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A Thesis Submitted to
The University of Birmingham
For the Degree of
Doctor of Clinical Psychology

Volume I
Sibling Relationships

By Marc Desautels

School of Psychology
University of Birmingham
September 2008

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Overview

This thesis is submitted in partial fulfilment of the requirement of the degree for Doctor of Clinical Psychology at the School of Psychology, University of Birmingham. The thesis consists of two volumes.

Volume I

This volume comprises of two parts. The first part is a review of the literature that has contributed to the understanding of the role that siblings play in the development of emotion regulation. The second part is an empirical study that investigates the experience of growing up with a sibling who has a learning disability. The literature review put forward the argument that siblings play a significant role in the development of emotion regulation. This paper has been prepared for submission to the journal Family Processes. The empirical study utilises qualitative methodology to examine the experience of eight people who have a sibling who has a learning disability and how this has impacted on their life, when they were children and now. This paper has been prepared for submission to the British Journal of Developmental Psychology. The Public Domain Briefing Paper is also submitted in this volume.

Volume II

Five Clinical Practice Reports (CPR) are presented in this volume. The first report details the case of a man with a learning disability, presenting with challenging behaviours, formulated from a psychodynamic and cognitive perspective. The second report is a service evaluation of an anxiety management group for people with learning disability. The third report details the treatment of a nine-year old girl with a bird phobia. The fourth report is a case study on a seventy-two-year old man presenting with cognitive difficulties, discussed from a systemic approach. The fifth report was assessed orally and so the abstract is presented in this volume.

All names and identifying features have been changed to ensure confidentiality.

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What role do sibling relationships play in the development of emotional regulation?

Abstract

This paper examines the role siblings play in the development of emotion regulation. The first part of this review examines ten studies that have investigated the role of sibling relationships in the development of emotion regulation. The Dynamic Ecological Systems model of emotion regulation within the context of sibling relationships suggested by Bedford and Volling (2004) is then considered and followed by a review of this model in relation to the findings of the studies reviewed in the first part. A discussion of clinical and research implications based on the findings obtained in the review follows. Although most of the studies provide support for the model, some also highlight its shortcomings; the model appears to be applicable to all types of relationships and not simply sibling relationships.

Introduction

According to Morris, Silk, Steinberg, Myers, and Robinson (2007), there has been an increase of interest in the study of emotional regulation in psychology over the last twenty years. Emotional regulation is seen in current research as essential learning that children must acquire to ensure successful and healthy psychosocial development. Being able to regulate our emotions in an effective manner enables us to interact with other people and develop friendships or relationships with them.

Indeed the capacity to regulate one's emotion is deemed to be an effective prevention tool against mental health difficulties (Frick & Morris, 2004). Difficulties in regulating emotions, such as anger or sadness, have been linked to the aetiology of depression and problem drinking (Silk, Steinberg, & Morris, 2003), personality disorders (Gerhardt, 2004) and conduct disorders (Schwartz, Hage, Bush, & Key, 2006).

However, as Thompson (1994) observed, most people have "shared, implicit notions of what emotion regulation is" (p.27) and as a consequence, many studies published on this topic lack a clear definition. Thompson notes that behind the apparent general agreement hides a diversity of concepts which are rather different from one another. For example, he asks "is emotion regulation primarily an issue of emotion self-management, or is the management of emotional reaction by others also included?" (p.27). For the purpose of this review, Thompson's definition of emotion regulation will be used. It reads as follow:

Emotion regulation consists of the extrinsic and intrinsic processes responsible for monitoring, evaluating, and modifying emotional reactions, especially their intensive and temporal features, to accomplish one's goal. (Thompson, 1994, pp.27-28).

This definition appears widely used in current literature. It is useful as it includes significant aspects of emotion regulation such as maintaining, enhancing or inhibiting emotional responses, as well as acknowledging that these are not necessarily relying on self-management but can also be managed by external influences such as other people. The choice of this definition for this review was made because of this latter point and its relevance for sibling relationships.

Indeed, other people significantly influence the way emotion regulation develops. Social encounters provide the opportunity to develop and exercise emotional management, by enhancing or disguising our feelings, and our expertise at these skills will also influence the outcome of the interaction. Emotion regulation is not an innate skill but one that develops through these social interactions.

This is where emotion regulation converges with attachment theory; Thompson (1994) proposes that the adaptive nature of emotion regulation enables infants to adapt themselves so they can respond flexibly to changes in the caregiving environment. Bowlby (1979) argued that infants seek to survive by staying in physical proximity to their primary carer. In order to keep the primary carer

within a safe distance, infants have to develop strategies that will help maintain the relationship with the care givers and prevent them from going too far away. These strategies consist of learning to regulate their emotions effectively based on an internal working model of how their parents function (Cassidy, 1994). For example, infants will learn to minimise emotions that are normally construed as attempts to elicit care, such as sadness or distress, if the primary caregiver rejects them when such emotions are displayed. This can be observed in the strange situation experiment with insecure/avoidant infants where on reunion with the caregiver, they will ignore him or her and carry on with their play as if the caregiver had never left the room (Ainsworth, Blehar, Waters, & Wall, 1978).

Other infants develop an insecure/ambivalent attachment where extreme distress is displayed on separation and difficulty in calming on reunion; they learn to regulate their emotions differently. Those infants typically experience inconsistently or minimally available caregivers and learn to amplify their emotions to retain the caregiver's attention (Cassidy, 1994). In securely attached infants, caregivers will respond in a sensitive manner to the displayed emotions and offer comfort and reassurance to the infants. Because the infants know that they are in safe hands with their caregivers, they can learn to tolerate and regulate threatening or frustrating situations; they gradually become skilled at regulating their emotions effectively and on their own (Cassidy, 1994).

However, the study of emotion regulation transcends the concept of attachment as it applies to all kinds of social relationship (Thompson, 1994).

The large majority of studies that have examined the development of emotion regulation have focused on the mother-child dyad. This dyad contributes significantly to the initial development of emotion regulation (Thompson, 1994) but as children grow, their world expands and new relationships outside this dyad are formed. There are few studies that have examined the contribution that these other relationships, such as sibling relationships, make to the development of emotion regulation. This state of affairs is rather puzzling as sibling relationships are amongst the most unique type of relationships human beings can ever experience in that they are potentially of longer duration than any other relationships one can experience (Cicirelli, 1995). Furthermore, by the age of one year old, children will spend as much time with their sibling as they do with parents (Dunn, 1983) and by middle childhood, siblings will spend more time together than with their parents (McHale & Crouter, 1996).

The first part of this paper reviews ten studies that have investigated the role of sibling relationships in the development of emotion regulation. It then examines a model of emotion regulation that goes beyond the parent-child dyad by focusing on sibling relationships. A discussion of the findings of the ten studies reviewed in the light of the model presented follows. Clinical and research implications are also considered.

Methodology

The databases PsychInfo, PsycArticle, Medline and Web of Science were used to search for relevant articles and book chapters in September 2007 with the use of keywords (see list below). Key words pertaining to psychosocial theories of development and emotions (for example, attachment theory or systemic theory) were initially generated. Once a relevant article was found, the keywords used to categorise it, if appropriate, were added to the search. The list of keywords was refined in the process and some key words were discarded if they proved to be too narrow in their focus.

The keywords were used in various combinations to reduce the number of hits. Most combinations were used until a core list of approximately twenty-four articles was generated. From this list, articles in languages other than English or French were excluded as well as dissertation abstracts. Articles that were published over twenty years ago were excluded. Studies that pertained specifically to the parent-child dyad were then excluded. Similarly, studies that mentioned sibling relationships without looking at their impact on emotion regulation were also excluded. Only studies that were relevant to one or several aspects of emotion regulation as defined by Thomson in the context of sibling relationships (1994) were included.

A final list of ten articles on, or closely related to, emotional regulation through sibling relations was produced. The reference section of these articles were examined and cross-referenced to ensure that all relevant articles were included. Some of these studies look primarily at the parent-child dyad but were nevertheless included because they also

explored the dynamics of sibling relationships in the context of the parent-child dyad and referred to their impact on the development of emotion regulation. See Table 1 for summary of studies. One book chapter was found; it contained the description of the model used in the discussion.

Keywords

Adjustment; Emotion; Emotion socialisation; Emotion* control; Emotion* development; Emotion* regulation; Family; Psychosocial development; Self-regulation; Sibling relations*; Siblings; Social learning; Social skills.

N.B. The asterisk was used to search for multiple forms of the same root/stem word or for different spelling of the words.

Table 1- Summary of Studies on Sibling Relationships and Emotion Regulation

Study	Aims	Sample	Measures	Outcomes/findings	Conclusion	Limitations
Bedford (1998)	To investigate the link between childhood sibling troubles and well-being in adulthood.	40 randomly selected US participants who were aged 59.1 years on average (<i>SD</i> 10.50). 42.5% of sample was female.	<ul style="list-style-type: none"> •Positive and Negative Affect Scale; •Semi-Structured interviews; •Intergenerational Solidarity Scale; •Conflict Negativity Scale. <p>Data were collected at 4 points over 12 years.</p>	Sibling relationships may contribute to well-being in terms of positive affect, but not negative affect. Positive reappraisal of sibling troubles in childhood was somewhat related to positive affect in later life.	Early experiences with siblings have a long-term effect on well-being. Emotional regulation learnt through sibling relationship, when reappraised positively, contribute to well-being in later life.	Participants' siblings were not involved in the study. Unrepresentative sample; Significant number of participants who dropped out at the first wave had negative sibling relationships, which might have affected the final results.
Brody, Kim, Murry, and Brown (2003)	To investigate the ways in which older siblings contribute to their younger siblings' development.	152 African American single-mother-headed families were recruited through community contacts the authors had. Older siblings' age on average was 11.7 years and second born children's age was 9.2 years. 79 girls and 73 boys made up the sample.	<ul style="list-style-type: none"> • Perceived Competence Scale for Children; • Rosenberg Self-Esteem Scale; • Centre for Epidemiological Studies Depression Scale; • Interaction Behavior Questionnaire; • Ineffective Arguing Inventory; • Children's Self-Control Scale (teacher's version) <p>Data were collected yearly over a period of 4 years.</p>	Exposure to academic and social competence in their older siblings, along with parenting processes that featured high levels of support and involvement with low levels of repetitive arguing, were positively linked with younger siblings' regulation. Older siblings contribute over time to their parents' psychological well-being, which in turn has an effect on the parenting of all children.	Older siblings contribute directly to the development of regulation in their younger siblings through modelling and tutoring behaviours. They can also contribute to the development of regulation indirectly by making their parents feel more competent and thus improve their general parenting abilities.	Sample limited to single-parent families of African American origins. Sample was self-selected and families who opted in might not have been representative of general population. Data regarding mothers' cognitive functioning such as efficacy was not included. Correlations are significant but weak.

Table 1- Summary of Studies on Sibling Relationships and Emotion Regulation

Study	Aims	Sample	Measures	Outcomes/findings	Conclusion	Limitations
Deater-Deckard, Dunn, and Lussier (2002)	To examine family type and sibling type differences in sibling relationship quality and to investigate links between sibling relationship quality and child adjustment.	192 UK white families with a 5-year old child and an older sibling of 9 years of age on average. The families can be divided in five types: intact, single-parent, stepmother families, stepfather families and complex stepfamily.	<ul style="list-style-type: none"> • Interviews; • Colorado Interview on Sibling Relationships; • Sibling Relationship Inventory; • Sibling Areas of Disagreement; • Child Behaviour Checklist (Teacher Report Form); • Strengths and Difficulties Questionnaire Data was collected once.	Sibling negativity (e.g. aggression) highest in single-parent families, and full siblings were more negative than half and step-siblings. In families where there are conflicting couples, siblings have also more conflicted and less supportive relationships.	Higher amounts of sibling negativity and lower amounts of sibling positivity are associated with child maladjustment. The developmental processes underlying sibling relationship quality and emotional adjustment operate in similar way for sibling regardless of the genetic similarities.	Small unrepresentative sample. Statistical power of analyses was limited.
Downey and Condron (2004)	To replicate the often-noted negative relationship between number of siblings and cognitive outcomes, and then demonstrate that this pattern does not extend to social skills.	20,649 randomly selected American kindergarten children of an age average of 6 years and 2 months.	Specific scales developed for the Early Childhood Longitudinal Study-Kindergarten (ECLS-K) class. The scales measured items such as interpersonal skills, self-control, externalising problems, reading skills and maths skills. Interviews with parents were used to collect information on numbers of siblings, age gaps, sibling types (full, half, step, adopted, foster).	Children have better social and interpersonal skills when they have at least one sibling. Once differences in family type are accounted for, there are no cognitive skill (reading and maths) advantages to having even one sibling.	The opportunity to interact even with just one sibling gives the children the chance to experience and control negative emotions.	Socio-economic status of the family was not taken into account (which might be more significant in terms of family size).

