UNIVERSITY OF SOUTHAMPTON

Faculty of Medicine, Health and Life Sciences

School of Psychology

Siblings of Children with Disabilities: A critical review of the literature

Rachael Brown, BA (Hons) MSc.

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General Abstract

This review explores the psychological impact of childhood disability on non-affected siblings. Research is considered in relation to components of The Transactional Stress and Coping Model (TSCM). Findings show that siblings of children with disabilities are at risk for adjustment difficulties, although this may be less than traditionally assumed, with positive influences identified. Methodological shortcomings may contribute to the lack of consensus regarding the nature of influence children with disabilities have on their siblings. Further research should include siblings' views and the high variability in psychological adjustment outcomes needs to be investigated.

The empirical paper investigates the psychosocial impact of childhood disability on typically developing (TD) siblings, comparing parent and sibling accounts. Differences in siblings of CWD and siblings of TD children are assessed in terms of the quality of sibling relationships and helping behaviour. Results of this study replicate findings that siblings of CWD are at risk for psychological adjustment problems as indicated by their parents. However, self-report did not suggest such differences. Findings indicate that siblings of CWD offer more emotional and custodial care to their sibling and the relationship may differ when one sibling has a disability in terms of greater power of the TD child and lower levels of conflict in these families. Only severity of disability was associated with parent rated adjustment. These findings confirm the importance of including sibling self reports and suggest factors other than helping behaviour and quality of the sibling relationship may affect adjustment.

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Literature review:

Throughout the literature review, siblings of children with a disability or chronic illness will be referred to as 'siblings'.

In discussing children who have a disability or chronic illness they will be referred to as 'Child with disability' or CWD.

Control groups refer to typically developing sibling dyads.

Empirical Paper:

The sibling who participates in this study and has a brother or sister with a disability will be referred to as Sib^d

The sibling who participates in this study and has a brother or sister without a known disability will be referred to as Sib^c

The children being referred to in this study will be

IC^d (Index child, disability)

IC^c (Index child, control group)

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Literature Review*

Siblings of Children with disabilities: A critical review of the literature

Rachael Brown, BA (Hons), MS.c.

University of Southampton

Requests for reprints should be addressed to Rachael Brown, Doctoral Programme in Clinical Psychology, 34 Bassett Crescent East, Southampton, Hampshire, SO16 7PB, UK. Email: rljb104@soton.ac.uk.

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Abstract

Purpose: To review studies investigating the psychological impact of childhood disability on non-affected siblings and to determine their risk of adjustment problems compared to siblings of TD children in relation to components of The Transactional Stress and Coping Model. Strengths and limitations of research to date are reviewed and implications for further research are considered. **Method:** Articles were identified using Medline, Embase and Ovid, and through scanning the reference lists of the articles identified. **Results:** Siblings of CWD are at risk for adjustment difficulties, although this may be less than traditionally has been assumed, with positive influences identified. Research has suggested that disability parameters, demographic factors, adaptation processes and family functioning may affect sibling adjustment. However there is no clear consensus regarding explanations for differences in sibling adjustment. **Conclusions:** The high variability in psychological adjustment needs to be investigated. Further research should consider disability and family factors that may underlie (mal) adjustment. Research should also include siblings' views. Theoretical frameworks should guide research in understanding sibling adjustment.

Introduction

*"The relationship between young siblings is distinctive in its emotional power and intimacy, its qualities of competitiveness, ambivalence, and of emotional understanding, that can be used to provoke or support. On common sense grounds these qualities, and the high frequency of interaction and imitation between siblings, suggests that the relationship will be of developmental importance-both through direct impact of siblings upon one another, and through the indirect effects of the siblings' relationships with the parents" (*Dunn, 1988, *p 119).*

Sibling relationships are among the most significant factors affecting lifelong experiences. Most siblings live together for a long time, have daily interaction, and spend a lot of time together. Sibling relationships are usually the longest and most enduring of family relationships, and this presents with the opportunity for two individuals to exert considerable influence over one another (Dunn, 2000; Kramer & Bank, 2005).

Research shows positive interactions can encourage positive emotions and behaviours. Knott, Lewis, and Williams (1995) note that children often acquire social skills through their relationships with siblings, which they later use in social exchanges with their peers. This sibling interaction provides children with opportunities to assume a variety of roles and develop skills. Sibling relationships are more forgiving than peer relationships and are helpful for learning emotion regulation. The sibling relationship allows the experiencing and expressing of many emotions, as well as for the practice, and perhaps mastery, of skills such as self-control, sharing, listening, conflict resolution, and fair play (Gibbs, 1993).

The relationship may be different if a sibling has a disability, however, the effect of this difference is unclear and it is therefore essential that we increase our understanding of the impact on children of possible disturbances within this subsystem (Ross and Cuskelly, 2006).

Most children with disabilities (CWD) live in a family with siblings (Stoneman and Brody, 1993). As a result of an increased emphasis on community care, CWD are living longer and spend more time at their parents' home, hence the length of time these siblings have with each other increases. The influence of their sibling's disability is frequently reflected in their career choices within helping professions (Turnbull & Turnbull, 1990), which indicates that, for better or worse, siblings with disabilities have a powerful effect on their typically developing (TD) brothers or sisters throughout their lifetime.

Defining disability

The World Health Organization (2007) (has made the following distinctions with regard to terminologies used in the context of health experience, between impairment, disability and handicap:

Impairment: 'Any loss or abnormality of psychological, physiological, or anatomical structure or function'.

Disability: 'Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being'.

Handicap: 'A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment off a role that is normal, depending on age, sex, social and cultural factors, for that individual.'

People with disabilities do not form a homogeneous group. For example, disability is inclusive of people with a mental illness, people with intellectual disabilities, those with sensory impairments, and those with restricted mobility or with so-called "medical disabilities". Individuals within these groups encounter different kinds of barriers, to be faced in different ways.

The Disability Discrimination Act (1995) defines a person with a disability as someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities. Children must have a significant and long-term impairment that limits their opportunity to take an equal part in the life of the community without the provision of specialist help. A child may be born with, or acquire impairment; this may include children with any of the following conditions:

Physical disability (e.g. limitations to dexterity or mobility)

Significant visual or hearing impairment

Significant developmental delay and learning difficulties: This refers to a variety of disorders that affect the acquisition, retention, understanding, organization or use of verbal and/or non-verbal information. Learning disabilities range in severity, interfering with the acquisition and use of one or more of the following skills: oral/written language, and mathematics.

Social communication disorders (e.g. Asperger's Syndrome/Autism Spectrum Disorder): According to DSM-IV Diagnostic Criteria, these involve a degree of qualitative impairment in social interaction, communication and restricted repetitive and stereotyped patterns of behaviour, interests, and activities (http://www.psychologynet.org/autism.html).

Severe mental health conditions (e.g. depressive disorders)

Chronic ill health (e.g. asthma, epilepsy, diabetes cystic fibrosis, severe epilepsy, sickle cell anaemia).

Children affected by disability may have to cope with possible negative consequences such as: difficulty accessing education, ongoing involvement of specialists, use of resources in order to undertake normal day-to-day activities, additional help to use leisure and out of school activities and more personal support than children of a similar age. Despite the diversity of conditions, it has been argued that many children experience shared psychosocial consequences such as social stigma. For example, MENCAP, UK (2007) reported that:

> *"The day-to-day lives of people with a learning disability and their families have always been much affected by the way they are perceived and treated by the communities they live in. The history of public and private attitudes over the last three centuries is one of intolerance and lack of understanding."* (Mencap, UK, 2007).

Investigating the impact of disability is challenging given the many types and severities of disability. Researchers have either chosen to investigate disability according to type or have taken a non-categorical approach as within the same 'type' as it has been argued that psychosocial dimensions may explain adjustment better than the given diagnosis (Wallander, 1998). Research using a categorical approach has lead to an unbalanced evidence base where certain disability types have been more frequently studied and others may have been given less attention. For example, most research has been carried out into chronic conditions rather than physical disability (Social Care for Excellence, 2004).

Adjustment to Disability

Most research looking at the impact of disability has considered the impact on parents and their care giving roles and there is evidence that parents may be negatively affected in terms of higher levels of distress and depression (e.g. Singer, 2006; Rentinck, Ketelaar, Jongmans, Gorter, 2007).

Siblings may also be affected due to the amount of time spent together, yet only a small proportion of studies looking at the impact of disability have investigated this in relation to sibling adjustment (e.g. McCubbin *et al.* 2001). It has traditionally been assumed that these children are at risk of developing low self-concept as they identify with the negative behaviour of their siblings who have disabilities (Knott, et al., 1995). However, little empirical evidence has supported this view, and more recent research indicates possible positive as well as potential negative effects of disability on the TD sibling (e.g. Stainton, 1998).

Views of the sibling relationship are more varied when a CWD is in the family (McHale, Sloan and Simeonson, 1986). This variability may contribute to contradictions in existing research on sibling adjustment. Although a few studies have investigated how children are affected by having siblings with disabilities, (e.g. Lobato, 1987), there have been few systematic studies and findings have been inconsistent (e.g. Coleby, 1995, Williams, 1997). Daniels, Moos, Billings and Miller (1987) found that sibling problems were associated with more problems among patients with Juvenile Rheumatism. This association may be influenced from both directions as the sibling's adjustment may in turn affect the functioning of their brother or sister with a disability. By understanding sibling adjustment and reducing sibling difficulties, it may also benefit their sibling with a disability.

Breslau, Weitzman, and Messenger (1981) studied families of children with cystic fibrosis, cerebral palsy, myelodysplasia, and multiple handicaps. Mothers (N=239) completed the Psychiatric Screening Inventory (Langner et al., 1976) for a randomly selected TD sibling aged 6 to 18 years old. Results were compared to data on 1,034 randomly selected children with TD siblings. Although total psychiatric inventory scores for siblings did not significantly differ from scores in the comparison sample, they did score significantly higher on the cognitive difficulties, fighting, and delinquency subscales.

Research considering whether the presence of a disability influences adjustment in siblings has found mixed findings (Stoneman, 2005), with high variability in adjustment outcomes (Wallander and Varni1998; Giallo & Gavidia-Payne, 2006). However, it has been argued that overall siblings seem to be at greater risk of adjustment problems than the general population, (Sharpe, and Rossiter, 2002) but the reasons for the high variability is unclear. A possible reason is the way adjustment outcomes are defined and measured.

Defining adjustment to disability

"Good adjustment is reflected as behaviour that is age appropriate, normative and healthy and that follows a trajectory towards positive adult functioning. Maladjustment is mainly evidenced in behaviour that is inappropriate for the particular age, especially when this behaviour is qualitatively pathological and clinical in nature" (Wallander and Thompson, (1995 pp 125-126).

Adjustment has also been viewed as achieving a good quality of life that incorporates functioning at school, in the family and with peers (Schalock, 1996). Adjustment problems have been defined as internalizing symptoms (e.g., anxiety, depression, social withdrawal), and externalizing behaviour (e.g. hyperactivity, oppositional behavior, aggression).

Sharpe and Rossitter (2002) carried out a meta-analysis of 51 studies of siblings of children with chronic illnesses. They found that studies tend to show that internalised symptoms are more prevalent and elevated in siblings of CWD relative to the general population, with more siblings demonstrating internalising than externalising behaviour problems (although aggression has been observed, particularly in younger male siblings (Breslau, 2005)). They also reported that siblings tend to have poorer psychological functioning (peer activities and cognitive development) than controls.

Models have been developed that incorporate psychological processes in order to better understand the possible adjustment issues of siblings of CWD. Pless and Pinkerton (1975) presented an 'integrated model of adjustment', which views adjustment to disability as a continuous reciprocal process whereby the functional level of a person influences others, for example with greater functional limitations others may need to offer increased support. The way others react to the functional impairments affects not only the adjustment and functioning of that individual with the disability, but in turn affects people around that person, and so the process continues. The model views psychological functioning to be influenced by the cumulative effect of earlier responses to stress. Pless and Pinkerton emphasise the importance of coping style and self-concept, as well as viewing the reactions of significant others to disability as mediating factors of adjustment. This model and many that have since been developed perceive disability as a stressor and adjustment outcome to be determined by the way people react to this stressor in terms of adaptation resources. These resources involve coping, cognitive processes, locus of control, efficacy, and family functioning.

Coping has been defined as: *'constantly changing cognitive, emotional and behavioural efforts to manage external or internal demands that are appraised as taxing or exceeding the resources of the person'* (Lazarus & Folkman, 1984, p. 141). Coping is therefore an ongoing process where a stressor is appraised and efforts are made to employ management strategies. Stress and coping have been explored in order to understand the effect of the presence of a child with disability on family functioning. In response to criticisms that research has not been theory-driven, some recent studies have been more explicitly guided by theoretical frameworks. Some have used models based on family systems theory, others on models of stress and coping.

