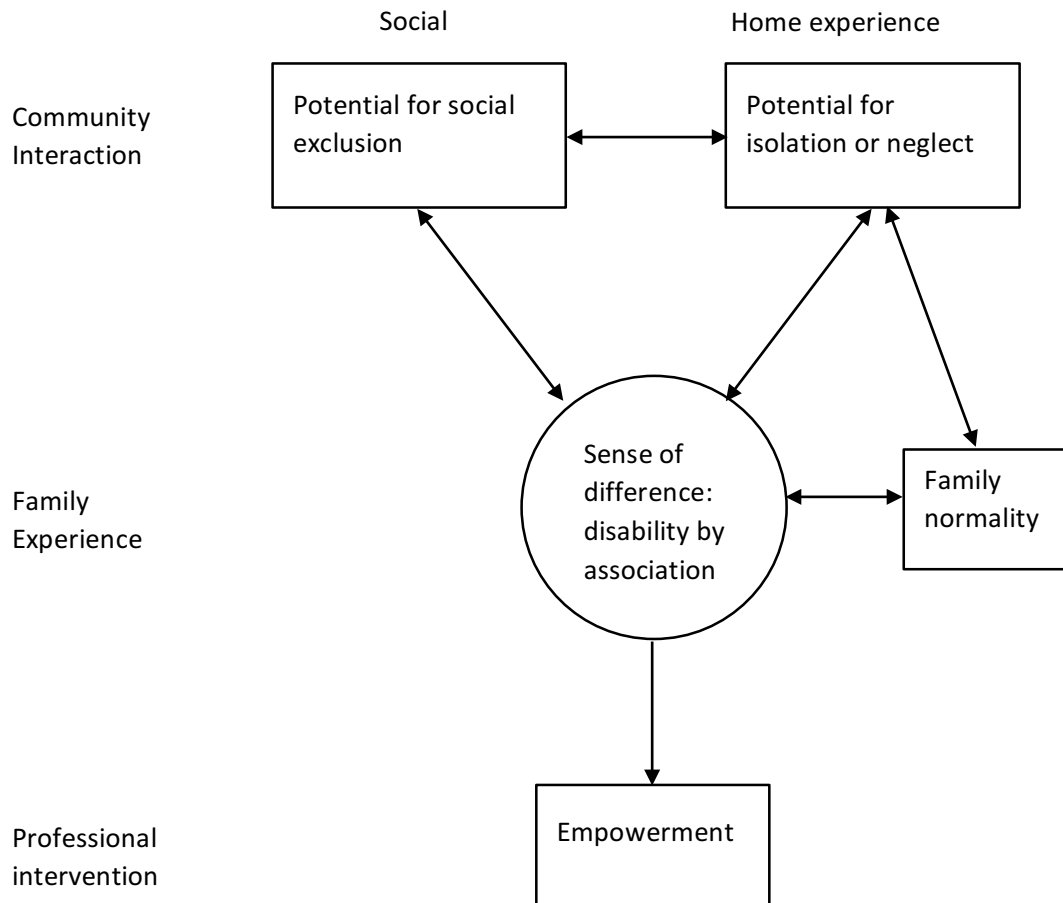
Book Chapter:

Singh, N.N., Winton, A.S.W., Singh, J., McAleavey, K., Wahler, R.G., & Sabaawi, M. (2006). Mindfulness-based caregiving and support. In J.K. Luiselli (Ed.), *Antecedent assessment and intervention: Supporting children and adults with developmental disabilities in community settings* (pp. 269-290). Baltimore, MD: Paul H. Brookes.

Tables

Tables follow the Reference section. Create tables using the table creation and editing feature of your word processing software (e.g., Word) instead of spreadsheet programs. Tables that are a single column are actually lists and should be included in the text as such. Number tables consecutively using Arabic numerals in order of appearance in the text. Cite each table in the text and note approximately where it should be placed. Type each table on a separate page with the title and legend included. Double-space the table and any footnotes to it. Set each separate entry in a single table cell. Do not use underlining. Properly align numbers, both horizontally and vertically. Use brief headings for columns. If abbreviations are necessary, define them in a key at the bottom of the table. Keep footnotes to a minimum; if necessary, use superscript letters to denote them.

Appendix B – Burke’s Model of Disability by Association (Burke, 2010)



DATA EXTRACTION FORM

Study Author(s):

Study Title:

Year:

Journal:

Type of study: Qualitative/quantitative/mixed methods

Number of participants:

Age range:

Quality score:

1. *Potential for Social Exclusion (social experience)*

2. *Potential for Isolation and Neglect (home experience)*

3. *Sense of difference (as family)*

4. *Family normality*

5. *Empowerment (including professional Intervention)*

6. Additional themes (additional to components of Burke's model)

Appendix D - Quality assessment tool

Mixed Methods Appraisal Tool (Pluye et al, 2011)

Responses: Yes (score 1), No (score 0), Can't tell, comments

Methodological quality criteria

Screening questions (for all types)

- Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?
- Do the collected data allow address the research question (objective)? E.g., consider whether the follow-up period is long enough for the outcome to occur (for longitudinal studies or study components).