Table 1- Summary of Studies on Sibling Relationships and Emotion Regulation

Study	Aims	Sample	Measures	Outcomes/Findings	Conclusion	Limitations
Kitzmann et al. (2002)	To test the assumption that having a sibling provides practice with skills that generalise to peer relations.	139 American children aged between six and twelve years from a primary school affiliated to a university. 58 boys and 81 girls made up the sample.	<ul style="list-style-type: none"> • Number of friends • Peer nomination for sociometric ratings • Peer nomination for social behaviours • Sociometric nomination by peers • Friendship Quality Questionnaire • Perceived Competence Scale for Children • Loneliness Questionnaire 	Only children were similar to classmates in terms of number of close friendship and friendship quality, but were less liked as a group by classmates. Only children were more likely both to be victimised and aggressive in the peer group.	Having a sibling might be useful in terms of learning to manage conflict.	Does not take into account quality of sibling relationship and its impact on forming and maintaining relationships. Age gap between siblings varied greatly and was not accounted for. Measures were taken only at one point in the study and therefore might not measure stable individual differences.
McElwain and Volling (2005)	To examine the extent to which friend and sibling relationship quality jointly contributed to children's social and emotional adjustment.	52 families with a 4-year old child and an older child between the ages of 5 and 10. Average age gap was 37 months. All siblings biologically related. 14 boy-boy dyads; 16 girl-girl dyads; 11 girl-boy dyads, and 11 boy-girls dyads.	Different teams of coders assessed individual behaviour and dyadic interaction from videotapes of the laboratory procedure. Mothers and fathers completed independently the Child Behaviour Checklist.	Children's interactions with friends had a greater symmetry and higher levels of social play than interactions with siblings. A positive relationship with a friend has a buffering effect on potential outcomes of a negative relationship with a sibling and vice-versa.	Sibling and friend relationships make separate contributions to adjustment. Having at least one positive relationship experience with another child may help prevent maladjustment.	Small unrepresentative sample. The two types of relationship differ greatly and have different dynamic often because of age difference and hence siblings are not in the same developmental position. This was not entirely acknowledged by the authors.

Table 1- Summary of Studies on Sibling Relationships and Emotion Regulation

Study	Aims	Sample	Measures	Outcomes/Findings	Conclusion	Limitations
Miller, Volling, and McElwain (2000)	To examine young children's abilities to regulate emotions during triadic interactions with their mothers, fathers and siblings.	60 white 'intact' US self-selected families with two children, where the youngest children were 16-months old on average and the older sibling were 50-month old (4.16 years) on average.	Videotapes of triadic sessions were assessed and coded in terms of global emotional displays and emotion regulation style, as well as parental and children's behaviours.	Older siblings were better at regulating jealousy response and focus on play. Younger siblings showed differences in jealous behaviours in the two play situations (play with mother and play with father).	It is important to consider sibling relationships as a socialisation context for the development of emotion regulation.	Small non-representative sample used. Findings are correlational in nature.
Volling, McElwain and Miller (2002)	To demonstrate children's ability to learn to regulate powerful emotions in a sibling-relationship context.	60 white 'intact' US self-selected families with two children, where the youngest child is nearing 12 months of age and the older sibling between the ages of 2 and 6 years.	Videotapes of triadic sessions were assessed and coded in terms of global emotional displays and emotion regulation style, as well as parental and children's behaviours.	Child jealousy reactions differed between mothers and fathers. Older and younger siblings showed jealousy but older children were better than younger children at regulating their emotions.	Younger children are more dependent on their parents to help regulate their emotions. Sibling relationships provide fertile ground for triggering varied and intense emotional responses.	Small non-representative sample used.

Table 1- Summary of Studies on Sibling Relationships and Emotion Regulation

Study	Aims	Sample	Measures	Outcomes/findings	Conclusion	Limitations
Pike, Coldwell, and Dunn (2005)	To identify links between sibling relationship quality in early/middle childhood with children's emotional adjustment	101 two-parent UK families with one child aged between 4 and 6 (average 5.2 years) with a sibling aged 8 years or under (average 7.4 years). Equal numbers of the four sibling sex constellations were recruited.	<ul style="list-style-type: none"> • Berkeley Puppet Interview; • Maternal Interview of Sibling Relationships • Expression of Affection Inventory; • Parent-Child Relationship Scale • Parental Feelings Questionnaire; • Parental Discipline Interview; • Parent-Child Conflict; Strengths and Diff. Questionnaire.	The quality of the parent-child relationship influences the relationship between siblings. However, the quality of the sibling relationship is not entirely mediated by the quality of the parent-child relationship. The eldest child's adjustment has more of an impact on sibling relations than that of the youngest.	Sibling relationship impacts on adjustment and a good adjustment influences back the quality of the relationship.	Children in the sample were already generally well adjusted. Only parental reports of sibling relationships were included. The authors did not include direct observation of siblings in their analysis.
Stormshak, Bellanti, Bierman, and CPPRG (1996)	To understand the relationship between sibling interactions and the social adjustment of children with behavioural problems.	53 white US children aged between 4 and 12 years with their closest sibling and mother were recruited. 27 male dyads; 9 female dyads, and 17 mixed dyads.	<ul style="list-style-type: none"> • Sibling Interview Scale; • Pictorial Scale of Perceived Competence and Acceptance for Young Children; • Maternal Interview about Children's Sibling Relationships; • Child Behaviour Checklist (Teacher Report Form); • Social Health Profile; • Sociometric nominations with classmates. 	Presence of conflict in sibling relationship is not always a negative factor, but the severity of that conflict and the degree of coexisting warmth may both temper negative outcomes.	Sibling relationships characterised by moderate levels of conflict combined with moderate levels of warmth may provide a healthy balance of interactions promoting effectively the development of emotion regulation.	Findings were correlational in nature and do not therefore indicate a cause-to-effect conclusion. Variables such as family relationships (e.g. marital interactions) were not considered..

Siblings and emotion regulation

Brody, Kim, Murry, and Brown (2003) conducted a longitudinal study where they examined the link between older siblings' social competence and the development of emotion regulation in their younger siblings. They investigated the direct and indirect contributions older siblings make in terms of development of younger children in the family. Data were collected yearly for a period of four years. They found a significant, but weak correlation between older siblings who are doing well at school and an increase in their parents' self-esteem and a decrease of depressive symptoms; this, in turn, contributes to younger sibling's socialisation and emotion regulation as, according to their hypothesis and findings, it has the effect of improving the parenting provided to other siblings. They also found significant, but weak, correlations between older siblings' social competence and younger siblings' emotion regulation. The findings are interesting but difficult to generalise as the sample is not representative; not only were the participants members of one ethnic group, African American families, but they had also self-selected. The study nevertheless suggests that emotion regulation is not an individual process but rather one that closely linked with sibling and parent relationships and that these exchanges contribute to the emotion regulation of all involved in the interactions.

Examining more closely the combination of sibling relationships and parenting, Miller, Volling, and Mc Elwain (2000) and Volling, McElwain, and Miller

(2002) conducted two studies to investigate how parents help their children to develop their own mechanisms for emotional regulation. They studied how young children learn to regulate jealousy in their interactions with their siblings. They created a laboratory experiment where mothers and fathers separately played with their children in two sessions. During those sessions, the parent had to focus on one child specifically whilst the researcher observed the reactions in the other child. They found that children who expressed negative affect were more likely to disrupt the parent's interaction with the other child and would find it difficult to focus their attention on an alternative play activity. They also found that the jealousy pattern in one triad did not necessarily generalise to the other triad. Thus if a child displayed jealousy in the triad with mother, the same child would not necessarily feel jealousy in the triad with father. Although they noted that if the child had been challenged first or second, it made a significant difference in the child's reaction. Volling et al. found that younger siblings who were challenged first (where mother or father focus on the other child first) expressed more jealousy, whilst older siblings were more jealous with their father if they had been challenged second. The researchers suggest that it might be because the older sibling, having received the attention first, feels cheated by seeing their father then turning to their sibling and ignoring them. On the other hand, younger siblings found it difficult to regulate their emotions if they had not been allowed to play with the parent and the new toy first. When the parent attended to them first, they did not express jealous affect when the parent then played with the other child in the later session. Volling et al. conclude that

younger children are more dependent on their parents to regulate their emotions, whilst older siblings are better at regulating their emotions on their own. The older sibling's cognitive understanding of emotions was also the sole predictor of jealous affect with mother. In other words, older siblings who were able to regulate their emotions were less likely to display a jealous response.

Although sibling relations were not specifically examined in these studies, both of them emphasised the importance of examining emotional regulation processes within the context of social relationships, such as sibling relationships. They showed that sibling interactions provide a fertile ground for triggering a wide variety of emotional reactions in children. This appears to contribute significantly to the development of emotion regulation by giving the siblings opportunities to learn how to manage them.

Pike, Coldwell and Dunn (2005) have studied actual sibling relationships and their effect on emotional adjustment. Using the 'spillover' hypothesis, which proposes that behaviours and emotional quality from one system will be transferred to another system (e.g., relations in the parental system will have a bearing on the parent-child system), they examined the parent-child dyad and its effects on sibling relationship and also looked at sibling adjustment after accounting for the parent-child relationship. Although they acknowledged and demonstrated that the quality of the parent-child relationship influences the relations between siblings, they actually found that "the link between sibling

relationship quality and children's adjustment is not entirely mediated by the quality of the parent-child relationship" (p.528). Thus, they concluded that not only does the sibling relationship influence adjustment and that a good adjustment does influence back the quality of the relationship, but that siblings are generally a resource for one another. There was however a certain pattern which showed that it was the eldest child's adjustment that had more of an impact on sibling relations than that of the younger sibling.

Sibling relationships, however, are not always positive and are generally characterised by their combination of positive and negative emotions (Dunn, 1996, 2002). Stormshak, Bellanti, Bierman and Conduct Problem Prevention Research Group (1996) studied the quality of sibling relationships and the development of social competence in aggressive children. They note that aggressive children tend to engage in more conflictual exchanges with their siblings and that these might be generalised to school peer interactions. However, they also suggest that aggressive children might also experience supportive and warm sibling interactions and that these might have the effect of promoting prosocial skills and positive peer interactions at school. If the relationship has this aspect of support and warmth, Stormshak et al. suggest that conflict might teach the sibling to regulate their emotions instead of fostering more aggression.

Stormshak et al. (1996) found that sibling relationships could be grouped in three categories, based on the conflict and warmth scales used in the interviews: conflictual (high conflict, low warmth), involved (moderate conflict, moderate warmth) and supportive (low conflict, high warmth). Children in 'involved relationships' were found to have significantly more emotional control and social competence than children in 'conflictual relationships'. Children in 'conflictual relationships' were more likely to be disliked by peers. No mention is made of how siblings in 'supportive relationships' compare to the others. As Stormshak et al. (1996) conclude, the presence of some conflict in a sibling relationship can be positive as long as the level of warmth moderates its impact. This type of relationship provides a good range of emotions which facilitates the development of emotional regulation and social skills, which can be transferred onto friendships with peers.