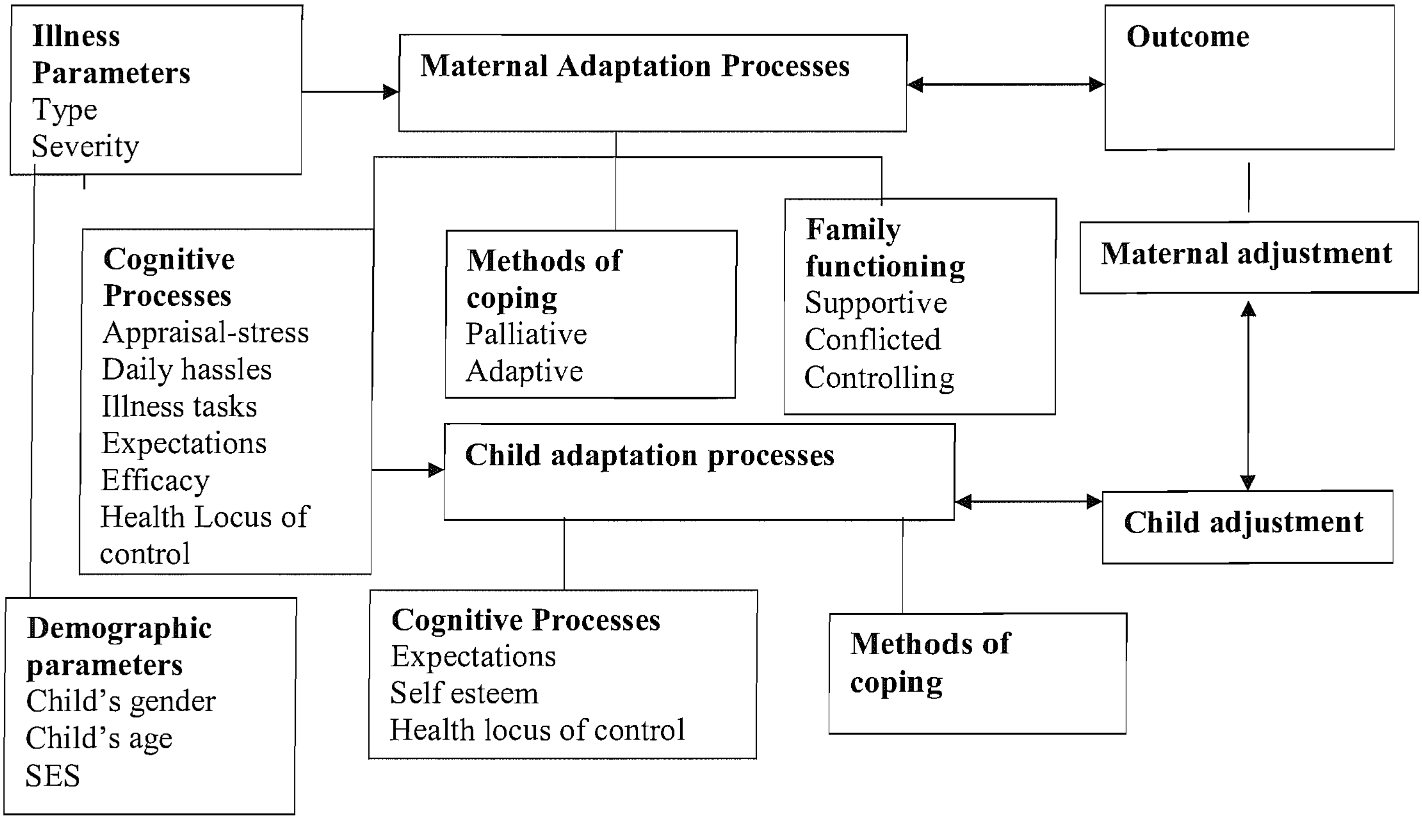
In this review, research will be considered primarily in line with a model that has developed through stress and coping research and has progressed from earlier models, to be more inclusive of factors relating to family adjustment to disability. Although a number of models exist, the Transactional Stress and coping model (Thompson, Gil, Burbach & Keith, 1993; Thompson, Gustafson, George & Spock, 1994), has been selected as it accounts for individual adjustment and it considers relationships as well as intrapersonal factors.

The Transactional Stress and Coping Model (TSCM)

In an attempt to understand the adaptation process based on stress and coping research, the 'Transactional Stress and Coping Model (TSCM) for chronic illness'

(Thompson et al., 1993; Thompson, et al., 1994), has been developed. This model is a framework for evaluating the processes of coping with stressful events. The experience of stress is mediated by firstly the person's appraisal of the stressor and secondly on the availability of social and cultural resources at hand (Lazarus & Cohen, 1977; Antonovsky & Kats, 1967; Cohen 1984). The model recognises differences in adjustment to disability by viewing disability as a potential stressor to which all the family have to adapt. Adaptive processes include cognitive processes of appraisal of stress, locus of control and expectations of efficacy, coping and family functioning. The model includes the mutual influence of parent and child adjustment (see Figure 1).

Figure 1: The Transactional Stress and Coping Model (TSCM), (From Thompson et al., 1994)



In the TSCM (see figure 1), disability/chronic illness is viewed as a potential stressor to which the child and family system attempt to adapt. The model considers the psychological adjustment of mothers and the CWD as an outcome. The 'outcome' is a function of the transactions of illness parameters with demographic parameters and psychosocial/mediational processes. 'Illness parameter' is considered in terms of type and severity of disability. Demographic parameters include the child's age and gender and socioeconomic status (SES). The model focuses on both individual and family processes that are hypothesized to further mediate the illness-outcome relationship over and above the contribution of illness and demographic parameters.

Figure 1 indicates that maternal adaptation processes are made up of: cognitive processes, methods of coping and family functioning. The 'disability parameter' relationship to adjustment is mediated by these adaptation processes. The child also possesses adaptation processes that mediate outcome and these processes ('cognitive processes' and 'methods of coping') are influenced by maternal adjustment and family functioning. Referring to the diagrammatic model of the TSCM, it indicates that mother and child adjustment influence each other in a reciprocal way.

Strengths of the TSCM

A strength of the TSCM is that it accounts for the dynamic continuum that exists in relationships between siblings of CWD and other family members. The model not only recognises variations in family systems such as age, gender, severity of the disability, family size, socio economic status, parental adjustment, and cultural differences but also acknowledges reciprocal influences regarding adjustment. All factors in the model interact and combine to produce multiple family responses to CWD (Powell & Gallagher, 1993).

This model has successfully been applied to understanding adjustment to a number of conditions including, cystic fibrosis, sickle-cell disease, spina bifida, and muscular dystrophy (e.g. Thompson, Gil, Abrams & Phillips, 1992; Thompson et al., 1993; Thompson, Gustafson, Gil, Kinney & Spock, 1999; Thompson, Gustafson, Hamlett & Spock, 1992; Thompson, Zeman, Fanurik & Sirotkin Roses, 1992). These studies indicated that a significant amount of variance in both mother's and children's adjustment outcomes is explained by illness parameters, coping and family functioning.

Examples of studies demonstrating the successful application of the TSCM include a study comparing families of 8–9-year-old children with spina bifida versus no disability Friedman, Holmbeck, Jandasek, 2004). They found that better parent psychological and marital adjustment were associated with better child functioning of the CWD (especially with regard to externalising behaviours), both concurrently and 2 years later. This study emphasises the reciprocal influence of adjustment outlined in the TSCM.

Other model factors have shown to be associated with differences in adjustment outcome, but in *siblings* of CWD's. For example, higher parental and patient dysfunction, more family stressors, less family cohesion and expressiveness were associated with more problems for siblings of children with juvenile rheumatism. (Daniels Moos, Billings and Miller, 1987). This indicates the model may also be useful in determining the adjustment outcome of other family members.

This model is therefore useful in understanding a range of disabilities and factors included in the model have been able to predict differences in adjustment outcomes of both mother and the child with a disability.

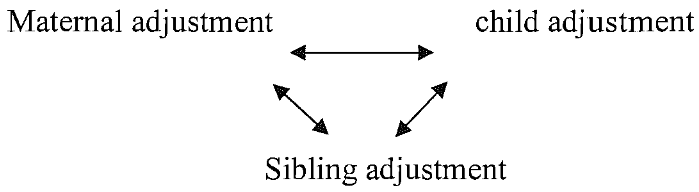
Changes in one member or characteristic of the family will mean changes for other members and other aspects of the family. Consequently, a disability that affects one member will likely affect other family members and, in turn, change the aggregate family complexion (Powell & Gallagher, 1993). Research needs to account for the relationships and processes that occur within families and using the TSCM may help to guide research in considering these factors.

Limitations of the TSCM and research

Although the TSCM distinguishes maternal coping from child coping strategies, suggesting that coping may be different between these family members, it does not explicitly account for developmental factors influencing child coping. Models need to take into account developmental stage and to consider children's responses separately to parent models as adaptation processes and development are intrinsically connected with each other (Schmidt, Petersen & Bullinger, 2003). For example, stress response processes are in place at birth and therefore precede the development of voluntary coping processes. Early voluntary coping efforts may include seeking soothing from others, behavioural withdrawal from threat, and use of tangible objects for soothing and security (Gunnar, 1994). More complex methods of problem solving emerge in early to middle childhood, such as restructuring a problem situation and generating alternative solutions to solve problems (e.g., Moss, Gosselin, Parent, Rousseau, & Dumont, 1997; Normandeau & Gobeil, 1998). With increasing metacognitive skills in early adolescence, a greater ability to match coping efforts to the perceived or objective characteristics of stress is expected. (Bruce, Connor-Smith, Saltzman, Thomsen & Wadsworth, 2001). However, although coping and development do seem to be intrinsically linked, research in understanding developmental changes in coping is in its infancy (Bruce, Connor-Smith, Saltzman,; Thomsen & Wadsworth, 2001).

A further criticism of the TSCM is the inclusion of 'maternal' and 'child' adjustment outcome, but the exclusion of other family members. Studies comparing outcomes within families for different family members have shown that mothers tend to be the most vulnerable to the effects of stress, probably due to higher levels of involvement with the CWD as compared to fathers (Kazac & Marvin, 1984). However, in a study by Treiber, et. al., (1987) comparing the psychological adjustment of children with sickle cell disease with their healthy siblings, healthy siblings, as compared to the CWD, were found to be at increased risk of adjustment problems, suggesting that all family members need to be considered. Maladjustment was associated with the CWD's reports of their problems and with maternal depression and anxiety. This emphasises the importance of considering all family members and their relationships to each other.

The reciprocal relationship outlined in the TSCM of maternal and child adjustment would be expected to affect the sibling, as one family member's adjustment is likely to have an affect on the adjustment of other family member:



Research on family adjustment

According to the TSCM, parental (maternal) and child adjustment are associated. It is therefore important to consider research on both parent adjustment and sibling adjustment. Below a brief overview of parent research is presented before discussing research on siblings in more detail.

Walker, Van Slyke and Newbrough (1992) compared stress in families of children with chronic conditions and families of TD children. Results indicated that families of children with chronic conditions did not differ from families of TD children on scales assessing generic aspects of family stress, such as family conflict. This suggests that family functioning is not disrupted by the presence of a child with a chronic condition. This finding is consistent with other research (e.g., Cadman, Rosenbaum, Boyle & Offord, 1991; Kazak, 1987; Lewis & Khaw, 1982). However, groups differed on scales assessing stressors specific to the child's disability (e.g., families of children with learning disabilities were characterized by concerns about caring for the child as an adult). There was no evidence of higher levels of stress for families of older children.

Donenberg and Baker (1993) compared the psychosocial impact on parents of pre-school children demonstrating externalising behaviours (hyperactivity, aggression), children with autism, and a control group. Parents of children with autism and those demonstrating externalising behaviour experienced more negative impact on their social life, higher child-related stress and less positive feelings about parenting than the control group, whilst marital well-being showed no significant variation. No differences were found between diagnostic groups, i.e. parents of children demonstrating externalising behaviour reported similarly elevated levels of impact and stress to parents of children with autism.

Lavigne and Faier-Routman, (1992) in their meta-analysis of studies looking at adjustment to paediatric physical disorders, found that there were differences between types of disability but the degree of variation was unclear. They found a trend for sensory and neurological disorders to show highest risk for maladjustment of the child with the disability.

Breslau, Staruch & Mortimer, (1982), studied 369 families with disabilities and compared them to 456 controls. They found that type of disability, (cystic fibrosis, cerebral palsy, myelodysplasia, or multiple physical handicaps) was unrelated to the mother's level of psychological distress. However, the more dependent the child, the greater their mother's distress was.

Lavigne and Faier-Routman, (1992) reviewed 87 studies looking at adjustment of children with physical disorders and found that it is not the features of any *specific disease* that most affect psychological functioning, but rather features that vary across childhood chronic diseases in general, such as whether it is life-threatening, that affects adjustment of the child with the disability supporting a non-categorical approach. However Lavigne and Faier-Routman (1992), found comparisons difficult in their meta-analysis due to few studies producing calculable effect sizes as well as the high variability in results involving individual disorders.

In summary, there is some indication of adjustment difficulties in families with children with a disability. In this respect it is not so much the characteristics of a specific condition that seems to affect adjustment but rather common/shared disability indicators and their effect on activities of daily living (ADL). Most research has focused on the parent (mother) and child itself. Mediating factors have been established in terms of mother's adjustment such as more “active” coping styles less likely to result in adjustment problems (Hodapp et al., 2005). Further questions need to address the extent to which siblings' reactions to their brother or sister with disabilities are mediated by their mother's coping style. Additionally, other potential mediational variables should be considered. More recently, there has been an increase in sibling research, which will be discussed below.

Research on sibling adjustment

The presentation of sibling research will be organised in terms of model parameters in the TSCM. Although discussed separately, this model reflects complex processes and their interrelationships. Greater consideration of this process-based model will be discussed following sections that report research on the model's parameters.

Illness parameters-adjustment (The TSCM)

a. Disability Type (i.e., the diagnostic classification of the disabled children)

As stated earlier, the label 'disability' encompasses many different types. These condition types have been unequally researched, with, for example, less research on physical health and sensory impairments than, for example on learning disabilities. Hence conclusions regarding disability type and sibling adjustment should be made with caution.

Howe (1993) conducted a meta-analysis of 21 studies of siblings of children with chronic illness and found that neurological conditions had more negative effects on siblings than non-neurological conditions, which manifested mostly as internalising behaviours in the siblings. Lavigne and Ryan, (1978) investigated three groups of children with chronic illnesses: Paediatric haematology, cardiology and plastic surgery. They found that siblings were at risk of maladjustment with significant group differences. Other studies have looked at the impact of chronic disabilities and suggest that siblings may have lower confidence levels, less self-acceptance and less academic success (Vance 1980).

Many studies have shown that the type of disability (such as intellectual disabilities vs. non-intellectual disabilities) plays an important role in attachment styles (Levy-Wasser and Katz 2004). This is evident in autistic disorders. However, studies on siblings of children with autism have shown both positive adjustment (Pilowsky, 2004), such as a positive sense of security, and negative adjustment (Ross 2006) such as depression (Gold 1993) and loneliness (Kaminsky 2002). A study looking at developmental delay and social communication disorders has shown that interaction between siblings is frequent. The interactions were usually directed by their sibling and although children with autism engaged in fewer bouts of communication and imitated less, they did reciprocate their siblings' initiations (Knott 1995). The significance of the nature of these different kinds of interactions in terms of sibling adjustment is not clear and needs further investigation.

The sibling relationship and its influence on sibling adjustment have been investigated in siblings of children with hearing loss (Verte, Hebbrecht & Roeyers, 2006). In this study, the quality of the sibling relationship was assessed and measures of adjustment were taken (behavioural problems and social competence). Results indicated no significant differences in the quality of the sibling relationship when compared to typically developing sibling dyads. Parents of children with hearing loss reported fewer internalizing behaviour problems of their siblings compared to those of controls. There were no significant differences between groups regarding social competence. In both groups, positive sibling relationships were related to fewer emotional and behavioural problems of both children and increased social competence; negative sibling relationships indicated the reverse. This highlights the importance of the sibling relationship in determining sibling adjustment. Overall, siblings of children who are deaf or hard of hearing were not at greater risk of maladjustment. However, in a study looking at parents' perceptions of siblings' interactions with their brothers and sisters who are deaf-blind, it was found that relationships between siblings consisted of unequal roles, with siblings primarily taking on a helping role (Heller, Gallagher, & Fredrick,1999) and this role has been implicated in poor adjustment.