Further appraisal may be not feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.

1. Qualitative

1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?

1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)?

1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?

1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?

2. Quantitative randomized controlled (trials)

2.1. Is there a clear description of the randomization (or an appropriate sequence generation)?

2.2. Is there a clear description of the allocation concealment (or blinding when applicable)?

2.3. Are there complete outcome data (80% or above)?

2.4. Is there low withdrawal/drop-out (below 20%)?

3. Quantitative nonrandomized

3.1. Are participants (organizations) recruited in a way that minimizes selection bias?

3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?

3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?

3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?

4. Quantitative descriptive

4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?

4.2. Is the sample representative of the population under study?

4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)?

4.4. Is there an acceptable response rate (60% or above)?

5. Mixed methods

5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?

5.2. Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (objective)?

5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results*) in a triangulation design?

Criteria for the qualitative component (1.1 to 1.4), and appropriate criteria for the quantitative component (2.1 to 2.4, or 3.1 to 3.4, or 4.1 to 4.4), must be also applied.

Appendix E – Quality Assessments

| Study | Qualitative | | | | Quantitative | | | | Quantitative Non Randomised | | | | Quantitative Descriptive | | | | Mixed Methods | | | Score |
|----------------------|-------------|-----|-----|-----|--------------|-----|-----|-----|-----------------------------|-----|-----|-----|--------------------------|-----|-----|-----|---------------|-----|-----|-------|
| | 1.1 | 1.2 | 1.3 | 1.4 | 2.1 | 2.2 | 2.3 | 2.4 | 3.1 | 3.2 | 3.3 | 3.4 | 4.1 | 4.2 | 4.3 | 4.4 | 5.1 | 5.2 | 5.3 | |
| Petalas et al, 2012 | 1 | 1 | 1 | 1 | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | 100 |
| Read et al, 2011 | 1 | 1 | 0 | 0 | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | 50 |
| Malcolm, 2013 | 1 | 1 | 1 | 0 | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | 75 |
| Petalas et al, 2009 | 1 | 1 | 1 | 1 | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | 100 |
| Hames et al, 2009 | 1 | 1 | 0 | 0 | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | 50 |
| Lovell et al, 2016 | - | - | - | - | - | - | - | - | - | - | - | - | 1 | 1 | 1 | 1 | - | - | - | 100 |
| Coleby, 1995 | - | - | - | - | - | - | - | - | - | - | - | - | 1 | 1 | 1 | 1 | - | - | - | 100 |
| Velleman et al, 2016 | 1 | 1 | 1 | 0 | - | - | - | - | - | - | - | - | 1 | 1 | 1 | 1 | 1 | 1 | 0 | 75 |

Appendix F – Criteria for identifying ‘Strong’ themes

For a theme to be considered ‘strong’ or ‘major’ the following criteria must be met:

- The theme appears in more than 4 of the reviewed studies
- The theme is applicable to the majority of participants in a reviewed study
- The theme was highlighted in the discussion section of a reviewed paper

Appendix G – Guidelines for submission

Style guide for Adoption and Fostering Quarterly Journal

Version UK3/August 2011

SAGE UK Style Guide SAGE UK Style Guide 2

CONTENTS

1.

2. *Article opening material* 3

2.1 *Headings* 3

2.2 *Article types* 3

2.3 *Article title* 3

2.4 *Author names, affiliations, and corresponding address* 4

2.5 *Abstract and keywords* 5

2.6 *Running heads* 5

3. *General style and layout* 6

3.1 *Logo and imprint box* 6

3.2 *Figures* 6

3.3 *Tables* 6

3.4 *Lists* 7

3.5 *Maths/equations* 7

3.6 *Appendices* 7

3.7 *Note and footnotes* 8

3.8 *Book reviews* 9

4. *Spelling, punctuation and formatting* 9

4.1 *Author style/voice* 9

4.2 *General spelling rules* 9

4.3 *Punctuation and formatting* 9

4.4 Abbreviations 11

5. Technical content: maths, equations, etc. 13

5.1 Maths notation convention 13

5.2 Equations 13

5.3 Units 14

5.4 Symbols and operators 14

6. Appendices 15

6.1 General STM acceptable 2-letter abbreviations 15

6.2 Engineering acceptable 2-letter abbreviations 16

SAGE UK Style Guide 3 2. Article opening material

2.1 Headings

1. Headings should have an initial capital with everything else lowercase, unless proper names.
2. Italics can be included in A heads (H1) if needed, e.g. mathematical symbol or genus name.
3. Headings are unnumbered and formatted as below.
4. Where headings are referred to in the text use section names, as headings are not numbered.