Friendship with peers can also play a role in the development of emotional regulation, which feeds back onto the sibling relationship and vice-versa. McElwain and Volling (2005) examined children's social and emotional adjustment from the point of view of their behaviour in interactions with siblings and with friends. They observed children's interactions with an older sibling and, in a separate session, with a friend in two different situations: a free-play session and a task sharing session. They found some support to show that sibling and friend relationships make a separate contribution to behavioural adjustment. Play with friends fosters more dialogue and collaboration than play

with siblings. More significantly, they found in this cross-sectional study that when the quality of one relationship is negative and the other is positive (for example, a child with a difficult sibling relationship but a positive friendship or vice-versa), the positive relationship had a buffering effect on the potential negative outcome of the low quality relationship. It is tempting to conclude that as long as a child has a positive relationship with a peer of the same age, whether sibling or friend, he or she will derive the same social-emotional benefits. However, there are significant differences between sibling relationships and friendships which need to be taken into consideration. As the authors highlight, friendships tend to be more egalitarian in their nature, whilst the relations between siblings tend to be unequal, often because of the age differences between the children. This also means that because of differences in age, siblings may be at different developmental levels and this might be reflected in their play interests. Furthermore, sibling relationships are generally longer lasting (Cicirelli, 1995) whilst friendships can be ended. It seems reasonable to conclude that although a positive relationship contributes to children's social emotional adjustment, there are significant differences between the two types of relationships and their contribution to emotional regulation are likely to differ.

It is estimated that around 80% to 90% of children have one or more siblings (Cicirelli, 1995; Wedge & Mantle, 1991) and these sibling will be the first non-parental relations a child makes (Sanders, 2004). One way of assessing the

contributions siblings make to the development of emotion regulation is to compare children with siblings and only children. Kitzman, Cohen, and Lockwood (2002) made such a comparison in terms of social competence with a sample of elementary school-age children. They found that in terms of number of friends, there was no difference between only children and children with siblings. However, they found that children with siblings were better liked by their peers and that only children were more likely to be victimised or aggressive with their classmates. Kitzman et al. conclude that having a sibling might be useful in terms of learning to manage conflict.

Building on these results, Downey and Condron (2004) looked at the effect of having one or more sibling, as opposed to being an only child, on the development of social and interpersonal skills. They found that, in their large scale study of over 20,000 kindergarten children, those who had one or more siblings “exhibit better social and interpersonal skills, on average, than children without siblings.” (p.347), suggesting that having the opportunity to interact with even just one sibling gives the children the chance to experience and control emotions, especially negative ones. Interestingly, they also found that having three or more siblings might have a negative impact on the development of social skills; teachers’ ratings of children interpersonal skills suggest that children with more than two siblings have no better social skills than children with no siblings. They suggest that in smaller families, there are more opportunities for parent-supervised sibling interactions and those interactions,

therefore, might degenerate less often into rows that are not conducive to emotional and social skills development. Finally, they also found that sibling relationships between full siblings are more beneficial, in terms of developing emotion regulation, than those between other kinds of siblings (step or half). However, the authors do not make any suggestion as to why this might be the case.

Deater-Deckard, Dunn and Lussier (2002) investigated this latter point by conducting a study examining family type (nonstep, stepfather, stepmother, and single mother) and sibling type (step, half and full) differences in sibling relationship quality. In addition, the links between the relationship quality and social-emotional adjustment were explored. The results show that in reconstituted families (where there is a stepmother or stepfather and stepsiblings), sibling relationships were similar to those of intact families in terms of positivity or negativity. Although they had predicted that siblings in intact families would have a better relationship, their findings showed that it is not necessarily the case. Other findings showed that sibling relationships in single-mother families were the most negative, in terms of quality, when compared with siblings in other family types and after accounting for socio-economic difficulties. Deater-Deckard et al. suggest that the absence of a partner deprives the single mother of the support couples in intact families have access to, which means single mothers face daily stresses and hassles on their own.

In terms of looking at the links between sibling relationship quality and social emotional adjustment, Deater-Deckard et al. (2002) found, like Stormshak et al. (1996), that higher amounts of sibling negativity (e.g. aggression) and lower amounts of sibling positivity (e.g. warmth) are associated with higher levels of externalising and internalising problems. When they examined how sibling relationships in different family types might affect the social emotional adjustment, they found that children in intact families had the highest correlations (typically exceeding .5) between sibling negativity and adjustment problems. Low correlations were found for siblings in other family types. The authors do not offer any explanation on these findings. One might suggest that siblings in intact families have a longer relationship history than in other family types and thus the negativity has a longer duration and greater impact on adjustment.

Sibling negativity might affect social emotional adjustment in childhood but this does not mean that the consequences will be negative on a long-term basis.

Bedford (1998) acknowledging that little is known about how sibling relationships contribute to the well-being of adults, investigated the links between sibling relationships in middle and old age and well-being. Forty participants were interviewed on sibling rivalry and conflicts, past and current, and completed several measures of general affect four times over a period of twelve years; well-being being defined in this study by general positive affect.

She found that positive cognitive appraisals of sibling troubles in childhood were linked to well-being in middle and old age. In other words, the ability to look back at sibling difficulties in childhood and appreciate what has been learned from them enhances well-being in later life. Bedford argues that people who are in this situation have learnt to regulate their emotions in a constructive way and benefits from it in middle and old age. However, she also found that reappraisal of current sibling difficulties did not have the same effect, hence her conclusion that sibling childhood experience are linked to well-being in adulthood.

Discussion

Bedford and Volling (2004) proposed a model of emotion regulation, which appears based on their own research, that specifically situates the individual within the context of sibling relationships. The model emphasises the interdependence between interpersonal and intrapersonal regulation. It also shows how siblings mutually influence each other over time in terms of social and emotional competencies, which in turn, create a relationship dynamic that reinforces or weakens these competencies (see Figure 1).

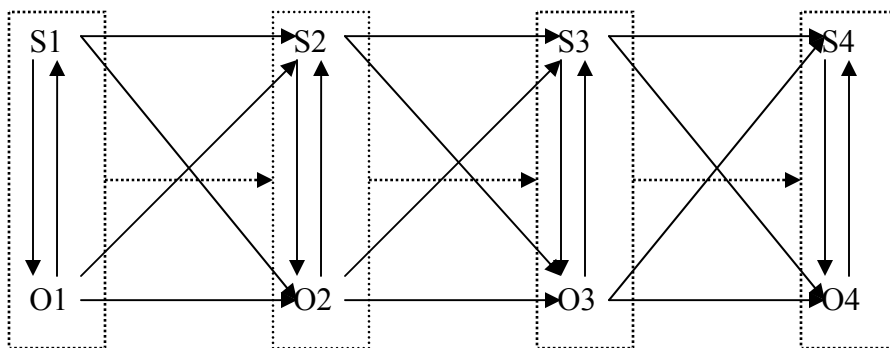


Figure 1- A dynamic ecological systems model of interpersonal, self-, and other-regulation in sibling relationships. *Note:* S= sibling 1 (self); O= sibling 2 (other). (Bedford & Volling, 2004).

The interactions between siblings, as shown by the bidirectional arrows, not only influence each other as individuals, but they also create a relationship context that affects their interactions. This process is indicated in the model by the dotted boxes. Moreover, the behaviour of one sibling will influence that sibling's behaviour at later points in time (as indicated by path *s*), which refers to self-regulation. This sibling will also affect the behaviour of the other sibling over time (as indicated by path *o*), which refers to emotion other-regulation. The dotted arrows between boxes indicate that future relationship dynamics are influenced by the context of past interactions.

The ecological perspective within the model acknowledges the importance of looking at the multiple contexts in which child and adult development occurs as well as the necessity to examine changes within the individual, the family and

the environment over time; although the latter point does not appear to be represented schematically within the model. Siblings influence one another, but will also be influenced in a similar way by their parents, extended family and the environment throughout their life.

The studies reviewed in this paper generally provide support to the DES model but also highlight areas of weakness. Pike et al. (2005), for example, have shown that sibling relationships are influenced by the children's relationship with their parents but they have also some degree of independence from them. Siblings help each other in developing the regulation of their emotions. This offers support for the need of a model such as the DES. Sibling relationships affect the development of emotion regulation and this, in turn, impacts on the quality of the relationship, as shown by the bidirectional arrows in the model.

Similarly, the studies of Miller et al. (2000), Volling et al. (2002), Brody et al. (2003) and Stormshak et al. (1996) underscore the significance of interpersonal interactions in the development of emotion regulation. Not only do they demonstrate how sibling interactions, especially when parents are involved, are a rich ground for triggering intense emotions, but they also show that older siblings' ability to regulate their emotions has an impact on the development of younger siblings' regulation, as suggested by the model.

The DES model also emphasises the development of emotion regulation over time. Bedford (1998) offers support for that aspect of the model. The findings of her study show that sibling intrapersonal regulation and interpersonal regulation occur over time and that past relationship dynamics influence emotion regulation in later life. Positive development of emotion regulation in the context of sibling relationships contributes to well-being in older adults.

The other studies reviewed in this paper also offer some support to the DES model; they show in various ways how the intrapersonal and interpersonal dynamics are enacted in sibling relationships, which can be easily mapped on to the model. They, however, highlight other areas that are more difficult to map on to or explain within the model.

For example, studies such as Kitzman et al. (2002) and Downey and Condrón (2004) suggest, to a limited extent, that children develop better emotion regulation through sibling relationships than through friendships; the DES model does not offer any explanation as to why sibling relationships are more ‘potent’ than friendships. Indeed, the model could be applied to long-standing friendships and other types of relationship. The study by Deater-Deckard et al. (2002) raises the same issue; their data suggests that sibling relationships, when the siblings are full siblings, are actually less restrained or less inhibited than when they are half or stepsiblings. Once again, the model appears applicable to

all relationships and does not explain how sibling relationships, especially between full siblings, differ from other relationships.

It is also important to highlight that most of these studies, with the exception of Brody et al. (2003), have merely looked at white middle-class ‘ordinary’ families with no significant issues. These studies do not contribute much in trying to understand sibling relationships in families where there is a disabled child or a substance-abusing parent, families where there is a history of mental health difficulties or families where there is violence and abuse of all types.

In summary, sibling relationships contribute to the development of emotion regulation. All the studies reviewed in this paper suggest that siblings’ influence on one another and their relationships contribute to their social and emotional adjustment. Sibling relationships, especially between full siblings, are unique in their nature and create situations where the development of regulation skills is paramount for one’s mental health (Frick & Morris, 2004). The findings discussed here generally support the model developed by Bedford and Volling (2004) but the model fails to convey what is unique about sibling relationships.

Clinical and research implications

The research reviewed in this paper demonstrates the significance of sibling relationships to child development. It is interesting to note, in the light of this,

that the Children's Act 1989 asserts that services do not need to be directly targeted at children but may be directed at their families. The Act, however, puts very little emphasis on the significance of sibling relationships, except to say that children, when looked after by local authorities, must be placed with their siblings (Section 27(3)(b)).

When professional interventions are required with families who are experiencing difficulties, the research described in this paper suggests that special attention should be given to sibling relationships. Siblings contribute to the processes of development and this should be considered by psychologists and other professionals working with families. When assessing families in difficulties, the relationship between siblings should be taken into consideration and included in the formulation. Professionals need to be aware that the type of family (e.g. intact, reconstituted, etc.) can affect the nature of sibling relationships and that extra support for the development of emotion regulation might be needed by families with more than three children. Clinical intervention should focus not only on the parent-child relationship but also pay special attention to sibling relationships. Although not discussed in this review, siblings are often sources of support for one another, especially when parents are unavailable or unable to provide the emotional resources needed by the children (Kosenen, 1996). Professionals working with families where the parents are unavailable should try boosting the strength of the sibling relationship and research could help by finding ways of doing so.

Siblings can be a source of support for one another but this is not always the case. Some sibling relationships are characterised by their abusive (physically, emotionally or sexually) nature. There is a popular expectation that sibling relationships will have a strong element of rivalry and unpleasantness, which means that sibling rows can often be ignored and deemed 'normal' (Sanders, 2004); professionals working with families should not belittle the significance of sibling relationships. Because siblings play such an important role in the development of emotion regulation and other psychological aspects of children's development, undetected abusive sibling relationships could have severe consequences for its victims.