Siblings of psychiatrically ill patients have also been found to experience burden in their daily life and in relating to their sibling and other family members (Schmid, Speissl and Cording, 2005). Siblings of patients with schizophrenia have also been found to experience more intense negative feelings, greater levels of burden, less closeness and more shame than control group siblings (Barak, Solomon, 2005). However, this study did not compare sibling adjustment to other chronic conditions making conclusions regarding disability types difficult.

It seems that some domains of adjustment in siblings may be affected whilst others are not. Hommeyer, Holmbeck and Willis (1999) considered adjustment outcomes in 8 and 9 year old children with Spina Bifida in terms of proximal and distal outcomes. They defined proximal outcomes as functional consequences of specific disability-related symptoms such as athletic competence (due to physical impairments) and attentional problems (due to cognitive impairments). However, distal outcomes such as internalising and externalising symptoms are not so clearly linked to the limitations related to Spina Bifida. They highlighted the need to examine illness parameters individually as different illness parameters may be associated with different outcomes (Holmbeck and Faier-Routman, 1995). It could be that siblings' distal outcomes are moderated or mediated by their brother or sisters' proximal functional status, which could explain differences in domains of adjustment.

Although types of conditions have been compared in several studies, it could be the degree of severity of illness or disability, which accounts for differences in findings regarding impact on siblings. Studies investigating the impact of severity on adjustment will be discussed now.

b. Disability severity

Severity has been assessed in a number of ways, for example level of functional disability, whether a condition is fatal or not, level of behavioural disturbance, and level of cognitive impairment. For example, Sharpe and Rossiter, (2002) found no difference in the psychological functioning of siblings when their brother or sister had more or less severe (mortality rates) childhood illness, however they found that siblings displayed more adjustment problems if their siblings' condition affected day-to-day functioning more, so having a greater need for assistance. Research defining severity in terms of cognitive impairment has shown that more independent, higher functioning, more verbal CWD tend to have better adjusted siblings (e.g. Farber, 1968).

Walker, Van Slyke and Newbrough (1992), examined the effects of illness severity on stress of families with CWD (as measured by maternal responses on a measure of family stress). Severity was measured on two dimensions: fatal/not fatal and presence/absence of cognitive impairment. They found that generic aspects of family stress, e.g. family conflict, did not differ significantly between groups. In contrast, differences were found in relation to stress specific to the child's disability, e.g., greater cognitive impairment meant greater concerns regarding caring for the child as an adult. It is unclear however to what extent the two severity indicators fully reflect the differences between the disability groups in the study (cystic fibrosis, moderate LD and diabetes); hence these findings should be interpreted with caution.

More recently, severity has been defined in terms of the level of behavioural disturbance. In a longitudinal study, Hastings (2006) found that initial levels of behavioural disturbance in children with developmental disabilities were associated with sibling adjustment problems both initially and at a 2 year follow up. An advantage of this study was that it was longitudinal and therefore could investigate the changing nature of the way siblings adjust. However, no control group was used, and there was a large age range in both siblings in the dyads studied (3-19 years), and a reliance on maternal reports.

It has been argued that differences in reported results may (in part) reflect the methodological differences between studies, with better-designed studies showing fewer differences in sibling adjustment between groups of children who have siblings with and without disabilities. For example, studies using better matched controls have shown less significant effects (Cuskelly, 2004) and differences seem greater when norms are used as opposed to control groups (Lavigne and Faier-Routman, 1992)

Although there does appear to be some effect of severity (depending on how it is conceptualised and measured) on adjustment, there is wide variability and some contradictory research findings. This could be because of adaptation processes as described in the Transactional model of stress and coping mediating effects. Research examining adaptation to the illness will now be considered.

Demographic Characteristics

Developmental factors may account for differences in adjustment outcome of siblings. For example, in early childhood, siblings frequently believe that they have caused their brother or sister's problem (Lobato, 1993). As a result, they often try to compensate for this by being well-behaved in an effort to reduce their anxiety and not to burden their parents. In addition, they are particularly affected by the visible aspects of the disability as measured by increased social withdrawal (Lobato, 1993). Toddlers and preschool children often experience jealousy towards their brother or sister due to the proportion of time that parents spend attending to the CWD's needs so may act out (Turnbull & Turnbull, 1990). Siblings who are school age are frequently at risk for greater anxiety, associated with their brother or sister's disability (Powell & Gallagher, 1993). Often, for the first time, siblings are faced with the dilemma of attending the same school with their brother or sister, and are frequently expected to take the role of 'keeper' (Gamble & Woulbroun, 1993). Siblings may face conflicting emotional 'pressure' to defend the CWD but at the same time be accepted by their peers (Powell & Gallager, 1993). Adolescence generates uncertain feelings in siblings who have brothers and sisters with disabilities (Gibbs, 1993). Begun (1989) suggested that adolescent siblings of CWD experience more discord than do peers with non-disabled brothers or sisters. While they may have a greater understanding of their brother or sister's disability and a greater appreciation of individual differences, adolescents often encounter embarrassment and the stigma attached to being a sibling of a CWD (Turnbull & Turnbull, 1990)

Study results have tended to vary depending on birth order and gender make-up of the sibling dyads examined (Howe, 1993; Williams, 1997). A study looking at these demographic characteristics specifically (Breslau, 1981) found after comparing

237 siblings of disabled children to 248 siblings from a general population sample that younger male siblings, specifically those in close age-spacing relationship to the disabled child, scored higher on measures of psychological functioning, indicating more problems, than older male siblings. Psychological functioning was conceptualised as 'the extent to which a child can function within a context: with parents siblings, peers and teachers' (Langer, Gersten, McCarthy et al., 1976) and level of impairment was assessed using the Psychiatric Screening Inventory (Langner et al., 1976). Younger sisters were psychologically better off than older sisters and their age-spacing was not significantly related to psychological functioning. Brothers were more likely to demonstrate aggressive behaviours and sisters reported more internalising problems. This suggests that maladjustment may express itself differently in boys and girls. Siblings of CWD have been reported to have greater household responsibilities and are involved in more housekeeping chores and child-care, and are often used as a source of parental support. With increased involvement at home, they may also have decreased involvement in school and social activities (Brett, 1988; Tritt & Esses, 1988; Williams et al., 1993). This can lead to social exclusion (Lackey and Gates, 2001). It has also been reported that sisters may have the greatest increase in responsibility for household tasks and child care (Lobato, Barbour, Hall, & Miller, 1987), suggesting a more negative impact on females' social activities. This may be of importance in light of research by Gath, (1974) suggesting that sisters are at greater risk of adjustment difficulties than brothers and that increased care-giving responsibilities may account for such differences. It is important to consider how the sibling relationship is altered for boys and girls and how psychological maladjustment may be manifested differently depending on gender.

Culture and ethnicity

With few exceptions (Weisner, 1993), cultural context has been given little attention in research on sibling adjustment to disability. On the basis of ecocultural theory (Weisner, 1993), it would be expected that children growing up in a culture that places significant value on the sibling relationship would respond differently to a sibling's disability than children raised in a culture in which sibling relationships are less important. In many societies, siblings are the primary caregivers of children (Weisner & Gallimore, 1977). It has been suggested that the sibling role is probably less valued in American culture, though it remains important (Hodapp, Glidden, & Kaiser, 2005). In addition, many differences exist across subcultures within American society. For example, the percentages of adults with disabilities living in family homes (versus in independent apartments or in group homes) is higher in Latin-American versus Anglo populations, and much discussion in family circles concerns the role in Latin-American groups of strong family identification and ties (Blacher, 2001). Yet, how such family-related feelings and perceptions relate to sibling perceptions, actions, or understandings have yet to be adequately examined (Hodapp, Laraine Masters Glidden, and Ann P. Kaiser, 2005).

There is evidence of disproportionately higher rates of certain disabilities in minority populations (Stoneman, 1993), perhaps due to a higher incidence of poverty, resulting in poor prenatal care, inadequate nutrition, and drug use during pregnancy (Stoneman & Brody, 1993). Other disability types may occur less frequently in certain ethnic groups, e.g. spina bifida is found more frequently in white populations whilst others like sickle cell disease only occur in people from African/Caribbean origin. However, most family studies in disabilities have focused primarily on Euro American, middle-class families, although this is beginning to change (Hodapp, et al., 2005). This is especially important as western society is increasing in its cultural diversity.

Lobato, Plante and Kao (2005) studied forty matched healthy Latin American and Non-Latin American siblings (ages 8–14 years) of children with developmental and physical disabilities. Siblings completed interviews and questionnaires assessing sibling knowledge of and adjustment to disability and sibling global psychological functioning. Latin American siblings had significantly less accurate information about the disability and reported more internalising problems than non-Latin American siblings. Sibling and parent wishes for the healthy sibling reflected cultural values, e.g. sometimes a child born with a disability can be seen as touched by evil caused by the self (e.g. being immoral), others (e.g. witchcraft), or by an act of God (Ingstad, 1990) and this can increase parents' hopes for a healthy child. The results indicate that Latin American siblings of children with chronic disabilities may be at risk for internalising psychological problems. An alternative view is that they may have motives for over reporting difficulties such as to gain access to support.

Several studies have reflected individual cultural differences between families from different ethnic groups regarding adjustment, attitudes about disabilities, and sibling relationships (Boss, 1993; Weisner, 1993). Conclusions drawn from research into sibling adjustment can not therefore be generalized to families from different cultural backgrounds (Hanline & Daley, 1992). Additional roles for siblings may also occur in immigrant families who may use the sibling as an interpreter between health care professionals and parents. This has been shown to have a negative effect on the sibling translator in certain circumstances. For example, a single case study of a 10 year-old girl who was translating for her parents about her brother who died following renal failure experienced increasing health problems following dealing with the distressing information (Jacobs & Green, 1994).

Crnic et al. (1983) found that religion has the potential to positively influence the lives of families with CWD. Families who hold religious beliefs demonstrated greater acceptance, more positive adjustment, less stress and a greater propensity for caring for their CWD in the home than did comparison families, suggesting that siblings in these families might be better adjusted.

McHale and Gamble (1987) reported that mothers of CWD who were involved in religious activities used more positive coping techniques. Similarly, siblings of CWD who participated in church functions demonstrated fewer anxiety symptoms and less depression than comparison siblings, and reported increased self-esteem (McHale & Gamble, 1987).

Perceptions of disability differ across cultures. For example in a qualitative study of Somali immigrants in America, it was found that these individuals consider mental disabilities as more severe than physical. In Somalia, the family cares for disabled family members, treating them as if they were ‘normal’. They considered caring for a person with a disability as stressful for the family (so although considered as ‘normal’, it was still not necessarily adaptive for family members). They also believed that Allah determines whether or not a child will be disabled, and this cannot be predicted or altered (Greeson, Veach and LeRoy, 2001). Different religious and cultural beliefs may therefore influence the meaning disability has and in turn adjustment to that disability.

Socio economic status

SES is a confounding variable in that research shows that SES is associated with a variety of health, cognitive, and socio-emotional outcomes in children, with effects beginning prior to birth and continuing into adulthood (Bradley, Robert, Corwyn, 2002). SES could therefore affect the adjustment of the TD sibling regardless of their brother or sister's disability. Furthermore, due to the strong association that exists between some disabilities and SES e.g. cerebral palsy (Sundrum, Logan, Wallace and Spencer, 2005) and disabilities associated with low birth weight (Pattenden, Dolk and Vrijheid, 1999), this affects the make up of research samples. Although some research has confirmed the association between SES and psychological adjustment of carers (e.g. Emerson et al, 1998) and children with disability (e.g. Stein and Bauman, 1999) to date no research explicitly focusing on the affect of SES on sibling adjustment has been published.

Adaptation Processes

This review will focus on: Stress: Appraisal of daily hassles (and its relation to methods of coping), illness tasks (carer role-level of involvement), family functioning and the role of social support in the adaptation process.

Stress: Appraisal of daily hassles, and coping.

Stress depends on the interaction of two complex systems (the environment and the person) with a process of reciprocal influence (Lazarus, and Folkman, 1985). Therefore, appraisal of the stressor is an important variable to consider in outcome adjustment, where according to Gamble and Woulbroun (1993) coping responses are:

"Children's attempts to change their perceptions of the situation and attempts to change the situation itself" (p. 308). Appraisal of the stressor by siblings would therefore determine their efforts and ways to cope with it.

Daily hassles are psychosocial stressors that have been considered a risk factor of adjustment problems (Wallander and Varni, 1992). The way these daily stresses are appraised may influence coping and adjustment outcome. Weiss, Rapoff, Varni et al., (2002) investigated daily hassles and social support as predictors of adjustment in children with rheumatic disease. They used the Children's Hassles Scale (CHS), (Varni et al., 1996) which is a self-report questionnaire, which assesses the severity and occurrence of daily hassles. The 'hassle', such as 'your mother and father were fighting' is rated by the child as whether it did or did not happen and if it did how much it bothered them. Weiss et al (2002) found that the CHS correlated with adjustment of children with a disability. The way that the hassles were appraised (how much it 'bothered' the individuals) influenced adjustment. Hassles had predictive main effects, accounting for between 5% (for state anxiety) and 25% (for trait anxiety) of the variance in adjustment measures.

Although research has indicated associations between appraisal and adjustment in parents of children with disability and the children themselves (e.g. Beresford, 1994; Bombardier, D'Amoco and Jordan, 1990; Lavigne' & Faier-Routman, 1992; Fisher, 2001) few studies have focused on this association in siblings (Gamble & Wouldbroun 1993). The few studies that have been identified report variable findings. It would be interesting to see of daily hassles and the appraisal of those hassles would predict adjustment in siblings of children with disabilities.

Hamama, Ronen and Feigin (2000) investigated self-control, anxiety, and loneliness in sixty-two siblings aged 9-18 of children with cancer. The outcomes demonstrated a link between self-control as a coping skill and in turn higher self-control rates were associated with lower anxiety and loneliness reports.

Van Riper (1999) explored how children respond to the experience of living in a family that includes a child with Down's syndrome (N=76). The results indicated that for many siblings, the experience of living in such family might be a positive, personal growth producing experience. Overall, siblings had above average self-concepts. Maternal reports typically indicated that these siblings were socially competent, with a low incidence of behaviour problems. Family appraisal, family resources, and family problem-solving communication were significantly associated with sibling well being, suggesting that how stress is appraised and coped with is related to adjustment.