A head (H1) (bold with initial cap, all the rest lowercase)

B head (H2) (*italic with initial cap, all the rest lowercase*)

C head (H3) (*same as B head, but set as first line of paragraph, full out; italic with initial cap, all the rest lowercase, followed by a full stop. Following text runs on*)

Headings for Abstract, Keywords, Funding, Acknowledgements, Conflict of interest (in that order), References, Appendices are same as A head but smaller font size

(CEs: where a template is being used there is no need to format these. Where no template is being used, please format as bold/italic, but there is no need to mark the font sizes, TS will format.)

2.2 Article types

Where a journal displays article types, these should appear on the first page of each article, left aligned above the horizontal rule, and in italics.

General technical or research papers should be classified as *Original Article* (with uppercase initial caps) for STM, and *Article* for HSS. (Check with the PE, as there is some variation between journals.)

Other usual paper types are as follows: *Review Article*, *Case Study*, *Technical Note*, *Case Report*. Individual journals may also have other paper types, as agreed with the Editor. Where no particular convention has been agreed, *Original Article* should be followed for STM, and *Article* for HSS.

2.3 Article title

Please format with an initial capital only and remaining words lower case, unless proper names. Italics can be included where necessary (e.g. genus name). Run on subtitle after colon, with initial capital after colon. SAGE UK Style Guide 4

2.4 Author names, affiliations, and corresponding address

Authors

List authors in the order that they appear on the manuscript. Authors' first name should be in full, middle names should be initials *without* full stops (e.g. Simon PS Sharma) and no spaces between multiple initials. No series comma before the 'and' before the final author name.

Affiliations

Affiliations should contain only the following: department *or* faculty, institution, country. Some HSS journals may have institution and country only. Do not include titles, positions, qualifications, street names, or postcodes/zip codes. Affiliations should *not* end in a full stop.

STM: author names should be annotated with superscripted numbers (CE: do not use automated endnotes against names and affiliations). If all authors are at the same affiliation no superscript numerals are required. Affiliations appear separately with the corresponding address at the bottom of the right column (see next page):

Mark A Creager¹, Reena L Pande¹ and William R Hiatt^{2,3}

HSS: affiliations should directly follow each author name, as follows:

Mark A Creager

(Department of Engineering,) Southampton University, UK

Reena L Pande

(Department of Engineering,) Southampton University, UK

William R Hiatt

County Hospital, CA, USA; Harvard Medical School, USA

Multiple affiliations are separated by a semi-colon.

Corresponding author

The affiliations and corresponding author information is positioned as follows:

Bottom of the right column on the first page of each paper, separated from the text with a horizontal rule (some exceptions apply for specific journals).

Corresponding author: John Smith, Department of Social Studies, South Bank University, 4 Sample Road, London SE17 9OP, UK

Email: john.smith@sbu.ac.uk

STM: Affiliations and corresponding author details should appear as follows, bottom of right column.

HSS: corresponding author appears in the same position, minus the affiliations.

Please remove any fax or telephone numbers, titles (e.g. Dr, Professor), positions (e.g. Senior Lecturer).

SAGE UK Style Guide 5 Please note: 'Email' with cap E and without hyphen. Email should start a new line. There *should* be a full stop after the country in the corresponding address.

Affiliations and corresponding address text should be left aligned, not justified, to avoid irregular spacing between words.

2.5 Abstract and keywords

Abstract should appear in bold without a colon, text should start on the next line, with no indent.

Keywords (all one word) should appear in bold without a colon. The keywords should start on the next line, separated by commas only, not semi-colons. The first keyword should have an initial cap.

In some journals, Abstracts have sub-headings, e.g. Methods, Conclusion etc. These should be formatted in bold with a colon in bold and each sub-heading should start a new paragraph. The text should run on after each heading with an initial capital.

Submitted/accepted dates

For journals that publish received/revised/accepted dates (applies to specific journals, if unsure please check with the PE), this should appear after the Keywords and be formatted thus:

Date received 29 July 2010; reviewed 30 August 2010; accepted 5 November 2010

2.6 Running heads

Recto: should be author surname(s), e.g. *Smith*, or *Smith and Jones*, or *Smith et al.* (for three or more authors, and et al. is also in italic).

Verso: full journal title in italic, followed by 0(0).