Needless to say, more research is needed not only to provide a thorough understanding of how siblings contribute to the development of emotional regulation but also to language development, cognitive development, psychological adjustment and social skills (Brody, 2004). Future research is needed to improve and validate the DES model. Research is also needed in looking more specifically at how sibling relationships differ from other types of relationships and how they actually operate, whilst controlling for parental influence; the challenge is to identify the unique contribution siblings make to child development and emotion regulation.

Conclusion

Children learn to regulate their emotions firstly with their parents. This is their first relationship and the role of the parents is to provide the emotional support that will enable them to make sense of their world. Children will then have to transfer these skills to other relationships as their world starts to expand.

Relating to an older sibling or having to share the parents with a younger baby will bring new challenges and contributions to the regulating of one's emotions. New regulating skills will need to be forged to survive and these can be built through these new relationships.

Children play a role in mutually teaching and helping their siblings to learn emotional regulation. The relationship with the parents often serves as a model and the sibling relationship also appears to have an influence on the development of regulation. The contributions are both direct and indirect. Like the parents do, siblings model emotional regulation to one another; they also imitate what they witness. In addition, siblings trigger strong emotional responses in each other; these relationships are often characterised by their ambivalent combination of love and hate. This gives the child with siblings the chance to learn several skills such as negotiating and managing conflict, adapting themselves to the needs of others and self-soothing. Siblings learn to interact with others in an effective manner. These skills are then transferred to other relationships. Although friendship with peers also helps children further the development of emotional regulation, the duration and intensity of these

relationships are not as significant. This is also reflected in family types; the relationship between full siblings is often more intense than between half or step siblings.

Sibling relationships are not easy to conceptualise into a model. The relational model presented in this paper offers some insights into the development of intrapersonal and interpersonal emotion regulation. The model was designed with sibling relationships in mind and the studies reviewed here support its concepts. The processes suggested by the model are, however, not unique to sibling relationships and could be applied to other types of close relations and this appears to be a significant limitation to the model.

Published research on emotion regulation and sibling relationships is very limited. The studies that have been conducted are promising with links between the development of emotion regulations and sibling relationships. However, the use of cross-sectional designs and correlational analysis means that more research is needed to understand the dynamics of sibling relationships and its uniqueness in the development of emotion regulation.

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The experience of growing up with a sibling who has a learning disability

Abstract

This paper presents an account of a qualitative study on the experience of growing up with a sibling who has a learning disability. Literature on this topic has often been contradictory and its findings difficult to interpret. Some claim that growing up with a disabled sibling has negative consequences, whilst others claim the contrary.

Interestingly, most research done in this area has used a quantitative methodology. Eight participants were recruited for this study and took part in an interview. The interviews were transcribed and analysed using Interpretative Phenomenological Analysis principles. Four superordinate themes emerged from this exercise: normal within the family, guilt and self consciousness, subordinate needs, and improving the disability and promoting independence. Each theme was discussed and is illustrated by quotes from the participants. The discussion makes links between the themes obtained in the analysis and current literature on the topic. Although there are similarities with the literature, there are also differences and new perspectives that have been brought by this study's findings. A graphical representation of the superordinate themes is included.

Introduction

Sibling relationships are amongst the most unique type of relationships human beings can ever experience in that they are potentially of longer duration than any other relationships one can live through (Cicirelli, 1995). Even when the siblings have not seen each other for decades or have poor relationships, being a brother or a sister remains part of their identity. Now that fewer children with learning disabilities are institutionalised, they grow up with their brothers and sisters and spend more time together than in previous decades (Foundation for People with Learning Disability, 2001).

According to the Joseph Rowntree Foundation (1999) there were over 300,000 children with physical or learning disability under the age of sixteen in England and Wales at the time of their research. A considerable proportion of these children have more than one disability and a significant number of families have more than one disabled child.

Indeed, the Joseph Rowntree Foundation suggest that a health authority area covering 500,000 people will have around 250 families that have two or more children with a high level of support needs. The report also states that children with a high level of care needs are increasing in number.

Growing up in a family where one of the children has a learning disability is different from being in a family where no one is disabled (Burke, 2004). Bearing in mind that the birth of a second child in a family is always disruptive (Joyce, 2005; Stewart, 1990), Dew, Llewellyn, and Balandin (2004) suggest that if the new sibling has a learning

disability, the impact can be even greater as the non-disabled child might feel left out since the care needs of the disabled child will be much greater. Even when the disabled child is older than the non-disabled sibling, the caring activities and additional demands on the parents leave them less time to give attention to the other children (McHale & Pawletko, 1992). If the non-disabled child also helps with providing the care for their sibling, feelings of guilt, anxiety and isolation can be experienced (Dew et al., 2004).

McHale and Gamble (1989) compared children with and without siblings with a learning disability in terms of relationships and adjustment. They found that children with a disabled sibling spent more time in caregiving activities than children who did not have a disabled sibling. They also found that in terms of psychological well-being, which was assessed with depression, anxiety and self-esteem scales, siblings of children with learning disability performed more poorly on most measures, although their scores were higher than the comparison group, they were still within the normal range. They also found that children reported being happier with their sibling relationships when their sibling had a learning disability than when the sibling was not disabled.

However, other studies have shown that older siblings who have significant caring responsibilities have greater conflicts and fewer positive interactions with their sibling with learning disability (Stoneman, Brody, Davis, & Crapps, 1987). Similarly, Gath and Gumley (1987) found that older siblings who are significantly involved in childcare responsibilities are more likely to experience behavioural problems.

Research findings in this area are not, however, unequivocal. Studies such as Boyce and Barnett (1993) and Zetlin (1986) have reported positive outcomes: non-disabled children might benefit from a sibling relationship where the opportunities for competing with one's sibling are significantly reduced; a different type of sibling relationship might emerge through the closeness of providing care; qualities such as tolerance and an awareness of prejudices might develop more easily in families where there is a disabled child. Indeed, Frude (1991) reports that the siblings of disabled children have a better awareness of the needs of other people.

Lardieri, Blacher and Swanson (2000) investigated social competence, behavioural problems and perceived impact of having a sibling who has a learning disability on children aged between nine and eighteen years. They concluded that no difference could be found between children with a sibling with a learning disability and children with a non-disabled sibling in terms of sibling behaviour, sibling self-concept and perceived sibling impact. Furthermore, they found that in families where there is a sibling with a learning disability, the relationship between siblings had the same type of positive and negative characteristics found in all sibling relationships.

Reviews of the literature on the topic of non-disabled sibling providing care for their disabled brothers or sisters reach various conclusions: the effects of childcare responsibilities on children are not clear and are often contradictory (Faux, 1993; Sanders, 2004; Stoneman, 2001). Del Rosario and Keefe (2003) found in their systematic review that although many studies showed a positive effect or no difference between groups (for studies that compared sibling of disabled children with siblings of non-

disabled children), there was an overall suggestion that non-disabled sibling of disabled children are at risk of psychological and behavioural problems.

Sanders (2004) goes further in his criticisms of the literature. He states that most of the research done on brothers and sisters of children with learning disabilities have focused on the impact of the disability on the non-disabled child and hence adopted a disabilist position. He explains that most studies in this area have focused on the impact of the disability thus assuming that it is the dominant factor in determining the impact of the child on his or her siblings. He suggests that “shifting the focus of research to the contribution of the child with the disability (and not just the contribution of his or her disability) to the quality of the sibling relationship may be a useful avenue to explore” (p.128).

Furthermore, there are few studies on siblings of people with learning disability using qualitative research methods (e.g. Burke, 2004; Burke & Montgomery, 2000). Most studies in this field used quantitative methodology. The majority of studies appear to look at specific issues, such as psychological adjustment, well-being, behaviours and other similar discreet variables. Their conclusions have been varied and contradictory as they measured different aspects of the experience. Independent variables have been selected in what appears to be a random manner as most of the studies were not theory driven. There are indeed no theoretical models that offer an explanation as to how having a sibling with a learning disability might impact on an individual’s development. This makes it difficult to integrate the available studies, as some of the systematic reviews

have attempted, and assess whether having a sibling with a learning disability affects the non-disabled sibling or not.

The aim of this qualitative study is to illuminate some of the existing research on growing up with a sibling who has a learning disability and attempt to develop a model that gives an insight into the phenomenology of the experience.

Method

Participants

Eight female participants were recruited. They were aged between 21 and 28 years at the time of interview. Their ethnic background was British for seven of them and one was of Mixed European-Chinese origin. They were all born in the United Kingdom and Republic of Ireland and had grown up in their country of birth. Written consent to take part in the study was obtained from all participants prior to the interview. They were also reminded of their right to withdraw at any time during the data collection period and were assured of the confidential nature of the interview.

Ethical approval from the University of Birmingham School Research Ethics Committee was sought and granted prior to the recruitment of participants. Participants were then recruited via several methods. A total of twelve participants approached the researcher and eight were offered an interview. Of those who were selected, two were recruited through adverts posted at two universities; one was an English Literature student and the other was a counselling student. The remaining six were recruited through an advertisement posted in *The Psychologist* (the monthly magazine published by the British

Psychological Society). Of these six participants, two were employed as assistant psychologists, two were trainee clinical psychologists, one was employed by a research trust as a researcher and one worked in a museum. Four people, including two males, were excluded from the study because they did not meet the study criteria: one had a sibling with learning difficulties (dyslexia), two were significantly above the age limit and one was not available for the period when the interviews were being conducted.

Every participant had a sibling who had been diagnosed with a learning disability according to the three core criteria provided by the British Psychological Society (2000), which are:

- Significant impairment of intellectual functioning;
- Significant impairment of adaptive/social functioning;
- Age of onset before adulthood.

Other inclusion and exclusion criteria are listed in Appendix III. Participants were asked in the interview to describe the nature of their sibling's disability with regards to intellectual functioning, adaptive/social functioning and the age of onset. These details were carefully discussed in supervision and an impairment category was allocated by the author. 'Significant' was assigned to siblings who were deemed to have an IQ between fifty-five and sixty-nine and 'Severe' to those whose IQ was deemed to be below fifty-five (British Psychological Society, 2000). Two of the participants had siblings who were diagnosed with a genetic syndrome and none of the six others had a formal diagnosis.

Six participants were the eldest child in their family, one was the middle and one was the youngest child. Six of the participants also had a non-disabled sibling; four had a brother and two had a sister. See Table 2 below for a summary of participant family information.

Table 2- Participants Family Information

Pseudonym	Age	No of Sibs	Participant's Birth Order	Disabled Sib's Birth Order	Age of Disabled Sib.	Other sibling in the family	Level of disability
Hannah	25	2	Eldest	Youngest	13	Brother	Significant
Ann	25	2	Eldest	Middle	21	Brother	Significant
Kate	27	2	Eldest	Youngest	24	Sister	Significant
Sophie	21	1	Eldest	Youngest	24	None	Significant
Pam	22	2	Middle	Youngest	25	Brother	Severe
Vicky	28	1	Eldest	Youngest	26	None	Significant
Clare	25	2	Youngest	Middle	28	Sister	Significant
Julie	26	2	Eldest	Youngest	18	Brother	Significant

Interviews

Semi-structured interviews were carried out. This format is less restrictive than a structured interview and enables the interviewer to probe interesting areas that arise. It also gives participants the opportunity to focus on what they find relevant to their experience. The interview schedule consisted of headings based on the main themes of the research, as suggested by Burman (1994) (see Appendix V for interview schedule).

Participants were interviewed at the place of their choice, the interviews lasting between 35 and 60 minutes.

All interviews were digitally recorded and transcribed. A copy of the transcript was then sent to each participant for comments and approval.

Analysis

The transcripts were analysed on the basis of the Interpretative Phenomenological Analysis (IPA) principles (Smith & Osborn, 2003). This was deemed to be the best method as the aim of the study is to provide an understanding of the experience of growing up with a sibling who has a learning disability. IPA was selected as opposed to other types of analysis on the grounds that it offers a systematic way of capturing and exploring the meanings participants give to their experience. IPA also enables the researcher to draw upon other theoretical frameworks (unlike Grounded Theory) to inform the interpretations of the material shared by the participants (Willig, 2001).