Appraisal of stress is closely linked to coping as the way stress is appraised influences the coping strategy used (Varni, 1993). However, Cox, Marshall, Mandleco and Olsen (2003) recognised that there exists minimal data regarding sibling reports on coping. The lack of data may be in part due to siblings growing up with a child with a disability and when younger not being able to reflect on their coping. Lobato (1993) reported that toddlers and preschoolers, in particular, have difficulty understanding the nature and cause of their brother or sister's disability, and they are often left to depend upon their own unrelated experiences and imaginations to define and interpret the situation. Cox et al., (2003) therefore investigated everyday responses to stressful events using a sentence completion task for 46 siblings of children with a range of disabilities. This task involved responding to 18 open-ended statements about real or hypothetical stressful situations. Content analysis of verbal responses revealed four modes of reaction, these being proactive, interactive, internally reactive and non-active. They highlighted the importance of developing research further to see how the differing coping responses influence adjustment.

A study by Beck, Daley, Hastings, Stevenson (2004) assessed mothers' expressed emotion (criticism, hostility, and overprotection) during a five-minute speech sample about the mother's relationship with the child. It was found that expressed emotion was higher and more negative toward their CWD compared with siblings. Significant relationships were found between negative expressed emotion and child behaviour problems of the child with the disability, and it was suggested the negative emotion was likely to be child driven. This could influence sibling adjustment in terms of observing parents coping with the negative behaviour through expressing negative emotion.

Illness tasks

Moos & Tsu (1977) identified four 'illness tasks' undertaken by mothers of CWD. These were (1) dealing with the child's medical problems and symptoms, (2) maintaining the child's emotional well-being, (3) maintaining their own emotional well being and (4) preparing for an uncertain future. Siblings may also be involved in 'illness tasks', for example by offering emotional support and taking on a caring role for their sibling.

McHale and Gamble (1989) investigated sibling relationships of children with disabled and non-disabled brothers and sisters. Siblings of children with learning disabilities appeared to take on more household and care giving responsibilities. They reported more negative experiences with their mothers, and exhibited poorer adjustment than controls, suggesting their increased care giving role may impact negatively on their relationship with their mothers and their adjustment.

Family functioning

The Transactional Stress and Coping Model considers the role of family functioning in adjustment to disability. Specifically it considers whether a family is supportive, conflicted or controlling.

In a cross sectional study applying the TSCM to siblings of children with sickle cell disease (Gold, 1999), interrelationships among ecological parameters and individual and family characteristics were examined in terms of their impact on sibling adjustment defined as externalising and internalising behaviour reported on the Child Behaviour Checklist (CBCL, Achenbach, 1991). The study examined existing components of the TSCM, and cultural aspects of the extended family network. Primary caregivers, children with sickle cell disease (N=56), and their siblings (N=97) all completed three questionnaires, and a chart review was used to ascertain measures of disease severity. Emergency room visits and family adaptation processes were associated with sibling adjustment, while family functioning also emerged as a significant predictor of sibling adjustment. Family support and expressiveness and low family conflict partially mediated the predictive effects of emergency room visits on sibling adjustment. Children with sickle cell disease and their siblings rated themselves as having similar levels of coping, perceived social support and self-efficacy. On measures of adjustment, both groups scored below the clinically significant level, therefore not indicating maladjustment. Findings indicated the importance of family functioning in mediating the effects of chronic illness on siblings of children with sickle cell disease.

Nixon and Cummings (1999) found that in comparison to a control group, siblings of physically disabled children reported higher levels of emotional reactivity and negative cognitions about themselves in response to scenarios illustrating hypothetical “everyday” family conflicts. Specifically, they reported higher levels of sadness and worry, and perceived themselves to be responsible for the conflict. The authors concluded that this particular group may be more sensitive to family conflicts and therefore at greater risk for emotional maladjustment in comparison to their peers.

Three groups of siblings: control group, siblings with learning disabilities (LD) living at home, and siblings with LD in a residential placement, were studied by Eisenberg, Baker and Blacher, (1998). They found that siblings from all three groups had similar perceptions of their family environment, except for the expressiveness domain. Siblings in the LD groups and especially in the LD residential group, reported lower levels of family expressiveness than siblings in families with only typically developing children. It could be that these adolescents feel more inhibited about discussing their own concerns when parents are preoccupied with their brother or sister. Control siblings reported the highest levels of warmth and closeness, but also of conflict and rivalry. Warmth and closeness and conflict were perceived as lowest by siblings in the LD residential group, suggesting differences in how the family functioned between these groups.

Bank and Kahn (1982) theorized that siblings who have greater opportunities for contact and interaction are more likely to experience greater intensity of both positive and negative affect than are siblings who have less opportunity for interaction. So it seems that more ‘intense’ emotions may be experienced in typically developing sibling dyads. In addition, findings from a study by Eisenberg, Baker and Blacher (1998) involving siblings of children with LD living in the family home reported less warmth and closeness and conflict and rivalry than TD siblings suggesting it is not just about time spent together but the quality of that interaction.

Bendor (1990) suggested that disruption of personal and family routines such as chores, social activities, meal time and bedtime procedures may lead siblings to feel isolated as they are constantly given the message that plans are purely focused around the needs of the child affected by disability.

According to a number of researchers (e.g. Corter, Pepler, Stanhope, & Abramovitch, 1992; Lobato et al., 1991; McHale & Pawletko, 1992; Stoneman et al., 1987), parents direct more attention to CWD than to TD siblings. When siblings of CWD are dissatisfied with differential parenting, they experience increased anxiety and depression (McHale & Gamble, 1989). However, most research on parent partiality has been on TD sibling dyads (Brody et al., 1991). Differential treatment in families with non-disabled children has shown that the perception of parent partiality is associated with the quality of sibling relationships, with non-partiality leading to more pro-social behaviour and less conflict (Brody, 1987; McHale and Gamble, 1989). However, Wolf, Fisman, Ellison and Freeman (1998) have argued that the situation is more complex when one sibling has a disability. Parent-child relationships have been shown to differ on some dimensions when the child has a disability. For example Levers, Drotar, Dahms, Doershuk and Stern (1994) found that mothers of children with chronic illnesses (Cystic fibrosis and diabetes) were less likely to set limits regarding their behaviour.

Wolf et al., (1998) investigated siblings of children with pervasive developmental disorder (PDD), Down syndrome (DS), and TD controls. They found that the association between sibling adjustment and differential parenting depended on the child's disability. Siblings of children with PDD felt that their parents preferred them the most, whereas siblings of children with Down's syndrome believed their brother or sister was favoured. The direction of perceived parental partiality is different according to disability type. Furthermore, differential treatment of siblings when sibling dyads include a CWD is not associated with lower warmth in the sibling relationship as it has been associated in TD sibling dyads (Wolf et al., 1998). Modry-Mandell, Gamble and Taylor (2007) examined the impact of family emotional climate and sibling relationship quality on behavioural problems and adaptation in preschool-aged children and found that sibling warmth was related to child adjustment. Perceived partiality may not, therefore have a negative impact on sibling relationships when a CWD is involved, suggesting that it may not affect sibling adjustment as might have been expected if mediated through the sibling relationship.

Pit-ten Cate and Loots (2000) investigated the experiences of Dutch siblings of children with physical disabilities (n = 43). The interviewed siblings reported positive relationships with their parents, based on open communication and trust. They acknowledged their parents' attempts to treat all their children equally, even if they were not successful in doing so. This follows work by McHale and Pawletko (1992) who found that in well-functioning families, differential parenting may be interpreted by siblings not as parental favouritism, but as a justified response to the needs of the child with a disability (McHale & Pawletko, 1992; Stoneman, 1998).

Kaminsky and Dewey (2001) found that siblings of children with autism and siblings of children with Down syndrome reported greater admiration of their sibling and less conflict in their relationships compared to siblings of TD children and found no adverse effects relative to siblings of TD children.

Fife and Lancaster (1984) noted that when parents focus most of their attention towards their disabled child, any non-disabled children within the family are likely to experience feelings of rejection and also become resentful of both their sibling and their parents.

Family functioning does appear to have a mediating effect on adjustment in siblings. With greater family support, communication, low family conflict, and a perception of being treated equally (or understanding that differential treatment is not necessarily due to being favoured differently) siblings appear to be better adjusted. These findings generally support the TSCM, which suggests the effect of disability on adjustment is mediated by family functioning.

Social support

Social support differs in its function e.g. emotional support, information, practical help, or encouraging feelings of normality (e.g. Barrera and Ainley, 1983) and its availability. In addition there may be individual differences in the extent people choose to utilise (social) support. Making use of social support has been described as a coping strategy (e.g. Holahan & Moos, 1985; Quittner, Glueckauf & Jackson, 1990) and has been linked to how well parents have adjusted to the birth of a child with a disability (Trute & Hauch, 1988).

The need for support for parents of CWD has been identified where parents have been described as perceiving themselves as lonely and isolated (e.g. Bradshaw and Lawton, 1978; Philip and Duckworth, 1982). Parental stress and limited resources are associated with behaviour problems and lower social competence in siblings of CWD (Cuskelly et al., 1998; Dyson, 2003; Fisman et al., 1996, 2000; Stores et al., 1998; VanRiper, 2000). However, Hastings (2003) found that parental stress was not a strong predictor of the adjustment of siblings of children with autism after other factors such as social support were controlled. Effective social support has been shown to buffer some of the negative effects of family stress on siblings of CWD (Benson et al., 1999; Hastings, 2003; Rivers & Stoneman, 2003).

Associations between parent and sibling adjustment

Raising a child with a disability may require changes in lifestyle patterns in the family. For example Quittner, Opipari, Regoli, Jacobsen, and Eigen (1992) investigated the impact of care giving and role strain on family life, comparing mothers of children with cystic fibrosis (N=23) and matched controls (n=23). All subjects completed a home interview, standardized questionnaires, and six daily phone diaries. Demographic and medical information were gained through home interview. Maternal perceptions of role strain were measured using self-report questionnaires. Following this, tape-recorded phone diaries were used. Mothers were interviewed by phone for three consecutive evenings at two time points, separated by two to three weeks. Daily phone diaries were only collected during "typical" weeks (i.e., no significant disruptions in family routines) to gather information regarding daily activities which were coded as either recreational, chores or activities related to medical care. Findings revealed that mothers of children with cystic fibrosis spent more time in medical care activities on both week and weekend days, and more time in chores and child care on weekends, had a less diverse pattern of recreation and spent less time in play and recreation activities. It has been argued that if family members do not adapt to changes in circumstances this could lead to increased stress (Koch, 1985). This is important in that parents' and children's functioning are closely connected, and research has examined the relationship between parental well being and adjustment of the child with disabilities.

Some models have taken development into account, for example, Eisenberg, Fabes, & Guthrie (1997) included volitional and automatic responses to stress in understanding coping. Studies have shown that the way children and adolescents handle different stressors does vary (Plancherel, Bolognini & Halfon, 1998). In their study looking at differences in coping according to age using a community sample of 11-15 year olds, they found that using coping strategies in facing both internal and external stressors was more useful in the older adolescent group, with coping acting as a buffer to stress. However, this was not the case for the early-adolescent group. The reason for this difference could be the conceptualization of coping and its measurement not being appropriate for the developmental stage of the younger group. The study used the Adolescent coping orientation for problem experiences (A-COPE), (Patterson and McCubbin, 1987) which measures cognitive and behavioural strategies directed at managing stressful demands and is a similar conceptualization of coping to adult models (e.g. Lazarus & Folkman, 1984).

The TSCM and other ‘stress and coping’ models assume dysfunction on account of the child’s disability being a source of stress, but comparisons between families with and without a person with a disability indicate that families of people with a disability have a higher degree of stress, but less so than had been assumed. Differences in stress correlated with a range of variables rather than just the severity of the disability (Jaques, 1997). The TSCM, however, does consider factors beyond the disability, such as family functioning.

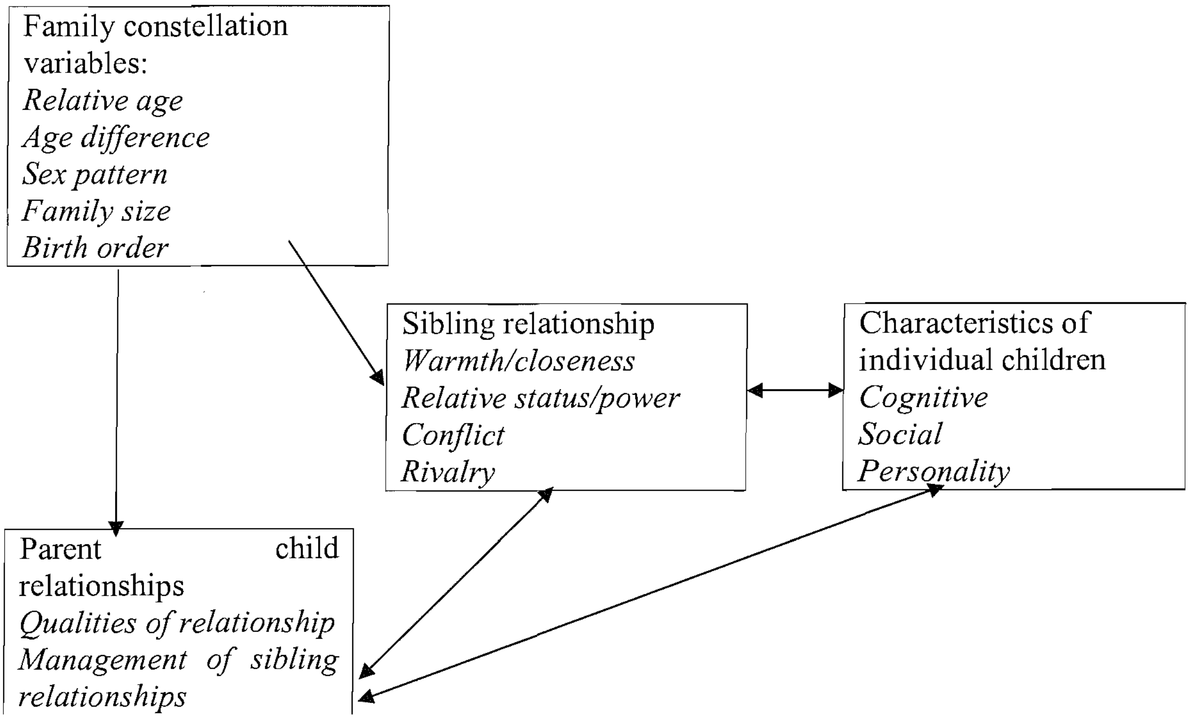
Stress and coping models perceive the child’s disability/illness as a potential stressor, and argue that adjustment is related to the ways that the stressor is coped with. There are differences in the factors that the models specify as mediating the relationship between illness and adjustment outcome. For example, the disability-stress-coping model (Wallander et al., 1989; Wallander & Varni, 1992) emphasises stress-processing factors. This includes, cognitive appraisal of stress and coping as mediators of adjustment. The TSCM includes cognitive processes, family functioning and methods of coping. The TSCM suggests that maternal and child adjustment is directly linked, suggesting a similar adjustment for mother and child. However, most models focus on the adjustment outcome of an individual family member, especially the mother of, or the CWD (Stoneman, 2005).