For IMechE journals: e.g. *J. Automobile Engineering 0(0)*, without the Proc. IMechE or journal letter).

3. General style and layout

3.1 Logo and imprint box

All papers in the standard SAGE design will have a journal logo in the top right with an imprint box underneath (although the logo may be missing on journals that are new to the SAGE design). The imprint box will contain the following information: journal name, vol/issue/page numbers (for papers in production, vol/issue are represented by 0(0), page numbers are the number of pages in the PDF, e.g. 1–9), copyright line, link to permissions web page, DOI, journal URL, SAGE logo:

3.2 Figures

1. STM: All figures should have a key line (i.e. be enclosed in a box). HSS: figures have no key line.
2. Figures should be appropriately sized (done by the TS). They do not need to be a full column width or page width.
3. Figure permissions: any figures reproduced from another publication need permission. In cases where those publishers listed on the STM permission Guidelines page (<http://www.stm-assoc.org/permissions-guidelines/>), permission is not required and only the reference number need be present in the caption. Some publishers ask for certain text, e.g. Elsevier.

4. Source:

in cases where permission is required and has been obtained, this should appear below the caption in the following form: Source: reproduced with permission from publisher, year, reference number (Vancouver), author, date (Harvard).

5. Any abbreviations needing to be spelled out should be listed after the caption, starting on the next line, in the following format: IC: internal combustion; PID: proportional–integral–derivative).
6. Captions are positioned below the figures and left aligned.
7. Captions should start, for example, **Figure 1.** (with a full point also in bold) and have a full point at the end. Where the text runs onto multiple lines, the captions need not be justified but should be aligned left.
8. Where figures have multiple parts, these should be labelled as (a), (b), (c), etc. (not A, B, C). Captions should contain subheadings for all parts if not present in the figure itself.
9. All figures should be numbered consecutively and cited in the text as Figure 1, Figure 2 etc. (Figure should be spelled out in full, not abbreviated).
10. Text citations: figures should be referenced in the text as follows: Figure 1, or Figures 1 and 2,

or Figures 2 to 4, or Figure 1(a) and (b), or Figure 2(a) to (c). Where the figure citation is not part of the sentence it should be placed in parentheses Examples:

Please see Figure 2 for an illustration of the model used

The model used was an X3G standard type, exported from Germany (Figure 2 or see Figure 2).

3.3 Tables

1. Tables do not need to be a full column width or page width, but should be the appropriate width for the content. They will be laid out by the TS so no work is required by CEs on table layout, only on content.

2. Table headings should be left aligned, even when they relate to multiple columns, unless this creates confusion.

SAGE UK Style Guide 7

3. Tables should only have minimal horizontal rules for clarity, and no vertical rules (done by TS, no need for CE to format).

4. All tables should be numbered consecutively and cited in the text as Table 1, Table 2 etc. (Table should be spelled out in full, not abbreviated).

5. Table permissions: any tables reproduced from another publication need permission. In cases where those publishers listed on the STM permission Guidelines page (<http://www.stm-assoc.org/permissions-guidelines/>), permission is not required and only the reference number need be present in the caption. Some publishers ask for certain text, e.g. Elsevier.

6. Source: in cases where permission is required and has been obtained, this should appear below the table in the following form: Source: reproduced with permission from publisher, year, reference number (Vancouver), author, date (Harvard).

7. Any abbreviations needing to be spelled out should be listed under the table (smaller font, TS will format), in the following format: IC: internal combustion; PID: proportional–integral–derivative.

8. General notes to the Table should be positioned below the Table, typeset in a smaller font and should start 'Note:', and end in a full stop. Do *not* add the word 'Note:' unless needed for clarity.

9. Footnotes should be represented in the table by superscript letters a, b, c, etc., and appear below the Table (smaller font, TS will format). Each footnote should start a new line and end with a full stop. These notes should precede the source for the table, if included.

10. Captions are positioned above the table and left aligned.

11. Captions should start, for example, Table 1. (with a full point also in bold) and have a full point at the end. Where the text runs onto multiple lines, the captions need not be justified but aligned left.

12. Dates in Tables can be shortened to, for example, 4 Dec 10, if space is lacking. Do not use the form 04/12/10, as this could be confused as 12 April in US.

13. Normal text in columns should always be left aligned. Data in tables should be aligned on units if all the data in that column take the same units. Otherwise, the data should be left aligned. Units in table headings should be enclosed by parentheses, not square brackets (if any brackets are required at all).