Each transcript was read and re-read before themes were identified. The themes were then revised and refined. Relationships with other themes were also considered and established where possible. The themes for each transcript were then grouped in cluster themes. The cluster themes for each transcript were then compared and integrated with the other transcripts in order to generate superordinate themes. See Appendix XII for sample of transcript, sample of individual cluster summary and summary table of cluster and superordinate themes. These superordinate themes were checked against each

transcript to ensure their grounding in data (Willig, 2001) and these were used to create an account of the experience of growing up with a sibling who has a learning disability.

Credibility check

The draft Finding section of this paper was sent to each participant to do a ‘credibility check’ (Elliott, Fischer, & Rennie, 1999). Participants were asked to comment on the representation of the subject matter to ensure that the analysis has yielded an account that they can identify with. The aim of the study is not to produce an accurate, definitive account of each participant’s experience but rather it aims at co-constructing an account between all the participants and the researcher (Osborn & Smith, 1998). It also helps to ensure that the study has good external validity.

Regular meetings were also held with supervisors during the analysis. The content of the interviews was examined and discussed during those sessions. Supervisors were able to question, challenge and scrutinise the emerging themes as the analysis was proceeding.

Reflexivity

My primary interest in this research project is the sibling relationship as opposed to a specific interest in learning disability. I have an older brother, who is not disabled, and our relationship as children was not always good. During my undergraduate and graduate studies in psychology, I have always been surprised and intrigued that siblings were often not discussed in developmental psychology. This sparked off my interest in sibling relationships.

I have worked in the caring industry for five years as a care worker and as a care agency manager. I worked with people who had severe physical disability and learning disability. This gave me some insight into the lives of people who lived with disability and also a direct experience of the impact of the disability on their family. What I witnessed was not always positive and was, at times, plainly disturbing. This meant that I approached this project with some negative ideas about what the experience of growing up with a sibling might be like.

Findings

Four superordinate themes emerged from the analysis: 'normal within the family', 'guilt & self-consciousness', 'subordinated needs' and 'improving the disability and promoting independence'.

Normal within the family

This superordinate theme appeared for all participants in one form or another. During childhood, unless the sibling is much older than the child with the disability, both children will have a similar mental age and as such there are no differences between them. Even if the disabled child has physical traits associated with the disability, as in Down's Syndrome, these appear to be seen as part of the physical appearance of the child and accepted as such by the non-disabled sibling.

“we just used to do lots of silly things together, you know, we were/ you know/ more on a same sort of plain and, you know, more/ I suppose like we were the same age, almost” (Clare, 50-53).

“ we bought him a teddy and my dad was saying ‘oh, you should name it for him’ and I said ‘oh, we should call him’- it’s really bad- ‘we should call him Chinky ‘cause he looks like a Chinese baby’ and so I kept going on about this not knowing” (Hannah- 102-105).

The invisibility of difference appears to be especially true when the disabled child is an infant. Both children are young and appear to function at the same level. The parents might not even be aware at that stage that one of the children has a learning disability.

“Um well actually when he was born no one knew anything was wrong with him and he came home and he was fine” (Ann, 62-63).

Many participants only realised that their sibling had a disability when they reached school age and their sibling was sent to another school. Going to a different school highlighted the difference between them and their sibling in a very clear manner. Even when the sibling attended the same mainstream school, the difference is made obvious through the need for extra classroom support. It is at that stage that many realised their sibling was disabled.

“I suppose in terms actually realising it would have been at school, erm, and probably when she started school because she went to a different school in the area where I lived everyone tended to go to the same primary school” (Vicky, 66- 68).

For other participants, they came to realise that their sibling had a disability because of long hospital stays or because of their parents’ reactions.

“I knew something was wrong with him because, just because of the fact that he was in hospital for such a long time” (Ann, 70-71).

“my mum was crying all the time and um the number of visitors, you know, being kind of hurried into the sitting room and it being very hushed and me being told to, to go out and play” (Julie, 107-109).

Even when the non-disabled child has understood that their sibling has a learning disability and goes to a different school, life in the family follows a routine which becomes the norm for that family and forms an integral part of family culture.

“like there were just like routines that we do like Saturday mornings me, my brothers and my dad would go out and do the Saturday morning shop around Hillingdon and then come back and mum would have cooked um lunch and we’d do things like go out “ (Pam, 358-359).

The participants, as they grow up, develop a relationship with their sibling within that family culture. The disability becomes a trait that may characterise their sibling but the relationship is developed with the sibling and not with the disability. The participants relate to their sibling like any other sibling and the extra need for care or support that is required is simply accepted without any further thought. The disability becomes an integrated aspect of the family life and, in fact, fades away from everyday life. The caring and support aspects do remain but it is done to a family member who needs it, not to a disabled being.

When the participants are not in the family environment, the norms are different and the disability becomes visible to other people. It can come as a shock to the participants when the disability is reflected back to them.

“well, actually one person when I took my sister swimming and one person mistook me for her carer I think so, and I find that very difficult to deal with” (Julie, 253-255).

‘Normal within the family’ refers to the invisibility of the learning disability in childhood. The non-disabled sibling does not realise that their sibling has a learning disability because it has always been part of their experience. It is only when they start school and come into contact with children who do not have a disabled sibling that they understand that their sibling is different.

Guilt and Self-Consciousness

This superordinate theme also appeared in all participants’ narratives but often in various contexts. Different situations triggered responses and reactions that led to the same feelings of guilt and self-consciousness.

Guilt

For the participant who is younger than her disabled sibling, the first feelings of guilt were felt when she ‘overtook’ her in terms of development.

“we were the same age, almost, erm, but then/ so that changed/ I sort of became an older sister, which was a bit strange, you know, that’s pretty weird.

M- Yes, you kind of overtook her

Yeah, yeah [pause] definitely, it left me feeling quite guilty and” (Clare, 52-56).

For this participant, the disability had always been invisible, or normal within the family, until the development pace started to distinguish them. Clare had a ‘normal’ family infancy and was suddenly confronted with her sister’s disability in a way she had not felt prepared for.

"I also think because I was [pause] the youngest I did go through that overtaking stage/ I think, erm, I think I certainly did and I continue to take it more personally/ I continue to get more emotionally involved than I think my/ my other sister or my parents." (Clare, 147-150).

Clare felt she was challenging a certain natural order and that by doing so, she was being disrespectful to her sister's integrity. She felt responsible and blameworthy. This was also experienced by Pam, although she seems to feel rather sad than guilty about it.

"I got older and like, things like my birthday parties would change or whatever and Robert would still want to have the same kind of thing" (Pam, 297-299).

Julie was an eight year-old child when her sister was born. She was not in a position to understand what was actually going on and believed that her mother was ill because of something Julie did. She blamed herself for the occurring events.

"I remember thinking that it was something I had done or something in a way that, you know, there was something wrong that I had done in, in some way." (Julie, 121-123).

Although Julie is told that it is not her fault and that her sister has got Down's Syndrome, she felt, in the interview, that she was too young to understand what she was being told and as a consequence, it did not make any sense to her.

"Yeah it didn't mean anything to me. It just, I was taking it as just explanation for what had been going on but it still didn't seem to answer it if you see what I mean, it didn't seem like a right answer to what had been going on." (Julie, 137-139).

Some of the feelings of guilt are induced by the participants realising that their disabled sibling gets more attention, or a different treatment, from the parents or other significant adults than they actually do. This often seemed to create a difficult situation where

resentment was initially felt but immediately followed by feelings of guilt for having such thoughts. For example, Sophie's sister was often paid all sorts of compliments by members of the extended family. Sophie noticed from early on that nothing of the sort was ever said to her, which left her feeling envious but guilty at the same time.

"Jenny's got a learning disability, why/ why on earth am I, you know, competing with this, sort of thing" (Sophie, 588-589).

Although most parents appeared to have treated their children in a fair manner, allowances were made for the sibling with the learning disability. This was sometimes difficult for the non-disabled sibling; they got told off for doing things that were usually ignored when they were perpetrated by the disabled sibling. This puts them in a difficult position as they understood why their sibling did not get told off for doing these things but felt at the same time that they were being treated unfairly knowing that they actually were not. This can lead to unexpressed feelings of guilt.

"I did use to get annoyed about that because then I'd get really cross with him and give him a slap and then of course I'd get told off but he wouldn't because his doing it was part of being autistic" (Kate, 375-377).

This differential treatment was also experienced by Clare.

"I remember just occasionally, erm, thinking, you know, that I got shouted at for doing something wrong and thinking "well, Sarah wouldn't have got shouted at for that" but I never/ I never really believed/ I never really used that as a tactic with them" (Clare, 399-403).

Similarly, sometimes caring for the disabled sibling is hard work not only for the parents but also for the other sibling who can get annoyed or irritated at them. The same

phenomenon occurs here where participants felt that they should not feel like this about their sibling as it is not their fault.

“I’m frustrated and annoyed and but then I can’t really feel like that because it’s kind of like you’re not allowed to have those feelings, you know.” (Julie, 508-510).

Guilt is also felt in relation to the other non-disabled sibling, especially if he or she is the youngest. Participants in this situation are aware that they had a chance to be an only child for a period of time before the others were born.

“I always felt a bit kind of sorry for him because he never really had like a kind of individual childhood because he always just kind of had to go along with whatever we did with Rupert um...” (Ann, 574-576).

Hannah’s non-disabled brother is older than their disabled sibling but she still felt that he lost out more than she did when Anthony was born and diagnosed.

“I think for him all of a sudden all the attention and the emotions and everything kind of went towards Anthony (M: yes) and I think he struggled with that quite a lot really (M: yes) he was, he was ignored at points” (Hannah, 244-247).

For Hannah, leaving home to go to university also triggered feelings of guilt as she was aware that the bulk of the care would now be done solely by her mother. She had always contributed to looking after her younger brother and now this help would be dramatically reduced.

“I knew it was going to be quite a change for her” (Hannah, 444-445).

This was also compounded by the fact that her disabled brother was not able to understand why she was going away.

“I tried to explain that I was going away and he’d be like “you come back in the morning?” “No, quite a few mornings” so that was quite upsetting so... ‘cause he couldn’t get his head around it” (Hannah, 429-432).

Self-consciousness

For some of the participants, as they grew-up, they realised that they have opportunities that their disabled sibling would never have. As they go through what is often regarded as normal stages in one’s development, such as getting a job or getting married, they become aware that the activities they are doing is not something their sibling will ever do. They felt an awkward sense of self-consciousness.

“she never had that, the kind of freedom, I suppose, to explore and do things like I’ve done, just things like learning to drive or leaving out of home and going to university all those sort of things she’s never really” (Vicky, 348-350).

During their teenage years, some of the participants felt exposed in their friendships because of their sibling’s disability. Having experienced, as described above, the disability through the eyes of people outside the family, many participants are wary of the potential reactions their peers might have to someone with a disability and even to someone related to an individual with a disability. If they want to invite friends around, many felt that not only the friends have to be ‘vetted’ but they would have to give some sort of explanation about their disabled sibling, which had the effect of making them think twice before asking a friend to come over.

“I suppose in the back of my mind there’s always been like if someone is coming over like when I was younger there, there was always that ‘Oh well they have to meet Robert’” (Pam, 404-406).

For one participant, a safe way of introducing her sibling to friends was by describing his eccentricities.

“pick out the things that were funny or fun... do you know what I mean? So that, so that... our friends thought, thought that he was a character or do you know what I mean?” (Kate, 295-298).

For Ann, she simply felt that she had to prepare friends who were coming over to her place.

“I think I always made an effort to kind of explain things (M- Right.) before, like say a friend was coming over I’d kind of mention ‘Oh my brother...’ blah-blah-blah um so that people were prepared”(Ann, 226-228).

For Clare, the feelings of self-consciousness came as a shock and were traumatic to a certain extent. The event she described happened in the context of a new school she was attending where pupils had to introduce another pupil to the rest of the class. As she was being introduced by her fellow pupil who mentioned the disability, it suddenly dawned on Clare that most of the children in the room did not have a disabled sibling. Her sister’s disability had always been part of the family’s normal life but now she felt exposed and stigmatised.

“I remember feeling [pause] very sort of vulnerable and sort of pensive when she, erm, when my friend sort of announced this to the class everyone was like “oh, what’s that?” you know, and I just/ you know/ it was all too much” (Clare, 187-190).