Stress and coping models applied to children have developed mostly from adult literature. However, age-related factors play a major role in shaping coping with stress (LaGreca *et al.* 1992). In a Medline search from 1975 to 2001 (McCubbin *et al.*, 2001), 391 articles were found related to coping with chronic disease. Only eight studies involved the perspective of siblings. Of the 71 studies, only a very small proportion of studies used an age-appropriate coping inventory. This is probably because a developmental approach complicates the difficulties that have to be faced in coping research (McCubbin *et al.* 2001).

In an overview by Schmidt, Petersen and Bullingher (2002) they found that self-report coping measures for children have rarely been developed as they are seen as less reliable. Coping measures also often involve complex tasks of imagining different scenarios, which may be difficult for children (Scmidt, Petersen & Bullinger, 2002). A measure that has been developed to be appropriate for children is the KIDCOPE (spirito et al., 1995; 1998) which although standardized for chronically ill children can be used in a variety of situations due to not identifying specific stressors in the questionnaire. Inventories have also been developed for 'healthy' children and includes the 'Life Events and Coping Inventory' (Dise-Lewis, 1998) as well as open-item lists asking adolescents to report how they cope with stress (e.g. Milouseheva et al., 1996). However, a lack of clarity and consensus in conceptualizing coping has lead to confusion in approaches to measurement, as well as difficulties in comparing findings across studies, and understanding differences in coping as a function of age (Compas, Connor-Smith, Saltzman, Thomsen, Wadsworth, 2001).

Furman and Buhrmester (1985) have identified factors that determine the quality of sibling relationships (see Figure 2). This diagram emphasises the importance of family constellation variables, characteristics of the individual child as well as the quality of parent child relationships.

Figure 2: A diagram of the main determinants of the quality of sibling relationships.



(From Furman, W. & Buhrmester, D. (1985). Children's perceptions of the qualities of sibling relationships. *Child Development. 56(2)* 448-61).

This model ties in with the 'family functioning' aspect of the TSCM. The TSCM considers how a supportive, conflicted or controlling family affects both mother and child adjustment. In Furman's model of the quality of the sibling relationship, aspects factors include: 'warmth/closeness', 'relative status/power', 'conflict' and 'rivalry'.

These all appear to relate to family functioning. For example, both models account for conflict. How controlling a family is may relate to power and how supportive a family is may relate to 'warmth and closeness'. The quality of the sibling relationship could be an aspect of family functioning or related to family functioning and so may contribute to sibling adjustment. Furman's model depicts a reciprocal influence of the sibling relationship on parent child relationships, further emphasising the importance one relationship in the family may have on another.

Methodological Issues

Results of studies regarding families of CWD have yielded contradictory findings. Examples of methodological concerns will follow as these may in part explain the inconsistent findings.

Research has often been limited to a specific disability (Cuskelly, 1999), and has led to small sample sizes where there has been difficulty in identifying and recruiting families for research (Moore, Howard and McLaughlin, 2002). These authors suggest that in order to obtain larger samples of siblings of children with disabilities, rather than focusing on specific forms of disability, recruitment might include children with any form of disability and instead select families based on broader factors such as parental attitudes, overall reasons for family stress or family behaviour patterns. This would not only help increase sample sizes but might assist in moving away from 'disability' as an explanation for adjustment difficulties as it has been argued that disability as a construct is unable to explain why siblings differ in adjustment outcomes (Stoneman, 2005).

Studies have often recruited through health care systems. This may exclude families who have not requested assistance or support from health care systems. A further consideration is also missing data from families at the other end of the scale who were so distressed that they isolated themselves from health care systems and consequently, research. Alternative ways of recruiting might therefore reduce this bias, for example through the education system.

Although there are a disproportionate number of disabilities in children from ethnic minorities and children living in poverty, most studies have focussed on white middle class traditional families (Moore, Howard and McLaughlin, 2002).

Studies have also used a high variability of participants in terms of age e.g. 3-7 years (Lobato, Barbour, Hall and Miller, (1987) compared to studies including children up to 18 (e.g. Breslau, 1982, Breslau, Weitzman & Messenger, 1981). However, issues appear to vary according to the developmental stage of the children concerned.

A further limitation of research is that it has relied almost completely on data from mothers of CWD. Little research looking at the effect on sibling adjustment has come from the standpoint of the sibling. For example, Guite *et al.* (2004) reported that although many previous studies have used parent reports to measure sibling adjustment, they found discordance in child and parent reports in their study. Others (e.g. Achenbach et al., 1987) have also emphasised the importance of obtaining sibling self-report measures.

A bias has existed concerning research expectations of negative family outcomes and individual maladjustment to the disability. It has been argued that researchers expect negative effects and so do not predicted positive outcomes for siblings of CWD (Moore, Howard & Laughlin, 2002). Assuming maladjustment in response to the presence of a disability, may distort the facts (Drotar & Crawford, 1986). However, all families experience stress in the course of their life times.

Families with and without the presence of a disability generally accommodate to change when the need presents itself. Adaptation to change and challenges brought on by a child with a disability can bring about competence to individual family members and to family units as a whole.

With more longitudinal research perhaps there would be less bias as researchers could gain insight from families who have done well over time regarding adjustment to challenges that occur. There have, however, been a limited number of longitudinal studies considering family adjustment in response to CWD, perhaps due to the expense in time and cost. Furthermore, very few studies had been replicated which also makes conclusions made following individual research studies extremely tentative.

Future directions

Following on from considering the limitations in current and past research, a number of factors need to be considered in carrying out future research.

Firstly, future research needs to be theory driven. The TSCM has been applied to understanding the adjustment of parents and the child with a disability, however many of its components that have been associated with parent and child adjustment have not yet been applied to understanding sibling adjustment. Research could therefore investigate further the impact of illness parameters e.g. severity of the disability, type of disability, adaptation processes, relationship influences in the family and demographic factors such as socio-economic status and ethnicity.

Secondly, the appropriateness of measures needs to be considered in sibling research, in terms of content and the source of information. In the research carried out, a number of instruments have been used; some of these instruments may be more sensitive and pick up differences which may not have clinical significance (Cuskelly, 1999). Measures addressing this potential limitation of findings include the Child Behaviour Checklist (Achenbach, 1991) and the Strengths and Difficulties Questionnaire (Goodman 1997, 1999) as these both include norms with clinical cut off scores to indicate problems that are clinically significant. However, some studies using the Child Behaviour Checklist (CBCL) have found differences in sibling adjustment to disability (e.g. Achenbach & Edelbrock, 1983) whilst others have not found that these siblings are at greater risk for psychosocial impairment. (e.g. ferrari 1984). This suggests that differences may not only be due to researchers using instruments that vary in their sensitivity.

Families could have both positive and negative experiences. If viewed as outcomes, positive perceptions are different outcomes to stress and other negative experiences. Both positive and negative dimensions should be measured as dependent variables in order to understand the full picture. With the recognition of the potential gains made living in a family with a child with a disability, some research has used positively framed measures, but this work is in its infancy.

Thirdly, siblings' views should be listened to, without reliance on parental or teacher reports. Many of the studies reviewed have relied on English speaking volunteers, so limiting generalisability, and have relied heavily on parent (especially mothers') assessments. This is an important consideration as identified risk of maladjustment has been shown to vary according to the source of information (e.g. parent, teacher, mental health professional, and sibling).

Fourthly, the focus should not be entirely on the assumption of maladjustment and negative effects. Further research needs to consider assumptions regarding disability as research plays an important part in shaping the way a family perceives themselves and their child with a disability. Research regarding siblings of CWD could be viewed as a natural continuation of the research on TD brothers and sisters (Brody & Stoneman, 1993). This might also reduce the selection bias which exists in research where groups have not always been representative, due to low rates of family participation.

To date research looking at positive factors related to living with a sibling with a disability is sparse. For example, current research does not deal with the question of whether families with a child with an intellectual disability differ from other families with regard to positive impacts (Stainton and Besser, 1998). Further research should consider the positive impacts on disability on the family in order to broaden our understanding of disability. Recognition that the experience may not be wholly negative and may indeed have many positive aspects may be encouraging for families raising CWD (Stainton and Besser, 1998). According to Pit-ten Cate and Loots (2000) more research is needed to explore the effect of positive adjustment outcome on the relationships using a theoretical framework.

Recent studies on family resiliency (Antonovsky, 1993; McCubbin, Thompson, Thompson, & McCubbin, 1993; Singer & Powers, 1993) found evidence that families are stronger and more flexible than was traditionally assumed so suggesting that research needs to consider an alternative focus rather than assuming 'the worst'.

There has been an increase in reports of positive outcomes or growth resulting from coping efforts. Anecdotal accounts indicate that people report that they have grown through their coping experience (O'Leary, Alday, & Ickovics, 1998). Empirical research has also shown that many people experience stress-related growth following stressful situations such as bereavement (Calhoun & Tedeschi, 1989-90), cancer

(Taylor, 1983), and HIV (Siegel, 2000). However, not all people feel they have grown from the stressful experiences and even when they have, this does not imply that they haven't had to face considerable challenges. A question to consider is why is it that some people feel able to gain from their experiences when others do not?

Fifthly, research considering issues of culture and ethnicity should be carried out. Few studies have taken account of cultural differences, so future research regarding cultural factors affecting sibling adaptation to childhood disability would be valuable as studies to date cannot be generalised across cultures.

A sixth consideration is that control groups need to be included in research, however it is recognised that it is difficult to define and recruit comparison groups that are comparable in age range, birth order, number of siblings, type and severity of the disability, socio-economic status, support systems available, and parental influences. These factors would need to be evaluated or controlled for statistically if the recruitment process does not allow for this.

Tew and Laurence (1973) were the first to use a comparison group in their study; however, they used more than one child from same families which may have confounded results (Lobato, 1983). Future research needs to consider the impact of using more than one sibling from families.

Ross and Cuskelly (2006) suggested that future research should use well-matched comparison groups of children with TD siblings to determine if siblings of children with ASD present with unique stressors in their sibling relationships. This can be applied in understanding the effect of any disability type; it would also be helpful to use comparison groups of siblings of children with different types and severity of disabilities in order to identify unique stressors and strengths between types.

There is limited knowledge on what siblings *actually do* for their sibling with a disability, over and above siblings of TD children. This needs further investigation, so that interventions can be based on an understanding of their actual needs, rather than on assumptions. A seventh point therefore, is that further questions need to be considered regarding exactly how a sibling relationship may differ in families with a child who has a disability. Knowledge can be gained on the extent that the sibling may be involved in a helping role for their brother or sister and the consequences of this.

Finally, researchers need to consider the ages of the siblings they are investigating and the changing needs and concerns based on developmental factors. In studies that are not longitudinal, they should perhaps narrow the age range used for participants as important factors may vary depending on the age of the siblings.

Conclusions

Research has produced inconsistent and contradictory data; this may be in part due to flawed methodology, which needs to be addressed in future research. This also means that interventions based on research that understands the real issues faced by siblings, such as whether they hold greater responsibilities than siblings of TD children, is unlikely to be possible at present.

Studying sibling adjustment is complicated as it seems that individual child and family characteristics influence sibling outcomes in adjustment to disability. These variables therefore need to be incorporated in future research. Sibling relationships and interaction may differ when a brother or sister has a disability, but little is known about how this is related to sibling adjustment. The voices of these young people need to be heard in order to address their needs or to understand the potential benefits of living with a sibling with a disability. There have been few applications of the TSCM in understanding sibling adjustment, which would be beneficial as it takes account of family variations and suggests how these may interact in producing different outcomes for siblings. The application of the TSCM to research may help to increase understanding of the high variability in psychological adjustment outcomes.

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Empirical paper*

The psychosocial adjustment of the siblings of children with physical and/or learning disabilities

Rachael Brown, BA (Hons), MS.c.

University of Southampton

Requests for reprints should be addressed to Rachael Brown, Doctoral Programme in Clinical Psychology, 34 Bassett Crescent East, Southampton, Hampshire, SO16 7PB, UK.

Email: rljb104@soton.ac.uk.

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(Appendix 2)

Abstract

Objective: This study compared the psychosocial adjustment of siblings of children with disabilities to siblings of typically developing (TD) children. Groups were also compared on quality of their sibling relationship and helping behaviour. Relationships between demographic characteristics, sibling role (helping), quality of the sibling relationship, disability parameters, and psychosocial adjustment (parental and child ratings) were also investigated. **Method:** Sixty-eight children who had brothers or sisters with a disability (disability group) and 46 siblings of typically developing children (control group) completed questionnaire measures on psychosocial adjustment, sibling helping behaviour and the quality of the sibling relationship. Primary care-givers completed measures of psychosocial adjustment and demographic characteristics. **Results:** No group differences were found on children's ratings of psychosocial adjustment. However parents reported significantly more adjustment problems for children of siblings with a disability. Children in the disability group reported more helping behaviour, less conflict and greater power in their sibling relationship. These differences were not associated with adjustment. The only significant predictor of adjustment (parent rated), was severity of disability. **Conclusions:** Severity of disability predicted parent rated sibling adjustment. Group differences were found in the sibling relationship and helping behaviour, although these did not predict adjustment as hypothesised. These findings confirm the importance of including sibling self-report and suggest that factors other than helping behaviour and the quality of the sibling relationship may affect adjustment. Implications for clinical practice and future research are discussed.

Key words: Sibling, disability, adjustment

Introduction

Over the last two decades an increased effort to investigate the impact of the presence of a child with a disability on the family has been noticeable in the research literature (Lavigne' & Faier-Routman, 1992). Research has shown that members of these families have been identified as being at greater risk of psychological adjustment difficulties (e.g. Sharpe, and Rossiter, 2002; Williams, 1997). Research has predominantly explored the impact on the affected child and their mother (e.g. Walker, Van Slyke and Newbrough, 1992). However it has been recognised that siblings' needs may have been 'forgotten' and more recently research has extended to understand children's experiences of having a sibling with a disability.