3.4 Lists

1. For lists where items are not full sentences, use (a), (b), (c) etc. or bullet points (whichever is more appropriate) and separate items with semi-colons. Start list with a preceding colon and end list with a full stop.
2. For lists where items are full sentences or multiple sentences, use 1. 2. 3. Start list with a preceding full stop or semi-colon (whichever is more appropriate), and end list with a full stop.
3. List numbering/bullets should be full out and left aligned, with text indented and aligned. Lists should be separated from preceding/following text with a line space.
4. Where list items include headings, that heading should be italic, same size as text and end in a full stop. The following text should run on.

3.5 Maths/equations (see section 5, p. 14 for more details)

1. Equations should be left aligned with a 3 mm indent, *not* centred.
2. Equations can be broken at operator symbols (x , $-$, $+$, etc.), and continue on the next line, starting with the operator itself.
3. Equations should be separated from text above and below by at least one line space.
4. Any equation numbers should be enclosed in parentheses and right aligned, and aligned horizontally with the bottom line of the equation or equations, where multiple terms are covered by one equation number. (Not all equations need be numbered, see section 5).

General note: text following Figures, Tables, equations does not need to be full out with no indent. If the next block of text after any of these items is a new paragraph, then this may be indented.

3.6 Appendices

Maths notation list

1. Where present, notation should appear as Appendix 1, following the references. The heading *Notation* should be a B-head (not Notations; it is not plural).
2. Abbreviations list should be separated from mathematical notation under a separate B-head *Abbreviations*. SAGE UK Style Guide 8
3. Notation should be listed in alphabetical order, English letters first, followed by Greek, followed by numbers, followed by symbols.

4. Subscripts and superscript should come under a separate C-head (italic and smaller font), and symbols should follow the same order as in point 2 above.
5. The Notation section does not need to be cited in the text, like other Appendices.
6. Notation list should be left aligned. Text in the notation section should be left aligned in general, not justified.
7. Please note that a notation list is not compulsory in mathematical papers, as long as all symbols are defined in the text.

Other appendices

1. Numbering of figures/tables/equations in Appendices should follow on from the numbering in the text.
2. All tables/figures should have captions.
3. All appendices should be cited in the text, e.g. (see Appendix 1). If they are not cited, authors need to be queried for a citation position.

3.7 Notes and footnotes

Textual notes

HSS

References: Vancouver style reference citations are represented as textual notes, as a numeral enclosed in a square bracket. Harvard style references are as follows (Smith, 1999).

Any other textual notes: are indicated by a superscript Arabic numeral placed *after* the punctuation. All textual notes should be collected and placed after the text and before the reference section with the heading Notes.

STM

References: Vancouver style reference citations are represented as textual notes, as a superscript Arabic numeral. Harvard style references are as follows (Smith, 1999).

Any other textual notes (whether references are Harvard or Vancouver) are indicated by a superscript Arabic letter and the corresponding footnote appears at the bottom of the relevant column.

In STM journals, footnotes should be edited into the text if appropriately and easily incorporated. However, please leave footnotes if this is not possible.

Authors' biographical notes

These should appear at the end of the paper with the heading Author biography (or biographies), in same font size as References/Funding etc. heading. Follow journal style.

3.8 Book reviews

Please check that the book details are given in this format at the top of each review.

Author, *title*, publisher: place, date of publication; 000 pp.: ISBN, price (hbk), ISBN, price (pbk)

4. Spelling, punctuation and formatting

4.1 Author style/voice

We will endeavour to keep the author's voice as much as possible:

1. Some authors write in the first person. CEs please note that we will *not* be taking articles out of the first person into the third person.
2. Where American authors have used American spellings, we should also endeavour to keep the author's grammar/punctuation, e.g. closed em-dashes instead of spaced en-dashes, single quotation marks within double, series comma etc.
3. Where UK authors have used –ise spellings throughout their papers in a consistent fashion, please do not change. Where there is inconsistency, use -ize.

4.2 General spelling rules

The general rules are as follows:

- UK spellings should be followed for European articles (-ise is acceptable)
- US spellings should be followed for North American articles
- Rest of the world – follow author style but make it consistent
- Canadian spellings should be standardized to UK or US, depending on author preference
- The following list shows some common exceptions to the '-ize' rule:

Samples

| | | | | | | | |
|-------------|------------|----------------|-------------|-----------|-------------|-----------|----------|
| advertise | arise | devise | enfranchise | expertise | merchandise | promise | surmise |
| advise | chastise | disenfranchise | enterprise | franchise | misadvise | reprise | surprise |
| affranchise | circumcise | disguise | exercise | improvise | premise | revise | televise |
| apprise | comprise | emprise | excise | incise | prise | supervise | treatise |

Appendix H – Ethical Approval Letter 1

REMOVED FOR HARDBINDING

Appendix I – Ethical Approval Letter 2

REMOVED FOR HARDBINDING

The Experience of Adopting a Disabled Child

Participant Information Sheet

My name is Colette Kon and I am a trainee Clinical Psychologist on the Doctorate in Clinical Psychology course at the University of Hull. I am required to carry out research as part of my course. I have chosen to look at the experience of parents who have adopted a disabled child. If you have adopted a child with a disability, I would like to invite you to take part in the study.