For two of the participants, the theme of bereavement also emerged. Although expressed differently from guilt and self-consciousness, it appears to be related. In this theme, the participant does not experience guilt as such but in her feelings of self-consciousness,

there is a great sadness that her sibling will always be disabled and will never be able to achieve what she was able to achieve. Hannah described a sense of ‘continual bereavement’ that she witnesses in her parents as well as feel herself.

“/ I watched my mum kind of get over the fact that he was never going to do certain things but then they get to certain landmark ages and they’re still not doing certain things “ (Hannah, 233-234).

Later in the interview, she expresses this same sense of bereavement witnessed in her parents and the effect it has on her. She appears to feel some guilt in her awareness that his childhood is going to be nothing like hers was.

“he wasn’t going to have the same benefits that I had (M: yes) so might as well make his childhood as fun as possible I suppose ‘cause he didn’t have the same number of friends around and things like that.” (Hannah, 352-355).

There is a sense of a great sadness, a continual bereavement, which stems out of her feelings of self-consciousness.

“ everybody else looks at him and thinks he’s not going to be able to do this and you kind of feel for him more than maybe he feels for himself I think/” (Hannah, 867-869).

Clare also expressed some similar feelings about her sister. When she became a teenager and understood more about her sister’s disability, she also felt this sadness for her but without understanding why. This seems to suggest that there was also a certain bereavement process occurring for her.

“when I was about thirteen I/ I felt, you know, really strangely about her/ I felt very, very protective/ extremely protective, extremely defensive, very sort of/ I didn’t really feel angry about/ but I felt very sad, really sad when I thought about her” (Clare, 172-175).

In summary, guilt refers to feeling at fault or blameworthy, often for the disabled sibling's situation or condition. Self-consciousness refers to the feelings of self-awareness induced in the non-disabled sibling in situations where the disabled sibling is at a disadvantage or is felt to be at a disadvantage. Self-consciousness involves feelings of guilt but these are generally triggered by external events.

Subordinated Needs

This superordinate theme appeared in most of the participants' interviews. For example, Hannah felt that some of her friends were able to spend time doing activities with their mothers, which is not something that was available for her. She understands the reasons why her mother could not devote as much time to her as to her disabled brother, but at the same time she seems to feel that she has missed out on something.

"I mean some of my friends went away with their mums and things and I've never done that (M: Hmmm) because I think my mum feels that her primary responsibility is Anthony probably because/" (Hannah, 659-662).

For most participants, they were able to observe that their disabled sibling did need more input than they did themselves.

" she had all these professional/ different appointments and all that sort of things and so I suppose just generally there was a lot more going on around her than there was necessarily going on around me" (Vicky, 286-288).

They might not have felt deprived as such but they had to learn to cope in a different way, like Kate and her non-disabled sister did.

"Usually me and my sister we were quite close so we'd... we'd just kind of... play together and mum would look after him and that was fine because... you know, we kept each other entertained" (Kate, 207-209).

Hannah was able to cope with her disappointments because she understood the significance of her brother's appointments. She nevertheless had to avoid thinking about it.

"I think as a child you probably pick up on some thing like that with an able bodied brother but I think/ I can remember thinking [pause] but then I knew that it was important enough to kind of not" (Hannah, 679-682)

They learnt a certain form of resilience and found other ways of meeting their needs. For other siblings, such as Sophie, the extra attention her sister received created some sort of discomfort in her. It seemed that her family felt sorry for her disabled sister and tried to boost her self-esteem by praising her. With this kind of logic, Sophie did not need praising as she was not disabled. But Sophie noticed the absence of compliments directed towards her and she felt inadequate as a result.

"I remember being younger and my grandparents always making comments about how lovely Jenny is and stuff but I'd never have anything that was on how nice my personality was." (Sophie, 569- 572).

Vicky also noticed that her sister needed more attention than she did and found herself competing with her at times. She also showed some understanding as to why she was not getting as much attention as her sister. This enabled her to find her own way of getting attention from her parents.

"I was quite academic at school and worked quite hard and I think that was probably my other way of getting/ you know, my way of competing for the attention to a certain extent" (Vicky, 294-296).

Having a sibling with a learning disability often meant that their share of parental input would be greater than that of the other siblings. It also meant, as for Hannah, that certain responsibilities were expected from the non-disabled children. Hannah felt that she had to behave herself as she felt that her parents would not have had time to deal with her. It also meant that some activities were restricted.

“we had to almost/ felt like you had to behave a bit better because they don’t have time for that” (Hannah, 622-623).

Clare had similar experiences. She learnt from early on that there was no time in her family to think about herself and who she was. Home life revolved around caring for her sister and school life was about schoolwork; there was little time for anything else.

“/ went without saying that I had to be considerate of what/ what the whole family and what Sarah was doing and that was just natural/ (...) every single spare moment in my family was devoted to Sarah and at school it was school work/” (Clare, 418-426).

Clare’s early experience is different to that of her two sisters. She knew that her mother had a close relationship with her eldest sister, who is not disabled, and with her middle sister. The disability was diagnosed before Clare’s birth and when she was born, her mother’s hands were already full.

“by the time I came along she didn’t really have time to do it with me/ but I don’t remember that ever being a problem (M- right) ‘cause I was always very independent and fit, you know.” (Clare, 392-395).

Clare had to learn from early on to look after herself and was left to her own device. She did not see it as a problem but one can question whether her feelings of being independent were genuine or simply those of a child who did not always have the care

she needed. Later on in life, Clare suffered from anxiety, depression and harmed herself at times. When she needed help from her mother, it was a new experience for both as she had always been cast in the role of the self-sufficient child.

“I was thinking these awful thoughts and/ and, erm, she sort of laughed it off/ it was all/ because you know/ because from her perspective I’d always been this really easy going child/” (Clare, 614-617).

In her second year at university, things deteriorated for Clare. Clare’s expectation for help was not high. She described herself as being in a serious state but suggests that it took a long time for her parents to acknowledge it. When they finally did, they were not there for her but “at the end of the phone”. They did not come to see her or asked her to come home, but simply suggested that she went to see a doctor or someone. Clare had to cope on her own as her parents were not available to her.

“And my/ my parents were great, you know, once they finally realised that something wasn’t right/ they were at the end of the phone and they were trying to help (...)but there was only so much they could do and, you know, they sort of said “you’ve got to go and see the doctor” (Clare, 629-633).

In summary, ‘subordinated needs’ refers to a sense of the disabled sibling being a priority for the parents or the focus of more attention from the parents and family. The participant’s needs have to take a second or third place.

Improving the disability and promoting independence

This superordinate theme is also common to most participants. It refers to a desire to make the sibling less disabled by improving their skills and abilities.

For example, Hannah knows that if her brother is not stimulated, the disability becomes more apparent in his play. She feels her parents should do more to stimulate him.

“do quite repetitive play if he’s left on his own now [pause] so I think they kind of thought that they need to get more involved and that kind of makes me a bit sad even now really/ he does/ he does spend quite a lot of time on his own” (Hannah, 606-609).

She is aware that the time she invests in him will help him and feels a certain responsibility for stimulating him as she feels that if she doesn’t do it, nobody else will.

“if you let Anthony on a blanket he would lie there for hours... he wouldn’t move and so you kind of felt that it would be better to stimulate him then have him lying there” (Hannah, 324-326).

Sophie experienced similar frustrations; her sister was too able for her special school but not able enough to attend mainstream school without adequate support. This support was unfortunately not available when she tried to attend it and she had to be removed after two months.

“but there wasn’t any support for anybody, erm, you know, that was/ she was straggling behind I suppose, erm, so that only lasted a couple of months” (Sophie, 142-144).

Hannah also realised that without the means to get private care, the amount of help available was limited and that had an impact on her brother’s disability. More physiotherapy and better speech therapy would have maybe made him more functional; this is significant for Hannah as she knows that one day she will be more involved in his care. This also makes her critical of her parents who might have become more indulgent in their care.

“I might end up being more involved in his care again/ I kind of want him to have as much independence skills as possible [pause] but my parents I think are quite [pause] it’s

easier to do his buttons up for him than wait for him to do it ten minutes” (Hannah, 554-558).

Similarly for Kate, the family had developed the habit of doing things for her brother that he was perfectly capable of doing himself, as it was later on discovered by school. In this extract, Kate is talking about putting his clothes on.

“actually when he went to school it turned out he was perfectly (laughing) capable of doing it himself but he... he’s always wanted if there’s someone to do it for him then and someone does it for him he lets them” (Kate, 214-217).

Like some other participants, Kate realised that her family had the potential of making her brother more disabled than he actually was. This is a significant point for many of the participants who, like Hannah realised, might have to take over the care of their sibling when the parents are no longer able to. This possibility, combined with the feelings of guilt and self-consciousness, often pushes the participants to do as much as they can to help emancipate their disabled sibling. They are aware that the norm within the family might actually have the effect of maintaining their sibling in a state of dependence and passivity. Some of the participants felt it was their duty to bring new challenges to their siblings and help them separate themselves from the parents.

Ann has this attitude with her brother Rupert.

“ he’s never going to get more independent because he’s being kind of mothered and I don’t think he ever will at, in the home environment, he won’t unless like mum and dad steps completely away from it” (Ann, 612-614).

To sum up, ‘improving the disability and promoting independence’ refers to participants challenging the ‘norm within the family’. Most participants realised that the care the

siblings receive from the often aging parents is keeping the sibling in a dependent and disabled position. They feel it is their responsibility to broaden their sibling's horizons.

Credibility check

Participants were sent a draft of the above section of the project and were invited to send comments. Four participants sent feedback, all of which was very positive. They generally expressed that the analysis made sense of their experience and brought a new meaning to it. Kate's feedback provides a good summary of the feedback received:

I found it really interesting to read and found I could relate directly to what a lot of the other interviewees talked about in terms of their feelings and experience. The analysis made a lot of sense to me as well and it was even quite helpful in making me recognise more about reasons behind some of my feelings when I was younger and even now (sometimes it's hard to analyse your own feelings because they're too close!).

Discussion

The superordinate themes that have emerged from the analysis can be conceptualised graphically (See Figure 2).

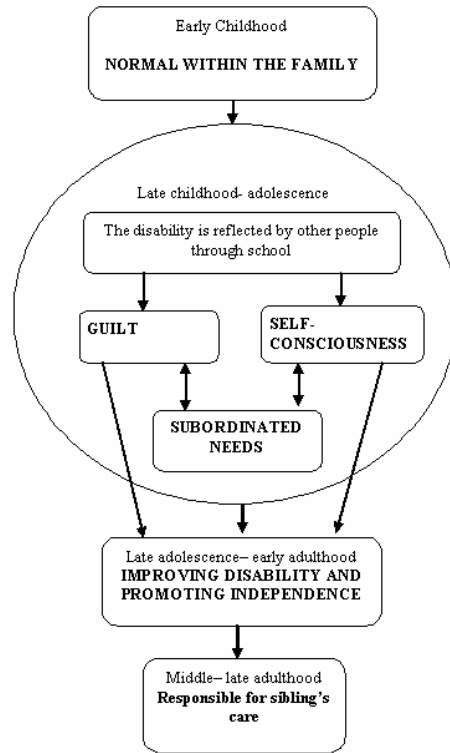


Figure 2- The process of growing up with a sibling who has a learning disability.

The graph shows that the superordinate themes can be arranged into chronological order. In early childhood, the disability remains invisible as it is an intrinsic part of family life. It is 'normal within the family' and does not appear to raise any concerns for the children. This seems to contrast significantly with the parents experience as reported in the literature; the parents will often feel various confused feelings such as joy of having a new-born child combined with shock, anger, denial and grief (Burke, 2004; Frude, 1991; Knight, 1996). As Burke reports, the parents will go through a period of adjustments

similar to those identified with loss or bereavement. It would appear that the parents managed to shield their children from the conflicting emotions of having a new child with a learning disability.

Later in childhood and early adolescence, the family norm becomes challenged as the sibling with a learning disability is often sent to a different school. This is how most participants realised that their sibling was different. Understanding that people outside the immediate family have a different perception of their sibling may contribute to the feelings of self-consciousness described by the participants. In terms of development, adolescents acquire the capacity to see themselves in a physical and social context (Fonagy & Moran, 1991); they realise that other people will have a perspective different to theirs and the capacity to judge positively or negatively their circumstances (Light & Oates, 1990). In other words, teenagers lose their egocentricity and become self-conscious.