A number of studies have identified adverse effects on the typically developing sibling in families with a child with a disability. These include, reduced contact with friends, increased responsibilities, pressure to achieve and feelings of embarrassment and guilt, (social) isolation, loneliness, loss and resentment, depressive symptoms, and aggression (e g. Boyce & Barnett, 1993; Fisman et al., 1996; Hannah & Midlarsky, 1999; Hastings, 2003; Howlin, 1988; Knafl Nixon & Cummings, 1999; Rodrigue, Geffken, & Morgan, 1993; Roeyers & Mycke, 1995; and Zoeller, 1993; Summers, White, & Summers, 1994). Although most research has indicated an increased risk of internalising problems in these young people (e.g. Howe, 1993), there is some evidence of increased externalising behaviours as well. For example Rodrigue, Geffken &. Morgan (2005) found increased levels of internalising *and* externalising behaviours in siblings of children with autism, as compared to siblings of typically developing (TD) children. Traditionally, research has assumed these siblings will be negatively affected by the presence of disability in their family (Lobato, & Spirito, 1988). However, more recently positive outcomes have been reported as well such as increased understanding of others (Stainton and Besser, 1998). Many studies show high variability in adjustment (Lavigne & Faier-Routman, 1992) suggesting that the presence of a disability in itself does not directly cause adjustment difficulties and that some families are able to find ways of gaining from the challenges faced by the presence of a disability (Glidden, Kiphart, Willoughby, & Bush, 1992).

It has been argued that disability specific parameters affect children's adaptation and adjustment (categorical approach) (Stoneman, 2005). In contrast the non-categorical approach has focused on the common factors between disabilities to explain the effect of disability on adjustment (e.g. Nolan and Pless, 1986, Lobato, 1983). An alternative would be to adopt a semi-categorical approach whereby both commonalities and disease specific characteristics are considered. Differences in focus have resulted in differences in research findings not only in regards to the disability-adjustment relationship, but also to the role of adaptation processes. For example it has been found that disability type can reduce the influence of protective factors. In a study investigating sibling adjustment in families with children with pervasive developmental disorder (PDD), children with Down's syndrome and typically developing (TD) children, a cohesive family was protective for siblings of children in terms of reduced psychopathology. However, this was true only for siblings of TD children and of children with Down's syndrome, but not for siblings of children with PDD (Fisman, 1998). There have also been mixed findings regarding the impact of severity. The most salient predictor of sibling adjustment is severity in terms of impact on daily life (Sharpe and Rossiter, 2001), whilst other indicators may not show such strong associations (Eksi, Molzan, Savasir & Güler, 1994).

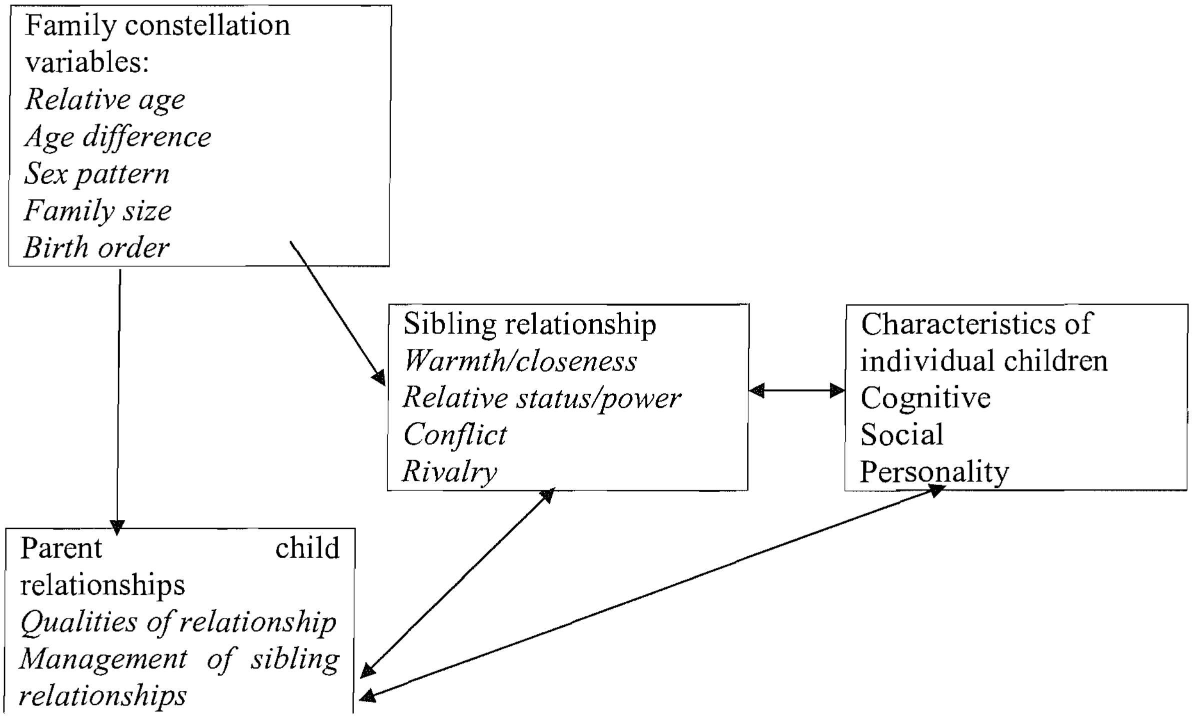
Another consideration when comparing research findings concerns the ways in which adjustment has been measured. Some studies have primarily focused on internalising problems (e.g. Stewart, Stein, Forrest & Clark, 1992) whilst others focused on externalizing behavioural difficulties (e.g. Thompson, Curtner & O'Rear, 1994).

Reviews have attempted to untangle the reasons for the contradictory findings and high variability by addressing methodological flaws and by considering differences and commonalities between families of children with disabilities and families with typically developing children (e.g. Lavigne, & Faier-Routman, 1992; Sharpe & Rossiter, 2001; Williams, 1997). One methodological issue regards the over reliance on parent accounts. This is a problem in that parent-child concordance commonly is found to be low (r = .4 - .6) (e.g. Connors and Stalker, 2004). Additionally, studies have often used small sample sizes (e.g. Silver and Frohlinger-Graham, 2000), and there is often an absence of control groups (e.g. Fielding et al, 1985, Hastings, 2006). A bias also exists in samples used, including the disability type, the ethnicity and socioeconomic status (SES) of participants selected, and frequently recruiting through health services, which may exclude families who have not requested assistance or support from health care systems (Sharpe & Rossiter, 2001). Conclusions from these reviews are that although a number of research studies have investigated how children are affected by having siblings with disabilities, (e.g. Lobato, 1987), there have been few systematic studies and findings have been inconsistent.

Despite a number of methodological issues highlighted in the research literature, factors associated with adjustment outcomes in siblings of children with disabilities have been identified. The ‘Transactional Stress and Coping Model’ (Thompson et al., 1993; Thompson, Gil, Burbach & Keith, 1993; Thompson, Gustafson, George & Spock, 1994), has highlighted illness (severity and type) and family characteristics (e.g. family constellation, SES) and adaptation processes (coping, family functioning) that may affect child and parent adjustment to illness/disability in the family. However, these factors need further investigation in their application to sibling adjustment.

It has been argued that supportive family functioning may mediate the impact of the 'stressful event' (presence of a disability) on adjustment, in that 'fair' parental management of children may influence the quality of sibling relationships which may, in turn influence sibling adjustment (Brody & Stoneman, 1996). Researchers have also suggested that family functioning and family roles may alter when there is a disability present (Williams, 1997), which may affect adjustment and the variability in adjustment. Furman and Buhrmester (1985) have identified factors that determine the quality of sibling relationships (see Figure I). This diagram emphasises the importance of family constellation variables, characteristics of the individual child as well as the quality of parent child relationships.

Figure I: A diagram of the main determinants of the quality of sibling relationships (From Furman, W. & Buhrmester, D., 1985).



One reason for the high variability in research findings is that the experience of having a sibling with a disability has been found to be more variable compared to experiences of siblings of children without a disability. For example, McHale, Sloan and Simeonson (1986) found that siblings of a child with a disability varied considerably in their views of the sibling relationship. This might explain some of the contradictions in existing research in terms of sibling adjustment. Furthermore, sibling interactions in families with a child who has an intellectual disability have been found to be more conflictual than when brothers and sisters are typically developing (Brody, Davis and Crapps, 1988).

To gain a better understanding of the range of experiences siblings of children with a disability have, it would be useful to investigate the quality of the sibling relationship. If differences in quality of sibling relationships can be identified this may help us understand sibling adjustment, though it would not address questions regarding the causes of these differences. One possible explanation might relate to differences in sibling roles and helping behaviour in families with children who have a disability. It might be that the role of the sibling is affected by the functional limitations experienced by their sibling. Functional status has been defined as: "The degree to which the child (can) perform daily tasks at an age appropriate level" (Lavigne and Faier-Routman, 1993, p. 119). Good functioning is shown when a child is able to use: "the full range of age appropriate physical, cognitive, emotional and social behaviours" (Dadds, Stein, and Silver, 1995, p. 529). If a child's functional status is impaired, siblings may be involved in helping behaviour, which may affect family functioning and the sibling relationship. Helping behavior has been conceptualized as those activities in which the 'helper' provides physical assistance, emotional support, tangible assistance, supervision, teaching, nurturance, or general aid to another person (Hannah & Midlarsky, 1999).

Caring is one type of helping behaviour and caring has been associated with higher levels of psychopathology. 'Burden of care' has been highlighted as an area of growing concern in sibling adjustment (e.g. Coleby, 1995). To investigate helping behaviour of siblings, Midlarsky (2005) compared siblings of children with learning disabilities (LD, N=50) and controls (N=50) on four dimensions of helping behaviour. Results showed that siblings of children with LD engaged in higher levels of certain types of care, i.e. emotional support and custodial care, as rated by their mother, whereas self report measures identified higher levels of custodial care. This research supports past evidence that the care-taking role is elevated when one sibling has a disability (Boyce & Barnett, 1993), however the study did not address the possible effect of elevated care-taking on psychosocial adjustment. It has been reported that female siblings may have the greatest increase in responsibility for household tasks and child care (Lobato, Barbour, Hall, & Miller, 1987), suggesting a more negative impact on females' social activities. This may explain findings suggesting that especially older sisters are at greatest risk of adjustment difficulties (Gath, 1974).

It has been suggested that internalising behaviours are the most likely response to greater care taking demands (Gold, 1993). Frustrations arising from parental inattention or care taking responsibilities may not be easily externalised by the healthy sibling into behaviours such as aggression, given the difficulties experienced by their brother or sister (Sharpe, and Rossiter, 2002). The 'helper' role may influence the nature of sibling relationships, for example with the TD child taking on a more dominant role, which in turn could translate to how these young people relate to others in the wider community as well as their psychosocial adjustment. Adjustment outcome therefore needs to be measured in terms of possible effects on peer relationships, and internalising problems. Studies have shown the reverse in problems of hyperactivity, which has been shown to be lower in children with siblings with Down's syndrome and mixed aetiology learning disabilities when compared to a normative sample (Hastings, 2006).

Results of research focusing specifically on age trends in emotional support and caretaking vary, with some researchers finding increases in care giving with age (Bar-Tal, Raviv, & Goldberg, 1982; Berman, 1987) and others finding no increases (Gottman & Parkhurst, 1980). Age also influences sibling adjustment with younger siblings reporting more concerns regarding parental attention, and sibling resentment. At school age (6-12 years), other factors predominate, such as division of responsibility, limited family resources for recreation and need for information. As adolescents, siblings seem to be more focussed on dealing with stigma, over-identification with their sibling, and participation in sibling training programs (Turnbull and Turnbull, 1990). At secondary school age (11-16), most children are still living at home but are beginning to make more choices for themselves and their peer group becomes more significant. It may be that assisting with chores at home may impact on their peer relationships, and this may be more noticeable at the age when children are beginning to become more independent of their families. For adolescents, research has indicated they are more likely than their peers to experience problems relating to going out and taking part in social activities (Crnic & Leconte, 1986) which may in turn impact on their adjustment.

Few studies have attempted to identify the positive aspects associated with being raised in a family with a child with a disability. However, some reports have highlighted positive effects including increased maturity, social competence, insight, tolerance, pride and loyalty (e.g. Williams, 1997). It may be that these siblings may demonstrate greater pro-social behaviour i.e. helpful behaviour intended to benefit another, in response to the needs of their brother/sister with a disability and through ongoing efforts to be the ‘easy’ or ‘good’ child (Seligman, 1983).

In reviewing the literature there are many mixed views and questions left unanswered with a need identified for further research. This study has been conducted to address some of the questions, as outlined below.

Research Questions

1) Do siblings of children with disabilities (Sib^d) experience more psychosocial adjustment difficulties than siblings of typically developing children (Sib^c) as rated by both parent and sibling?

It is hypothesised that parents and children will report greater adjustment difficulties in families with children with disabilities, especially in regards to internalising problems. In addition, ratings of pro-social behaviour are expected to be higher in the disability group.

2) Do siblings of children with disabilities (Sib^d) report a difference in the quality of their relationship with their brother or sister as compared to typically developing siblings (Sib^c)?

It is expected that the sibling relationship may differ in quality for siblings of children with disabilities, especially in regards to levels of conflict (e.g. Brody, Davis and Crapps, 1988) and warmth and closeness, with greater warmth being found more frequently between siblings when one has a disability (Stoneman, 2001). Siblings may differ in terms of power as this has occasionally been observed. For example in a study of siblings playing with their brother or sister with cerebral palsy (N=64), the child with the disability was found to be more passive and their typically developing sibling to be more directive. The child with the disability appeared to take on the role of the younger child regardless of age or birth order. Control dyads were more egalitarian in their interactions. (Dallas, Stevenson & McGurk, 1993). Others have also found this power difference (Farber & Jenne, 1963; Stoneman, 2005). In summary, it is expected that siblings of children with disabilities (Sib^d) will report higher levels of conflict, warmth/closeness and power compared to siblings of TD children (Sib^c).

3) Do siblings (Sib^d) report more helping behaviour than siblings of typically developing children (Sib^c)?

Siblings of children with disabilities (Sib^d) are expected to report more helping behaviour (Midlarsky, 2005).

4) Is there a relationship between the following and sibling adjustment (sib^d)?

a) Demographic characteristics (family size, gender, birth order).

b) Disability parameters (Level of functional impairment/activity of daily living problems).

c) Sibling 'helping' role (Emotional support, custodial care, information giving and tangible aid).

d) Sibling relationship (Warmth/closeness, rivalry, power/status and conflict).