Before you decide to take part, it is important for you to understand why the research is being carried out and what it will involve. This sheet gives you information about the research. Please read it carefully before deciding if you would like to take part. If there is anything you are unsure about or if you have any questions, please contact me using the details provided below. Please feel free to talk to other people about the research if you wish.

Part 1 – information about the study and what it involves

Part 2 – more detailed information about the research

Part 1

What is the study about?

This study aims to find out about the experiences of parents who have adopted a child with a disability. It will explore the stories of adoptive parents in order that we can have a better idea of the factors that improve the experience of adopting and living with a disabled child and the factors that make the experience more challenging. If we understand the experience better, we can help services develop ways to improve the experience for future adopters and also disabled children waiting to be adopted.

Why am I being invited to take part?

You have been identified as a parent who has adopted a child with a disability. Your consent is therefore being sought for a researcher to talk to you about your experience of the whole process.

What will happen if I take part?

If you decide to take part in the study, please contact the researcher using the details provided below. The researcher will then contact you to arrange a meeting. The meeting can take place at a time and location that is convenient to you including your home.

At the meeting, the researcher will explain in more detail what the research involves. You will then be asked to sign a consent form confirming that you agree to take part in the study. The researcher will then ask you a few questions about the adoption before the interview. You will also be given further opportunity to ask questions. The interview is expected to last approximately one hour and will be recorded on to a Dictaphone. The interview will involve you talking about your experience in as much detail as possible.

Will it cost anything?

No, there is no cost involved in taking part in this study.

If after reading the information in Part 1 you are still interested in taking part, please continue to read Part 2 for further details.

Part 2

Will my information be kept confidential?

Yes, your participation in the study and all information about you will be kept confidential. Information will be stored in a locked cabinet at the University of Hull. Only the researcher and her research supervisor will have access to the information. Once the study has been completed, the information will be kept for 10 years before being destroyed.

Confidentiality may be broken, in line with current legislation, only if information is shared that raises concerns for the safety of you, your child or anyone else. If such information emerges, the researcher will discuss with you what needs to happen next.

What will happen with the results of the study?

The results will be collected and analysed by the researcher. She will then write up the results and submit them for publication in an appropriate professional journal. The information will be transcribed after the interview during which all identifiable information will be removed. Direct quotes from the interview may be used in the write-up of the research and subsequent

publication but you will never be personally identified. If you would like to find out about the results of the study once it has been completed, please let the researcher know (details provided below) and she will feed back to you.

What if I change my mind?

You are free to change your mind and withdraw from the study at any point up to the time of transcription and analysis of the interview; you do not have to give a reason why. This will not affect the support or services that you or your child receives.

What if there is a problem?

If at any point during the study you have any questions or concerns you can contact the researcher or her supervisor (details provided below).

Has anyone reviewed the study?

The study has been reviewed and approved by the Research Ethics Committee of the Faculty of Health and Social Care at the University of Hull.

Thank you for taking the time to read the information sheet. If you would like to take part in the study or have any further questions, please contact me using the details below:

Researcher

Colette Kon

Trainee Clinical Psychologist

Faculty of Health Science

University of Hull

Hull, HU6 7RX

Tel: *temporary mobile number*

Email: c.kon@2014.hull.ac.uk

Supervisor

Annette Schlosser

Research Supervisor

Faculty of Health Science

University of Hull

Hull, HU6 7RX

Tel: 01482 464094

Email: a.schlosser@hull.ac.uk



Demographic Questionnaire

Parent

1. What is your name?.....
2. What is your age?.....
3. Are you a single parent or do you care for your children with your partner?
.....

Child

If you have adopted more than one child with a disability, please answer the questions with regard to your most recently adopted child.

1. How old was your child when you adopted them?.....
2. When did you adopt your child?.....
3. What is the nature of your child's disability?.....

Family

1. Do you have any other children?
 - How many?.....
 - How old are they?.....
 - Are they adopted?.....
 - Are they disabled?.....



Parent Consent Form

Participant ID:

Title of study: The Experience of Adopting a Disabled Child

Researcher: Colette Kon

Please read the statements below carefully and if you agree to them please complete your details in the spaces below

Please initial the boxes

1. I confirm I have read the information sheet about the above research project and would like to participate in the study.