Having a sibling who has a learning disability made the participants feel self-conscious and vulnerable in various ways. Dyson (1996) found that siblings are reluctant to bring friends over as they fear embarrassment by their disabled brother or sister. This was certainly experienced by several participants and was also consistent with other studies which have shown that non-disabled siblings do not usually share the fact that they have a disabled brother or sister with people outside the family (Atkinson & Crawford, 1995). Burke (2004) also observed, in his qualitative study, that siblings are acutely aware of the

differences between them and their disabled brother or sister, especially during family outings.

Another aspect of these feelings of self-consciousness occurs as the non-disabled sibling reached significant life stages and realised that their sibling would never get there. This does not appear to have been researched in the current literature; studies have been published where the non-disabled sibling's self-concept was examined using discreet quantitative measures (e.g. Dyson, 1996) but these only referred to how the children perceived themselves. This reflects the fact that most of the studies on siblings of disabled children, so far, have focused on behaviours, reactions and adaptation and thus leaving out other aspects of the experience (Sanders, 2004).

Feelings of guilt can also occur at this stage. It can be triggered by various situations faced by the non-disabled sibling. Research has indeed supported this finding; children's responsibilities for their disabled sibling can result in feelings of anger, resentment and self-reproach (Seligman, 1991). This is a significant difference with families where there are no children with disability; as the siblings get older, their relationship will reach a more equal status (Del Rosario & Keefe, 2003), whilst in families where there is a disabled child, the non-disabled sibling's role will permanently change to that of an 'older brother or sister'. The change of role has been discussed by some researchers (e.g. Farber, 1960) but more in terms of forming a new relationship and generating conflict rather than guilt.

Research has shown that greater levels of differential treatment occurred in families where there is a disabled child (McHale & Pawletko, 1992) and this was certainly reflected in all the participants' families. Participants had to learn from early on to cope on their own and develop some sort of resilience. Others, like Clare, developed lower self-competence and internalised her difficulties (Wolfe, Fisman, Ellison, & Freeman, 1998). These findings were all consistent with research. For example, Burke and Montgomery (2000) found that families found it difficult to do activities together and that the parents had generally less time for the other siblings because of their caring responsibilities for the disabled child. As a consequence, the non-disabled sibling received less attention. "Putting others before one's self is somewhat routine for siblings who care for their disabled brother and sister, and who minimise their own needs to their parents." (Burke, 2004, p.82).

In late adolescence and early adulthood, participants saw it as their responsibility to challenge, again, the family norm by wanting to improve the sibling's disability and promote their independence. . Little is known about the role of siblings over the life span of their sibling with a learning disability and most of the existing research appears to have focused on taking the role, or not, of principal carer once the parents have died (Rimmerman & Raif, 2001). There is indeed a certain social and parental expectation that the non-disabled sibling will take over the care of their disabled brother or sister, regardless of their feelings towards them, once the parent have passed away (Schatz, 1983). For most of the participants, they were keen on confronting the family norm as they realised that it had the potential of making their sibling even more disabled if left

unchallenged. This seems to be especially significant as many were aware that they would become one day responsible for their sibling.

An unexpected result came from the recruitment process: only female respondents volunteered for the interview. Four of the participants had non-disabled brothers and they were all asked to enquire after them to see whether they too would be interested in taking part. Although there is no way of checking whether the message was passed on or not, none of the participants' brothers made contact. This might be a reflection of gender attitude towards care; indeed, for some, but not all, of the participants, there were suggestions in the interviews that parental demands for help were greater for the non-disabled sisters than for the non-disabled brothers. There are certainly differences in the way sisters interact with their disabled siblings compared to the way brothers interact with them in terms of playing and spending time with them (Stoneman et al., 1987). Furthermore, the data gathered also suggested that participants were significantly more involved in caring for their disabled sibling than were their non-disabled brothers. McHale and Gamble's (1989) findings suggest that girls spent twice as much time daily as boys in care activities with their disabled sibling. This might also be a parallel reflection of the amount of care mothers generally provide to their disabled child compared with fathers (Kotelchuk, 1976) and thus create gender specific role models.

The analysis of the transcripts produced superordinate themes that reflect the experience of growing up with a sibling that has a learning disability. The process of analysis also revealed an aspect of the experience that is not reflected by the literature. The literature

on the impact of growing up with a sibling who has a learning disability constantly debates the 'positive' and 'negative' impacts of the experience. This is something that appear totally alien to the participants; they had only one experience of growing up and it happened to occur with a disabled sibling. The concept of positive or negative impacts was irrelevant to them; they all loved their sibling and as with any other type of relationships, there are good aspects and not so good aspects. Diminishing their experience to positive or negative impacts seemed simplistic and unfair to all of them.

There are clinical implications to the findings highlighted by this study. The first superordinate theme shows that for young children, the disability is invisible as it is part of their everyday life. This suggests that clinical interventions at this stage for these children might be of limited value. Support might be more appropriate when the non-disabled sibling begins school or when they move on to senior school. The findings discussed in this study show that for most participants, this was a difficult period, which would have warranted more support or interventions to help them develop the skills to manage this transition. This is where sibling support groups might help as they can provide a supportive forum for the siblings who might be, for the first time, in a group where they are not different from others. Research on sibling support groups by Burke (2004) showed that such groups can help participants dealing with their anxieties and alleviate their feelings of guilt, self-consciousness and might also help with the feelings generated by not being a priority in the family. Finally, when professionals are working with people with learning disability who have siblings in their late adolescence or early

adulthood, they should consider including them in their dealings with the parents as they might be more receptive to new ideas and projects.

The sample containing only female participants is a significant limitation to the findings of this study. The experience of brothers of disabled sibling is likely to be different from their sisters'. There are other significant limitations to the sample, which affect the transferability of the findings; not only were all the participants self-selected females, but the majority were from relatively affluent middle-class backgrounds. They were all educated to graduate level or above and six out of the eight were in psychology-related professions.

The interview schedule used in this study might have had an influence on the participants' perception of their experience. The schedule was designed to start with questions that were relatively easy to answer in Part One followed by questions about the nature of the disability in Part Two. Part Three focused on the experience of growing up with their sibling. This sequence of questions might have led the participants to focus more narrowly on the disability rather than on the sibling. This would need to be addressed in future research projects.

These limitations highlight the need for further research in this area. The same study could be replicated with different samples; for example, it would be interesting and useful to conduct this study with a male sample and proceed to compare and contrast the two sets of findings. Interviewing participants from different socio-economic background

would also contribute in making the findings more transferable. This study examined siblings with learning disability; a similar project could be replicated with people who have a sibling with a physical disability. Qualitative research projects are rather scarce in this area and more are needed to help us improve our interventions when working with such families.

Conclusion

Relationships between siblings where one child has a disability differs from sibling relationship where there is no disability (Stoneman, 2001). This does not mean however that they are any different in terms of love and friendship or rivalry. As the participants in this study have demonstrated, the disability influences the dynamics in the family and magnifies certain aspects of a 'typical' sibling relationship.

It was the aim of this study to illuminate the existing research on the impact of growing up with a sibling who has a learning disability. The experience has some positive and negative sides but the non-disabled sibling cannot be understood or thought about in isolation, as if they were not part of a family with a certain history and context. Further qualitative studies are needed to investigate and shed more light on this reality.

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Public Domain Briefing Paper

The experience of growing up with a sibling who has a learning disability

Marc Desautels

Outline

This study formed part of the thesis for the degree of Doctor of Clinical Psychology (Clin. Psy. D) at the University of Birmingham. The research benefited greatly from the support and supervision provided by Dr Gary U. Law and Dr Biza Kroese. A literature review on the role sibling relationships play in the development of emotion regulation (how we learn to manage our emotions) was also completed as part of the course requirements.

Background

Sibling relationships are amongst the most unique type of relationships human beings can ever experience in that they are potentially of longer duration than any other relationships one can experience. Even when the siblings have not seen each other for decades or have poor relationships, being a brother or a sister remains part of their identity. Now that fewer children with learning disabilities are institutionalised, they grow up with their brothers and sisters and spend more time together than in previous decades.

Growing up in a family where one of the children has a learning disability is different from being in a family where no one is disabled. There is a certain body of literature

that explores this reality. The studies in this area have relied on qualitative methodologies that have looked at specific issues, such as psychological adjustment, well-being, behaviours and other similar discrete variables. Their outcomes have been varied and contradictory as they measured different aspects of the experience and it is therefore difficult to draw conclusions from them.

Aims of the study

The aim of this qualitative study is to provide a structured account of the experience of growing up with a sibling who has a learning disability and attempt to develop a model that gives an insight into the phenomenology of the experience. The model has implications for clinical practice.

Method

Semi-structured interviews were conducted with eight female participants. The transcripts from the interviews were analysed using Interpretative Phenomenological Analysis (IPA). This was deemed to be the best method as IPA focuses on the actual experience of the individuals and how they make sense of it. It also provides a structured way of conducting the analysis.

Analysis

Four superordinate themes emerged from analysis: ‘normal within the family’, ‘guilt and self consciousness’, ‘subordinate needs’, and ‘improving the disability and promoting independence’.

Normal within the family refers to the invisibility of the learning disability in childhood. During this period, unless the sibling is much older than the child with the disability, both children will have a similar mental age and as such there are no differences between them. The disability is part of the individual’s family life and culture and a certain normality is experienced within the family. It is often through interactions with other children at school that the non-disabled brother or sister realised that their sibling was different.

Guilt refers to feeling at fault or blameworthy often for the disabled sibling’s situation or condition. For example, guilt might be felt when non-disabled siblings would like more parental attention but know that their disabled sibling has a greater need than them. Self-consciousness refers to the feelings of self-awareness induced in the non-disabled sibling in situations where the disabled sibling is at a disadvantage or is felt to be a disadvantage. Self-consciousness involves feelings of guilt but these are generally triggered by external events. For example, non-disabled siblings can feel self-conscious when they take part in activities that their disabled sibling cannot do.

‘Subordinate needs’ refers to a sense of the disabled sibling being a priority for the parents or the focus of more attention from the parents and family. The participant’s needs have to take a second or third place.

The last theme to emerge was ‘Improving the disability and promoting independence’. This theme refers to a desire to make the sibling less disabled by improving their skills and abilities. It also refers to participants challenging the ‘norm within the family’ as most participants realised that the care the siblings receive from the often ageing parents is keeping the sibling in a dependent and disabled position.

Conclusions

The superordinate themes that have emerged from the interviews can be conceptualised into a graphic process (See Figure 1) which can be used to derive implications for clinical practice. For example, it could be suggested that the use of support groups for non-disabled siblings might not be needed for young children, as having a disabled sibling is ‘normal within the family’. Sibling support group would be more appropriate when non-disabled siblings reach adolescence and begin to experience feelings of guilt and self-consciousness. A support group that enables them to express themselves amongst people who share a similar experience might help to alleviate the feelings of guilt and self-consciousness.

The findings of this process also highlight that participants do not see their experience with their sibling in terms of positive or negative. Each experience is unique and has good and difficult aspects, just like any other sibling relationship. Labelling the experience as positive or negative appears simplistic and stigmatising.

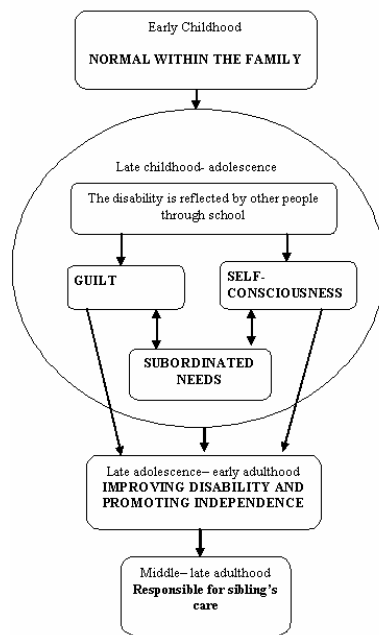


Figure 1- The process of growing up with a sibling who has a learning disability

Contact Details

Marc Desautels, [Address]

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APPENDIX I

Letter of ethical approval

March 5, 2007

Marc Desautels
2nd Year Clinical Trainee
School of Psychology
University of Birmingham

UNIVERSITY OF
BIRMINGHAM

School of Psychology

Dear Marc,

Ref 30/06

Many thanks for your response to the concerns of the School Research Ethics Committee (dated February 20). I am satisfied that you have appropriately responded to the concerns raised and am happy to grant chairman's action for approval.