Increased severity, higher levels of helping behaviour, and reduced quality of sibling relationships are expected to be negatively associated with adjustment problems and positively associated with pro-social behaviour.

Method

Design

A mixed design was used, comparing sibling and parent ratings of psychosocial functioning (within subjects) and the impact of disability on psychosocial functioning (between subjects). Independent variables included demographic characteristics, i.e. SES, age, gender, and birth order; disability characteristics, type and severity; the quality of sibling relationship and the sibling helping role. The dependent variable was psychosocial functioning, i.e. behavioural difficulties and pro-social behaviour.

Participants and Procedure

School of Psychology ethics approval was obtained prior to recruiting participants (see Appendix 3). Although data were gathered for 143 respondents, there were 114 complete data sets (both sibling and parent report) for children/young adolescents who had siblings either with or without disabilities and for their primary care givers. Families/siblings of children with disabilities were recruited in 3 ways: via school for children with special educational needs; via sibling support groups; and by following up a large sample of families of children with spina bifida and/or hydrocephalus previously recruited as part of the Child Health and Behaviour Study (CHADS, Stevenson & Pit-ten Cate, 2003). The control group of siblings of typically developing children (Sib^c) was recruited via mainstream schools. For all participants, both parent and child written consent were obtained. Questionnaires were administered either by sending paper copies home to complete or online. Information, permission letters and parent questionnaires were sent directly or via school to the parents (see appendices, 4 and 5). On receiving completed questionnaires, their children received either the web-link for online completion or were posted their questionnaire, depending on their preference.

Measures (see Appendix 6)

Demographic characteristics

Parents were asked to indicate their ethnicity, the age of both parents, school type of both the sibling (Sib^d) and their brother or sister (IC^d), family size, number of children they have with special needs and whether the sibling (Sib^d) attended a support group. Siblings (Sib^d and Sib^c) reported age and gender for both themselves and their brother or sister (IC^d and IC^c).

Disability parameters

The main analyses compared the Disability Group (siblings of children with a known disability; Sib^d) and the Control Group (siblings of children with no known disability; Sib^c).

Exploratory analyses categorised participants as siblings of typically developing children (control group), siblings of children with physical disabilities or sensory impairments (PD group), siblings of children with learning disabilities or social communication problems (LD group), or siblings of children with mixed learning and physical disabilities (MIX group).Two severity measures were adapted from measures used by Goodman and Yude in their studies involving families of children with cerebral palsy (Goodman, personal communication 1999). The first 6 item measure considered the amount of interference of the disability on the child's life (INT), e.g. 'How much do learning problems interfere with your child's life?' Questions are answered in a 3 point scale 0= 'No Problem', 1= 'Minor Nuisance', and 2= 'Makes a big difference'. The second severity measure regarded the amount of difficulty the child might have with activities of daily living (ADL), e.g. 'Does your child have difficulty with dressing?' The 6 items were rated on a 3 point scale: 0= 'No problems'; 1='Slight problems' and 2='Major problems'.

Item totals were summed and recoded between 0-3, 4-7, and 8-12 none, slight, and major problems respectively to gain severity scores on the INT and ADL for both the IC^c and IC^d. The rationale for all participants (both control and disability group) completing measures of severity relating to their brother or sister's functioning was that severity was conceptualized in a way also applicable in a 'typically developing' (control) population. It could not be assumed, for example, that the problems being rated, such as 'Teasing by other children' or 'Physical problems interfering with everyday life, sport and so on' only occur for children with a disability. The internal consistency of these scales was explored in a recent study looking at problems in children with hydrocephalus and spina bifida, and revealed Alpha internal consistency coefficients of .67 and .80 for the INT and ADL measures respectively. (Stevenson & Pit-ten Cate, 2003).

Adjustment

Adjustment of the siblings (Sib^c and Sib^d) was measured using 'The Strengths and Difficulties Questionnaire' (SDQ, Goodman 1997, 1999). Two versions were used in this study, the parent rated SDQ and the child's self reported SDQ. The parent rated SDQ is a 25 item behavioural screening questionnaire for use with children aged 4 to 16. Sample items include: 'Considerate of other people's feelings', 'Restless, overactive, cannot stay still for long'. The child's version (aimed at children aged 11-16) also has 25 items which map on to the parent version, such as 'I try to be nice to other people. I care about their feelings'. 'I am restless, I cannot stay still for long'. The questionnaire includes both negative and positive items. The items address: emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems and pro social behaviour (referred to throughout as SDQ emotion, conduct, hyperactivity, peer problems and pro-social). The respondent answers questions with one of the following options: Never, Not Very Often, Sometimes, Very Often, and Always. Scores of the first four subscales can be summed to derive a total difficulties score with a maximum score of 40 and minimum score of 0. In the present study, mean scores were computed and the four subscales are also analysed separately. The SDQ also has cut-off scores that suggest problems of clinical significance. The cut-off scores are considered in comparisons between the control and disability group.

Test-retest reliability of 0.85 has been reported for the SDQ total score (Goodman, 1999). It has also correlated highly with the Child Behaviour Checklist (Achenbach, 1991) and the Rutter questionnaires (Elander and Rutter, 1996) and has been able to discriminate between low and high-risk samples (Goodman, 1997; Goodman and Scott, 1999). It has been found to be a valid short measure for assessing and screening childhood behavioural and emotional problems. With the inclusion of pro-social behaviour it also increases the likelihood that parents will consent to it being administered (Goodman and Scott, 1999).

Sibling relationship

To measure the nature if their relationship, the short form 'Sibling Relationship Questionnaire' (SRQ-SF; Furman and Buhrmester, 1985) was completed by the children. The SRQ was developed in order to assess perceptions of relationships from the perspective of children (middle childhood to adolescence). The SRQ-SF includes 39 items, these items relate to: warmth/closeness, relative power/status and conflict and rivalry. Sample items include "How much do you and your older sister care about each other?"(Warmth/Closeness scale), "How much are you and your sister mean to each other?" (Conflict scale), and "How much does your sister order you around?" (Status/power scale). Response options are a 5-point Likert-type format. Responses range from 1 (hardly at all) to 5 (Very much).
Items on the SRQ make up the factors described above (referred to throughout as SRQwarmth, power, conflict and rivalry). To make up SRQwarmth, scale scores for items measuring intimacy, pro-social behaviour, companionship, similarity, admiration by sibling, admiration of sibling, and affection are added together and averaged. The same is done for the factor scores for SRQpower which consists of items measuring nurturance of sibling, dominance of sibling, minus the scale scores of nurturance by sibling and dominance by sibling. SRQconflict scores consist of quarrelling, antagonism, and competition. The SRQrivalry score consists of maternal and paternal partiality. Each of the scale scores which make up the three factors are derived from averaging two or three of the 39 items. Means of both total and subscale scores are used in the analysis. The subscale 'warmth' ranged from 0-

75, ‘power’ from -15 to +15, ‘conflict’ from 0-25 and ‘rivalry’ from 0-25. Total scores ranged from -15 to 150 and is a sum of the subscale scores.

The questionnaire has been reported to be well validated, have excellent psychometric properties and has been used successfully in numerous studies of children and adolescents (e.g.,Brody, Stoneman and McCoy, 1994; Burhmester and Furman, 1990; Stoneman and Brody, 1993). The scale has been reported to be useful in assessing sibling interactions across contexts, is reliable and has a low association with social desirability and the instrument’s internal consistency has been found to be high with Cronbach’s alphas for the Negative and Positive Relationship Characteristics subscales being .96 and .95, respectively (Swift et al, 2003). The validity of the SRQ has also been supported in a study of sibling relations of individuals with a learning disability (Begun, 1989).

Sibling Role

The Sibling Helping Scale (SHS) from the Family Helping Inventory (Midlarsky, Hannah and Corely, 1995) was used. This measures type of help offered by the sibling: custodial care, emotional support, information giving, and tangible aid. The Sibling Helping Scale consists of 52 items that are rated on a scale ranging from 1 (*none)* to 4 (*very much*), indicating the degree to which the sibling has provided that kind of help to his or her brother or sister.

The measure includes items that are made as behaviorally explicit as possible in order to decrease variability attributable to subjective interpretations. The items are also intended to include helping acts that could be engaged in by both boys and girls. Internal consistency coefficients for the scales range from .79 for Tangible Aid to .96 for Emotional Support. Convergent validity has been demonstrated by significant correlations between the

Sibling Helping Scale and measures of social responsibility (Berkowitz & Lutterman, 1968), nurturance (Jackson, 1974), altruism (Rushton, Chrisjohn, & Pekken, 1981), and self-reports of helping behaviour (Midlarsky, Hannah, & Corley, 1995). Factor analyses yielded 4 internally consistent subscales for the SHS (Hannah and Midlarsky, 2005). Scoring of the SHS is computed by summing all the responses (ranging from 1 to 4) for all items. To gain a score of each helping factor, items relating to that factor are summed. In this study, total scores are used in both an overall helping score and for the subscales. Subscale scores ranged from 7-28 (custodial care), 24-96 (emotional support), 13-52 (information giving), and 7-28 (tangible aid). Total scores range from 7-204.

Data Analysis

Data analysis was conducted using SPSS 15, all tests carried out were 2-tailed and the alpha value was at a significance of .05.

Question 1 was addressed using t-tests to establish (a) differences between the disability and control groups in terms of total adjustment scores on the SDQ and (b) differences in pro-social behaviour. A MANOVA was used to determine whether there were any differences on the four subscales of the SDQ (emotional, conduct, hyperactivity, peer-related problems).

Question 2 was addressed using a t-test to establish differences between the groups on total SRQ scores. A MANOVA was applied to see if there were any group differences regarding SRQ subscales (warmth/closeness, conflict, power/status, rivalry).

Question 3 was addressed using a t-test to see if there were differences between the two groups in terms of overall helping behaviour (total score of the SHS). A MANOVA was conducted to see whether there were individual differences on any of the subscales of the

SHS between the disability and control group in terms of type of helping behaviour (emotional support, custodial care, tangible aid, information giving).

Question 4: Pearson correlation coefficients were computed to investigate the binary associations between demographic characteristics, severity of disability parameters, helping behaviour and quality of sibling relationship and SDQ total score. Based on the correlation matrix, the following variables were entered into a linear regression analysis to predict variance in psychosocial adjustment: illness parameters (ADL and INT).

Results

A total of 114 families participated in the study (68 in the disability group and 46 in the control group). Demographic characteristics are summarized in Table 1. Participants were 114 children and adolescents between the ages of 10 years 5 months to 17 years 3 months (Mean 14.05 years, SD, 1.69) and one of their parents (87% mothers). The mean difference in the age of index children and siblings (of whom some were older and some younger) was 0.4 years in the disability group and 2.5 in the control group. The majority of families in the disability group (76%) were recruited through the ASBAH database as well as through schools for children with special educational needs. The majority of families in the control group were recruited through mainstream schools (58%) as well as through youth groups. In families where more than one sibling was willing to participate, the child closest in age to the child with the disability or the typically developing index child was selected as the participant.

Scores on the parent rated SDQ were not significantly different when rated by mothers or fathers. The children and adolescents were categorized into one of two groups: (1) siblings of children with a disability (referred to as Sib^d) (2) individuals who had a sibling with no known disability (referred to as Sib^c). The index child they report on is referred to throughout as IC^d and IC^c respectively). Group differences were examined using chi-square for comparisons of gender, family size, ethnicity, birth order, parent jobs and parent age categories. A t-test was applied to look at age differences of the siblings (Sib^c and Sib^d) and their brother or sister (IC^c and IC^d). T-tests were also used to identify differences in gender and ethnicity. No significant differences between groups were found except for mother's job, with more mothers in employment in the control group than in the disability group. This difference may be related to the increased care demands of the child with a disability.

Table 1: Descriptive statistics, t-values and statistics for demographic variables

		Control N=46	Disability group N=68	Analysis	
		Mean (SD)	Mean (SD)	t	df
AGE	Sib	14.10 (3.02)	13.83 (1.40)	-.640	101
	IC	14.51 (4.04)	16.35 (4.29)	1.01	112

		% within disability	% within control	χ^2	df
Gender Sib	Male	49	36	1.82	1
	Female	51	64		
Gender IC	Male	63	61	.75	1
	Female	37	39		
Ethnicity	White/UK	80	75	11.73	8
	Other[a]	20	25		
Number of children	2	44	46	1.37	5
	3	33	32		
	4+	23	22		
Birth order (Sib=)	Younger	57	51	4.14	2
	Same	10	2		
	Older	33	47		
Mother's job	No job	38	23	13.92**	2
	Manual	14	0		
	Non-manual	48	77		
Father's job	No job	27	18	2.91	2
	Manual	24	19		
	Non-manual	49	63		
Mother's Age	Under 30	0	0	1.45	3
	30-35	7	8		
	35-40	17	18		
	40-45	46	36		
	Over 45	30	38		
Father's age	Under 30	1.5	0	1.41	4
	30-35	1.5	0		
	35-40	14	12.8		
	40-45	36	40.4		
	Over 45	47	46.8		

[a] African, Irish, Asian Indian, Asian Pakistani, mixed Race (Asian and white), and Chinese

*p=.05, **p=.001

Disability parameters

Disability is categorized as either no known disability (controls) or the presence of a disability (disability group). Within the disability group, index children fell into one of three categories (learning disability N=23, physical disability N=21 and 'mixed' N=17). Due to relatively low numbers, these types are compared in an exploratory analysis. Both parents and siblings reported the severity of the index children's difficulties in terms of interference in their functioning (INT) and difficulties in activities of daily living (ADL). Please see table 2 which presents the proportions of index children falling into the categories of severity. As can be seen, 50-59% of children were reported not to have problems regarding ADL and INT, suggesting that a large proportion of the individuals with a known disability are managing without major difficulties in these areas. Results also indicate that a minor population within the control group experience difficulties with problems interfering with everyday functioning (according to parents 7% of the index children experience slight or major difficulties and this is higher at 14% when rated by siblings).

Table 2: Proportions of index children rated by siblings and parents as having difficulties regarding activities of daily living (ADL) and having problems that interfere with their daily functioning (INT).

		Control Group N=46		Disability Group N=68	
		% Sibling Rated	% Parent Rated	% Sibling Rated	% Parent Rated
ADL	No problem	91	99	59	53
	Slight problems	6	1	22	24
	Major problems	3	0	19	23
INT	No problem	86	93	52	50
	Minor nuisance	11	6	27	30
	Makes a big difference	3	1	21	20

Findings relating to question 1

Do siblings of children with disabilities (Sib^d) experience more psychosocial adjustment difficulties than siblings of typically developing children (Sib^c)? Are there differences between groups on measures of pro-social behaviour?