2. I understand what the project is for and what it involves

3. I understand that participation in the project is voluntary and that I can Withdraw at anytime for no reason without it affecting my, or my child's support or legal rights

4. I understand that my participation, information about us and contact details will be kept confidentially.

5. I understand that if I share information that raises concern for the safety of myself, children or anyone else confidentiality will be broken.

6. I have had the opportunity to ask any questions I had and confirm I have had satisfactory replies to these.

7. I have considered all of the information provided and would like to participate in the above study.

Name of Parent:

Signature of Parent:

Date:

Tel:

Name of researcher:

Signature of researcher:

Date:

If you any queries, please phone the researcher, Colette Kon

Tel: 07595321977

Email: c.kon@2014.hull.ac.uk

Appendix M – Interview Schedule

Dependent on participant's individual stories the following explorative questions could be asked:

- How has the experience of having a disabled child as part of your family been different to what you expected? Tell me about any unexpected experiences?
- What was the impact of your social worker's approach on your experience of adopting a child with a disability?
- How did your own life experiences influence your decision of whether or not to adopt a child with a disability? For example, did you have previous involvement with family or friends whose lives had been affected by disability?
- Tell me about how you were matched with your child?
- What was your experience of the support and encouragement offered by social services and family/friends regarding your decision to adopt a disabled child?
- How did other peoples' attitudes change following the adoption? How have your family and friends supported you before and after the adoption?
- Has your own understanding of disability changed following the adoption? How?

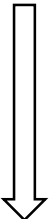


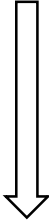
Sources of Support

If you have been affected by any of the issues raised by the interview today and would like further support or advice, please contact any of the following potential sources of help:

- Your GP
- Parentline: 0808 800 2222
- Adoption UK: 0844 848 7900
- SCOPE (for families with disabled children and young people): 0808 800 3333

Appendix O – Marked Transcript

| Emergent Themes | Rachel | Exploratory comments |
|---|--|--|
| <p>Challenge</p> <p>Doing her best</p> <p>Exhausting</p> <p>Attachment issues</p>  <p>Despair</p> <p>Support</p> <p>Relentless</p> | <p>So he had to be on sort of like safety reins for quite a while really because I was frightened ... <u>he's very unpredictable and spatial</u> ... and he wasn't aware of what was going on really. But that was quite</p> <p>because he didn't want to be on ... <u>but it's for his own safety really</u>. And this sort of behaviour sort of <u>continued and continued from October and it just wasn't easing off really</u>.</p> <p>And I thought he was getting ... he started pre-school, like a nursery class, they were sort of seeing some ... but I <u>put it down to attachment</u> and I kept putting it down to attachment 'cause it was only early days and said <u>it's only early days</u>, so all this erratic sort of hate ... phobia where he's up, you know, up high and you can't control what he's doing and whatever, I just put it down for the attachment ... <u>he didn't want to be with me</u> and he wanted to run away basically.</p> <p>Even though I was trying really hard it was really ... it was difficult and there were times when I thought, <u>I don't know if I can do this anymore</u>, to be honest to myself and I didn't ... and the support of my family and my friends was fantastic. <u>My mum, she ... my mum and dad looked after [child's name]</u> for a couple of hours or whatever 'cause obviously I was there all the time, you know, <u>24/7</u> because I wasn't at work for the year, I wanted to spend the time with him and we did</p> | <p><i>Hardwork</i></p> <p><i>Desperate –what to do?</i></p> <p><i>Relentless</i></p> <p><i>Not knowing what is normal</i></p> <p><i>what to expect</i></p> <p><i>Rejection and hate and hurt</i></p> <p><i>Overwhelmed – too much</i></p> <p><i>Brilliant parents – phew!</i></p> <p><i>Exhausting</i></p> |

| | | |
|--|---|---|
| <p>Attachment issues</p>  | <p>go out, we'd go for day ... we went on a caravan holiday but that sort of like ... the children are ... you know moved from place to place they don't actually know if it's going to be their next place to go and that's hard in itself, <u>they're frightened</u> because they think, well that's ... that's where they're going to be living again, so this is where another person is going to be coming in at any time and they're just waiting for it. <u>So that makes them really anxious, really anxious.</u></p> | <p><i>Unexpected problems</i></p> <p><i>Nice things turn horrible</i></p> |
| <p>Challenge</p> | <p>So it was hard so then in the ...<i>[child's name]</i> was coming up to school, to go to school in September and things were not settling down, <u>he was hitting, throwing things all the time and having massive tantrums.</u> And so I was thinking, I don't know how he's going to manage school really, so then I brought the post adoption support came in then because being</p> | <p><i>Really hard work + violent</i></p> |
| <p>Exhausting</p> | <p>October to June or something like that and then I thought, oh, <u>you know, things are just not getting any better.</u></p> | <p><i>On and on and on</i></p> |
| <p>Expectations</p> | <p>But my expectations were quite ... you know, <u>I didn't expect a lot but I didn't expect it to be that hard.</u></p> <p>Because I have got friends that have adopted children and it seemed a lot easier, you know what I mean, because they were, you know, they were going to</p> | <p><i>Shock disappointment – thought she was realistic</i></p> |
| <p>Expectations Limitations</p> | <p>places like <i>[name]</i> <u>Gala and things like that but I took <i>[child's name]</i> to the Gala and I just couldn't ... he just ran off.</u></p> | <p><i>Couldn't do simple things - no pleasure</i></p> |