Please do bear the following points in mind as you conduct your investigations:

1. Ethical conduct of the study remains your responsibility. Once investigations begin unexpected issues can arise and you are encouraged to think again about the situation of your participants.
2. You are free to make modifications to your procedures, without further ethical review, so long as you remain confident that your new procedures do not raise any general ethical problems or particular violations of BPS guidelines.
3. If funding is provided by the ESRC then outside review is mandatory from January 1, 2006. A Birmingham wide REC has been created for this purpose and will soon begin to accept applications.

If you have any questions or further issues arising then do not hesitate to contact me. I wish you the best of luck with your research.

Yours sincerely,



Stuart Derbyshire
Chair: School Human Research Ethics Committee

Copy to: Dr Gary Law

P.S. Please address any correspondence regarding your proposal to Dorothy Trinder, pigeon hole in Hills or Hills Box in Frankland

APPENDIX 2

Participant Information Sheet

The experience of growing up with a sibling who has a learning disability

Thanks you for your interest in this study on the experience of growing up with a sibling who has a learning disability. I would like to invite you to take part in the study by taking part in an interview.

The aim of this study is to examine and provide an insight into the experience of people who grew up with a sibling who has a learning disability. Current literature on the topic shows that it can be a difficult experience, but also can have some positive influence in terms of personal development. The findings of the study will hopefully help professionals dealing with families where there is a disabled child and where there are also siblings to take into account their needs and provide the support they might require.

I understand that you have grown up with a brother or a sister who has a learning disability. This is why I am contacting you. Firstly, keep in mind that you do not have to take part in this study. If you decide to take part in the study, you will be free to withdraw from the project at any time up to a month after we have completed the interview. Just let me know. I will not ask you why nor put any pressure on you to carry on with the study.

The process is simple; I would like to take a maximum of two hours of your time to conduct an interview. I do not intend on asking you a series of questions but rather ask you to tell me about your experience of growing up with a sibling who has a learning disability. It might feel more like a normal conversation rather than a formal interview. I understand that some of the information you will share with me has the potential to upset or distress you by reminding you of difficult times you have had during that period. If you wish to stop and have a break, please feel free to do so at any time.

Similarly, if there are any questions in the interview you are not happy to answer, just let me know and we will move on to the next one. Again, I will not ask you why or put any pressure on you.

The interview will be recorded digitally and once the interview is completed, the audio file will be downloaded onto computer. Your file will be given a code only known to the research team. This material will then be transcribed. All names and information that could identify you in the transcript will be removed or changed to ensure your anonymity. Once the digital recording has been transcribed, the audio file will be kept for five years after the completion of the study. The transcripts will be printed and kept in a locked cabinet. The transcripts will also be password protected and will be kept on computer. They will be destroyed five years after the completion of the study. Once the transcription is completed, I will send you a copy of the transcript. My copies of the transcript will be destroyed five years after the completion of the study.

Once we are done with the interview, we will have time to talk about the interview and your reactions to it. This debriefing session will not be recorded. This will give

me an idea of how you are feeling and point you to sources of help or support if you feel you need it.

Once I have completed the analysis, I will get in touch with you again to discuss my findings. This is to ensure that what my analysis has shown is actually what you think it should say and agree with. This will be done over the telephone and should only take a few moments.

After my analysis is completed and after I have been in touch with you, I will write up my final report. Direct quotations from the interviews will be used in the report; I will ensure that I do not use too many quotations from the same person in order to keep the material as anonymous as possible. There will, however, remain a very small risk that you could be identified through one of your quotations.

Finally, you are more than welcome to ask me any questions about the study at any time. I would also like you to be aware that I am a member of the British Psychological Society and abide by their code of ethics with regards to practice and research.

My contact details are:

Marc Desautels

[Address]

[Email:]

[Tel:]

My supervisor's details are:

Dr Gary U. Law

[Address]

[Email:]

[Tel:]

APPENDIX III Inclusion Criteria

The experience of growing up with a sibling who has a learning disability

Inclusion criteria:

1. To be aged between 18 and 30;
2. To have lived for a significant period of time during childhood and adolescence in a household where a sibling with a learning disability also lived;
3. You have not lived with your sibling for more than a year;
4. To be part of the same family (biological or social) as the sibling with the disability;
5. Your parents were the main carers for your sibling;
6. Your sibling must have a learning disability and significant care or support needs;
7. The family might have received help from statutory agencies (e.g. Social Services) but did not receive help from charitable organisations;
8. You should not be disabled yourself;

Participants should be between 18 and 25 years of age. The study is interested in looking at the recent experience of late teenagers and young adults who grew up with a sibling who had a learning disability. People who are currently living with the sibling should be excluded as they might still be involved in the care of the sibling; they might not be able to adopt a position that enables them to reflect on their experience. The experience should still be fresh in participants' memory and therefore young adults and late teenagers are targeted.

Participants should have lived for a significant period of time during their childhood and adolescence with the disabled sibling. If the sibling was in care outside the home, participants should be excluded as they will not have grown up with the sibling. Similarly, the sibling should be part of the same family where the participant grew up; participants who have grown up in families that provided respite care or foster placements cannot be included. Participants who were in families where full-time care staff was employed should also be excluded.

The sibling should have a learning disability and require care. The learning disability should be significant to severe. This is to ensure that the disability will have been severe enough to have an effect on the family dynamics. Participants' family might have received help from statutory agencies but not from charitable organisations. Help provided by charitable organisations is not available everywhere whilst statutory help usually is; this exclusion criterion will help to ensure that the findings of the study are transferable.

APPENDIX IV Consent Form

Title of Project: The experience of growing up with a sibling who has a learning disability.

Name of Researcher: Marc Desautels

I confirm that I have read and understand the information sheet dated (version) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

I agree to take part in the above study.

Name _____ Signature _____ Date _____

Researcher _____ Signature _____
Date _____

Name of Person taking _____ Signature _____ Date _____
consent (if different from research)

APPENDIX V Interview schedule

Part One

Can I first ask you:

Your age:

Your gender:

Ethnic origin:

Where did you grow up:

Number of siblings:

What is your birth order?

Is your disabled sibling older or younger?

What is their birth order?

What is the age difference between the two of you?

Part Two

Could you please describe the nature of your sibling's disability?

How old were you when you realised that your sibling was different?

What kind of care did your sibling require?

What was your input in their care routine?

Part Three

How do you think growing up with a sibling who has a learning disability affected you? (e.g. relationship with parents, friends, relationship with sibling, leisure activities, etc.)

What were the negative aspects of the experience?

What were the positive aspects of the experience?

Part Four

What is your relationship with your sibling like?

APPENDIX VI Text for advert in The Psychologist and Therapy magazines:

I am looking for people who have grown up with a sibling who has a learning disability to take part in an interview about their experience to complete my doctoral thesis in clinical psychology. If you are between the ages of 18 and 25 and no longer live with your sibling, I would be interested to hear from you. If you are interested, please contact me, Marc Desautels, on [Email:] or call [Tel:].

APPENDIX VII Advert for university campuses

LEARNING DISABILITY

I am looking for people who have grown up with a sibling who has a learning disability to take part in an interview about their experience to complete my doctoral thesis in clinical psychology

. If you are between the ages of 18 and 25 and no longer live with your sibling, I would be interested to hear from you.

Please contact me, Marc Desautels, on
[email address].

APPENDIX VIII Help and support available to siblings

Counselling

The British Association for Counselling and Psychotherapy (BACP) has a website where you can access a register of counsellors and therapists working in your area. The website is www.bacp.co.uk . Most of the therapists listed on this website charge for their services.

If you are a student at the University of Birmingham, there is a counselling service free of charge which you can access by calling 0121-414-5130. They provide short-term one-to-one help and also run a series of support groups.

If you are a student at the University of Leicester, there is also a counselling service free of charge which you can access by calling 0116 223 1780 or emailing counselling@le.ac.uk.

Voluntary organisations

The British Institute of Learning Disabilities (BILD) offers training and support for people with learning disabilities and for their carers. Their website is www.bild.org.uk and they can be contacted by phone on 01562 723 010 or by email on enquiries@bild.org.uk .

SIBS is for brothers and sisters of people with special needs. They run workshops and conferences on sibling issues throughout the UK; produce fact sheets on sibling issues for siblings, parents and professionals; maintain a website on sibling issues; set up networks of adult siblings; provide training for professionals working with siblings; listen to siblings, parents and professionals on the phone and give tips for dealing with sibling issues; raise public awareness of sibling issues; find out what really makes a positive difference for siblings and let people know about it. You can find their website on www.sibs.org.uk , call them on 01535 645453 or email them on info@sibs.org.uk .

Crossroads- Caring for Carers is a nationwide charity which support people who are caring for a relative, partner or friend, including young carers under the age of 18. Amongst the services on offered, they can provide a carer support worker who can look after the person with a disability on a regular basis thus giving a weekly break to the relative, partner or friend. Their website is on www.crossroads.org.uk and you can also telephone them to find out about your local scheme. Their number is 0845 450 0350.

APPENDIX IX Transcriber's Confidentiality Agreement

Not included in the web version of this thesis

APPENDIX X- Instructions for Authors British Journal of Developmental Psychology

Not included in the web version of this thesis

APPENDIX XI- Instructions for Authors Family Process

Not included in the web version of this thesis

APPENDIX XII Sample of coded transcript

Sample of a cluster summary for one transcript

A summary like this one was produced for each transcript. A short definition was produced for each theme and then they were grouped in relevant clusters. The themes in each cluster were either left intact or merged as they were listed in a table (see next page) along with the other cluster themes from the other transcripts.

Cluster One

Invisible in babyhood	The disability was not visible when the sibling was a baby.
Normal within the family	The family follows an established routine and the disability does not interfere with it.
Disability reflected by others	People see a disabled individual whilst participant sees her sister.
Disability more visible with age	The disability becomes more salient with age.

Cluster Two

Realising through parental distress	Participant realises that her sibling is not right because of her parents who are constantly upset.
Guilt	Participant, as a child, believes her parents are upset because of something she did.
Diagnosis is meaningless to a child	Although the parents have explained the diagnosis to participant, it does not mean anything and feels guilty.
Self consciousness	Participant is aware that her sister has fewer opportunities in life.
Forbidden topic	There is a covert taboo in the family about the disability. It is a private matter.

Cluster Three

Parental worries	Participant's mother worries about the future and becomes a different person when she is not caring for her disabled daughter.
Shared responsibility	Caring for her sister was an expectation in the family. Participant had more responsibility than her brother though.

Career influence

Participant feels that her sister's disability has influenced her choice of career.

Cluster Four

Guilt

Participant feels frustrated by her sister but feels she shouldn't as her sister will never have the same kind of life as she does. Some feelings have to be contained.

Other Theme

Promoting independence

Participant is keen on promoting her sister's independence.

Cluster themes	Superordinate themes
Invisible in babyhood Invisible in childhood Disabled to others/reflected by others Part of family life Gradual understanding Outside world disabling Normal within the family School as a difference Adapted world Continual bereavement Meaningless diagnosis	Normal within the family
Overtaking Anger Frustration Guilt Self-consciousness Lack of attention Blame Leaving home Not helping enough Able to do more than sibling Feeling vulnerable Fear Managing sibling	Guilt and self-consciousness
Resilience Unmet needs Giving way Relationship with parents Neglect Being ignored Parental distress Unequal treatment	Subordinated needs
Advocacy Fighting disability Disabling environment Investing in sibling Sibling specialist Parenting role Shared responsibility Emancipator Separating agent Frustration Worries Long-term care	Improving disability and promoting independence