Appendix P – Epistemological Statement

Before I started on this adventure, I liked to consider myself a scientist. I worked with facts and figures. I thought you could get to the truth by weighing up the evidence. In my previous career, the research I looked at had always been quantitative. This all changed when I was introduced to the world of qualitative research. I realised that what most interested me were the personal stories behind the numbers and statistics. The more I found out about the qualitative approach, the more I knew this was the methodology I wanted to use for my empirical study. I am interested in people and want to find out about their experiences. Fortunately this approach also fitted with the fact that there has been very little research in the field of adoption of disabled children and so a more exploratory approach was needed.

After personal reflection, I believe that I hold a relativist ontological position. I consider that each person sees the world slightly differently and therefore multiple different accounts of reality exist in line with each individual perspective. Bearing this in mind, the qualitative approach I chose to take was Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009). Key to an IPA methodology is an emphasis on phenomenology – the study of first-person experiences of a life-event (Smith & Osborn, 2003). IPA assumes that subjective experiences can be explored through reflection and that the process can be helped by the discussion of events and accompanying phenomena in semi-structured interviews (Larkin, Watts, & Clifton, 2006). The events will be made sense of by subjective interpretations made by those experiencing them (Smith et al., 2009). These interpretations will be influenced by the

idiographic experiences and cultural context of the interpreter. The researcher then assigns interpretative meaning to the participant's description of the event. In this way, a double hermeneutic is operating.

An important aspect of the IPA approach that appealed to me as a researcher is that the investigator's role and relationship with the data is clearly acknowledged. In addition, I welcome the fact that the interpretations are exploratory and subjective and that this is always openly acknowledged when using IPA.

Appendix Q – Reflective Statement

What made me choose to explore the adoption of disabled children as part of my thesis? I knew I wanted my research to have a positive psychology approach – I intended for it to focus on good things and to motivate people – all very Polyanna-like! I had read a book* that had inspired me – it told the story of parents who had adopted a child with cerebral palsy when their biological children were almost adults. Despite the challenges, the book had a very uplifting message and recounted the unexpected positives an adopted disabled child could bring to a family. I had a romantic idea that perhaps more people would consider adopting a disabled child if only they knew about these unforeseen benefits. A preliminary search revealed that there had been very little research in this area. So even better I thought, I would be meeting a need. However, the findings of my empirical study were not what I expected.

In preparing to write this reflective statement, I took another look at the book. Some of the often heart-breaking challenges the family faced suddenly stood out more clearly and I saw their story differently. Now it seemed more of a scary rollercoaster ride with swooping negatives as well as the unexpected positives. Had I too been guilty of wearing rose-tinted specs? Had I so wanted to see a rosy picture that I had focussed on the positives and glossed over the very real challenges the family had faced? Had I shown a similar confirmation bias to the participants in my research?

Through the process of carrying out this study, I have learnt that when you ask a research question, you don't already know the answer. This is, of course, stating the obvious, but I wonder if we often think we know the shape our research will take, we have a quiet inkling of the kind of messages that will come out. I certainly did, and I was wrong. This has highlighted the importance of always trying to keep an open mind, of being careful not to guide participants or let them know what we are anticipating but instead allowing their own voices to be heard as clearly as possible.

As I look back over the whole process, I realise that I had not anticipated how I would feel about my participants. It was SO difficult to find people to interview. I know everyone says this, but I found it really really hard. I followed so many leads and had many 'almost participants' (usually this was because partners were not happy about the personal nature of the research). At one point, I seriously thought that I might not get any parents willing to talk to me. There was clearly a reason why this research hadn't been done before – there weren't any participants! But finally, all my chasing paid off. If we had to do a quality assessment on participants, mine would get full marks. I was blown away by their honesty and how thoughtfully they spoke. I warmed to them and felt truly privileged that they had shared their very moving reflections with me. Their huge contribution to my thesis has motivated me to keep going when my workload has felt overwhelming. They have trusted me with very personal accounts of their lives and, consequently, I have felt a sense of duty towards both them and their stories.

*The Family Business by Robert Marsden