As described above, analyses involved t-tests to look at differences between groups in terms of total adjustment ratings and pro-social behaviour, and a MANOVA was conducted to look at differences between groups on subscales of the SDQ.

Sibling self report

Descriptive statistics and results of the analyses are reported in Table 3. Mean scores for both the disability and control groups were within the normal range. It should be noted that in the disability group (*Sib*^{d}) 11 children (17%) scored within a clinical range on the SDQ total (cut off score >16) whilst for the control group (*Sib*^{c}), 6 children (14%) scored above the cut off). Although this suggests little effect of having a sibling with a disability on children's perceptions of their own functioning, it is notable that parent ratings did indicate a difference (see next page). However, in this study, slightly more siblings (14%) of typically developing children also scored in the clinical range than expected in a community sample which according to Goodman (1997) is 10%.

Results revealed no significant difference for total SDQ or pro-social behaviour. Results of the MANOVA showed no significant difference between groups on the four subscales of the SDQ. This does not support the hypothesis that siblings of disabilities (Sib^{d}) experience elevated levels of behavioural difficulty and display more pro-social behaviour compared to Sib^{c}.

Table 3: Descriptive statistics, t values and MANOVA summary for child rated SDQ

	Control Group N=44 Mean (SD)	Disability Group N=65 Mean (SD)	df	F	p
Multivariate	λ=.965		4, 104	.95	.44
Emotion	2.52 (2.16)	2.64 (2.20)	1, 107	.84	.77
Conduct	1.61 (1.53)	2.01(1.71)	1, 107	1.58	.21
Hyperactivity	3.39 (1.97)	3.83 (2.43)	1, 107	1.02	.32
Peers	1.29 (1.47)	1.80 (2.02)	1, 107	2.02	.16
			df	t	p
Total score	8.82 (5.37)	10.29 (6.21)	107	-1,28	.30
Pro-social	8.178 (1.74)	7.79 (2.15)	111	1.00	.32

Parent report

Descriptive statistics, t-test and MANOVA results are reported in Table 4. Mean scores for both the disability and control groups were within the normal range. It should be noted that parent ratings indicated that in the disability group (Sib^{d}) 34 children (42%) scored within the clinical range on the SDQ total (cut off score >14) whilst for the control group (Sib^{c}), only 4 children (9%) scored above the cut off). This indicates elevated vulnerability of siblings of children with disabilities (Sib^{d}). Results revealed parents in the clinical group reported significantly more adjustment problems (total SDQ), but equal levels of pro-social behaviour. Results of the MANOVA showed a significant difference between groups on all four subscales of the SDQ. These results support the hypothesis that siblings of children with disabilities experience more adjustment problems. However, in contrast with the prediction no differences in pro-social behaviour were found.

Table 4: Descriptive statistics, t-values and MANOVA summary for parent rated SDQ

	Control Group N=44 Mean (SD)	Disability Group N=65 Mean (SD)	Df	F	p
Multivariate	λ=.860		4, 121	4.91	<.01
Emotion	1.50 (1.91)	2.89 (2.47)	1,124	10.77	<.01
Conduct	1.33 (1.91)	2.10 (1.89)	1,124	4.85	.30
Hyperactivity	2.15 (2.16)	3.85 (2.75)	1,124	12.92	<.01
Peers	1.15 (1.63)	2.71 (2.57)	1,124	13.73	<.01
			df	t	p
Total score	6.13 (5.81)	11.55 (7.17)	110	-4.62	<.01
Pro-social	8.08 (2.24)	8.02 (2.10)	132	.15	.88

Results for parent ratings show that the effect sizes for disability group range from .22 - .52, indicating that parents scores are ¼ to ½ a SD *higher* than the normative sample. For the control group negative medium to large effect sizes are found, indicating that parents' ratings in this sample are at least ¼ SD *lower* than normative group, except for the subscales emotion and pro-social behaviour. For child ratings results indicate both disability and control group scores are similar to norm scores, except for conduct rating in the control group (ES -.29). See table 5 for a comparison between sibling and parent ratings on the SDQ.

Table 5: Norm sample ratings and comparison between child and parent ratings on the SDQ

Variable	Norm sample Mean (SD)	Disability group Mean (SD)	Effect size	Control group Mean (SD)	Effect size
PARENT RATINGS					
SDQ emotion	1.9 (2.0)	2.8 (2.5)	.40*	1.7 (2.0)	-.10
SDQ conduct	1.6 (1.7)	2.1 (2.0)	.26*	1.2 (1.7)	-.24
SDQ hyperactivity	3.5 (2.6)	4.1 (2.8)	.22	2.1 (2.1)	-.59*
SDQ Peer problems	1.5 (1.7)	2.6 (2.5)	.52*	1.1 (1.6)	-.24
SDQ Total	8.4 (5.8)	11.3 (7.2)	.45*	5.9 (5.7)	-.44*
SDQ pro-social	8.6 (1.6)	8.0 (2.1)	.32*	8.3 (2.2)	-.16
SIBLING RATINGS					
SDQ emotion	2.8 (2.1)	2.7 (2.2)	-.05	2.6 (2.2)	-.09
SDQ conduct	2.2 (1.7)	2.0 (1.7)	-.12	1.7 (1.7)	-.29*
SDQ hyperactivity	3.8 (2.2)	3.9 (2.4)	.04	3.5 (2.1)	-.14
SDQ Peer problems	1.5 (1.4)	1.9 (2.2)	.22	1.3 (1.5)	-.14
SDQ Total	10.3 (5.2)	10.3 (6.1)	.00	9.1 (5.5)	-.22
SDQ pro-social	8.0 (1.7)	7.8 (2.2)	-.10	8.2 (1.8)	-.06

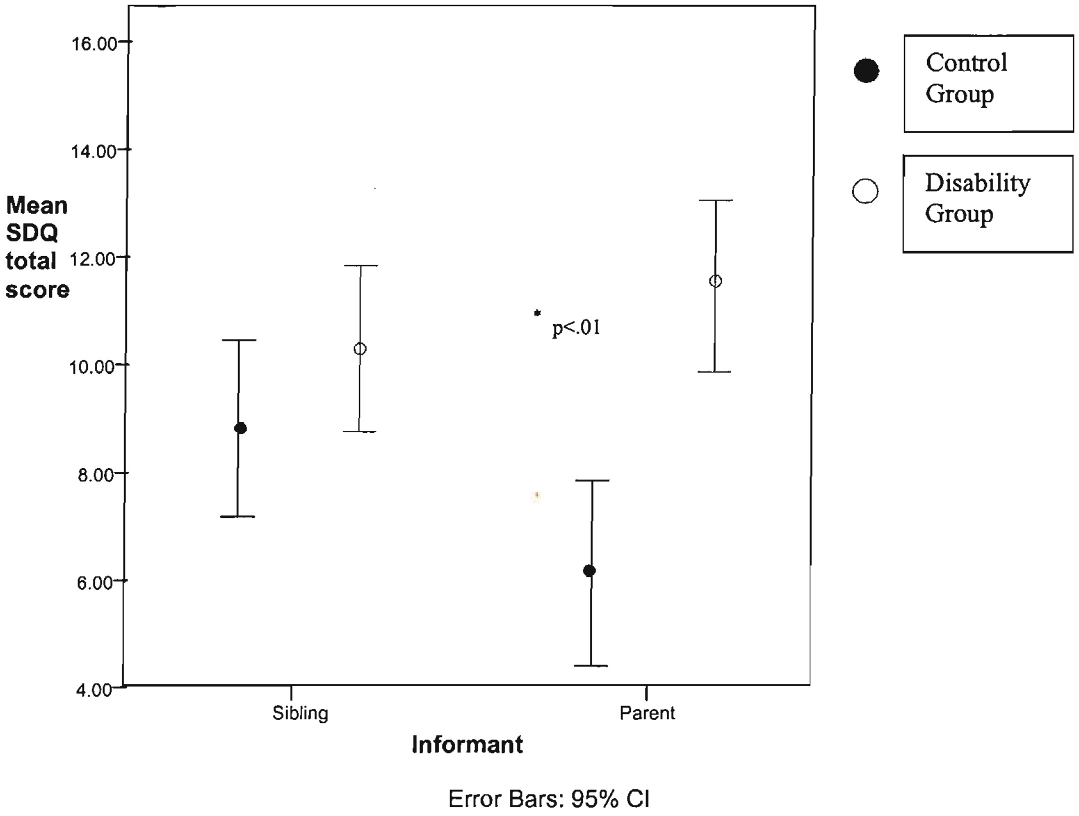
*Medium effect size ** Large effect Size (Cohen, 1992)

In summary: Parents in disability group report relatively more problems whilst at the same time parents in the control group report less problems than the normative sample. This results in significant differences between disability and control groups. The disability group ratings are comparable to previous findings in clinical samples (see Pit-ten Cate, 2003, page 130). Sibling self report does not indicate any psychopathology for the disability group, though children in disability group report relatively more peer problems than both the normative and control samples. The control sample report less behaviour problems than the normative group (ES total score = -.22). This difference is accounted for by fewer reported conduct problems.

Parent and child scores on SDQ ratings in the disability group were significantly different (parent M=11.32, SD=7.17; child M=10.29, SD=6.07; t(61)=12.42,p<.01). Ratings in the control group were also significantly different (parent M= 5.90, SD= 5.75; child M=9.12, SD=5.48; t(39)=6.50,p<.01) (see Figure 3).

At the same time correlations between parent and child ratings within the disability and control groups separately were similar (.53 and .41, respectively).

Figure 3: Mean SDQ ratings for parents and siblings in the disability and control group.



Findings relating to question 2

2) Do siblings of children with disabilities (Sib^d) report a difference in the quality of their relationship with their brother or sister as compared to typically developing siblings (Sib^c)?

The analyses for question 2 involved a t-test to look at differences between groups in terms of total ratings of their sibling relationship. A MANOVA was conducted to look at differences between groups on subscales of their self-reported measure of their sibling relationship (see Table 6).

Results of the t-test revealed no significant differences between groups for total SRQ scores. However MANOVA results for the subscales scores did reveal significant differences. Univariate results revealed that there was a significant difference in their ratings of 'power and status', with Sib^d children rating themselves as more dominant than the control group. Significant differences were also found in the rating of sibling conflict, whereby Sib^d children reported less conflict. These results are partly in keeping with hypotheses expecting greater ‘status’ of the child when their sibling has a disability but the reverse in terms of conflict as it was hypothesised that siblings of children with disabilities would experience greater levels of conflict.

Table 6: Descriptive statistics, t-values and MANOVA summary for Sibling relationship questionnaire

	Control Group N=44 Mean (SD)	Disability Group N=65 Mean (SD)	df	F	p
Multivariate	λ=.88		4,87	3.02	<.05
Warmth/closeness	46.69 (10.96)	47.44 (10.03)	1,90	.114	.74
Power/Status	-.86 (7.51)	2.86 (4.57)	1,90	8.74	<.01
Conflict	18.49 (5.01)	16.14 (5.18)	1,90	4.55	<.05
Rivalry	17.26 (2.09)	17.37 (2.89)	1,90	.039	.84
			df	t	p
Total score	81.57 (14.38)	83.81 (11.58)	90	-.82	.42

Findings relating to question 3: Do siblings (Sib^d) report more helping behaviour than siblings of typically developing children (Sib^c)?

The analyses involved a t-test to look at differences between groups in terms of total ratings of helping behaviour, and a MANOVA to look at differences between groups on subscales of the self-report sibling helping scale (SHS) (See Table 7). Siblings of children with disabilities (Sib^d) did report greater levels of helping overall. This difference was accounted for by emotional support and custodial care subscales. This finding supports the prediction that children in the disability group would help more, and especially in the domains of custodial care and emotional support.

Table 7: Descriptive statistics, t-values and MANOVA summary for sibling helping scale.

	Control Group N= 42 Mean (SD)	Disability Group N= 52 Mean (SD)	df	F	p
Multivariate	λ=.83		4,89	4.48	<.01
Emotional Support	53.32 (15.44)	60.63 (18.57)	1,92	4.06	=.05
Custodial Care	11.52 (3.68)	14.30 (4.97)	1,92	9.13	<.01
Tangible Aid	12.19 (2.54)	13.06 (3.73)	1,92	1.65	.20
Information giving	27.29 (8.54)	28.15 (8.78)	1,92	.23	.63
			df	t	
Total score	104.42 (25.72)	116.15 (32.68)	92	-1.95	=.06

Findings relating to question 4

To what extent is sibling adjustment associated with:

(a) Demographics (no of children, gender, birth order, age)

(b) Disability parameters (Level of functional impairment/activity of daily living problems)

(c) Sibling helping behaviour and quality of the sibling relationship

To investigate the relationship between gender and adjustment t-tests were conducted. These revealed no significant effects of gender on parent-rated or child-rated adjustment in either the disability or control groups. Similarly, an ANOVA revealed no significant birth order differences between siblings who were younger, the same age or older than the index child. To review the relationships between variables both a correlation and a regression analyses were conducted for the whole sample. Both children in the control and disability group were included as a number of children in the control group were also experiencing difficulties with ADL and general difficulties interfering with their lives (INT).

The interrelationships between variables were first explored correlationally as shown in Table 8. In order to determine whether any variables which were individually predictive of sibling adjustment accounted for additive rather than overlapping portions of the variance, those which were significantly correlated with adjustment were then entered as predictors in a regression analysis. The intercorrelations only partially support the hypothesis, i.e. disability characteristics are associated with adjustment, but family demographics (age, number of children), sibling helping, and the quality of the sibling relationship are not (see Table 8). Significant correlations existed however for severity indicators and the sibling helping (SHS total and subscale scores) and quality of sibling relationship (status), i.e. higher levels of severity were associated with more helping behaviour and more status. However, these variables were not associated with the outcome variables (SDQ scores) and so although related to disability, were not related to adjustment outcome.

Table 8: Intercorrelations between demographic data, disability parameters (as rated by parents), sibling adjustment as rated by parents and children, overall helping behaviour and custodial care and emotional support and the sibling relationship in terms of power and conflict.

$^{*}p<.05$ $^{**}p<.01$ $^{***}p<.001$

	V1	V2	V3	V4	V5	V6	V7	V8	V9	V10	V11	V12
V1 SDQ parent	1											
V2 Age Sib	.12	1										
V3 SHS ES	-.02	-	1									
V4 SHS CC	.15	.05	.66**	1								
V5 SHS Total	.04	-	.95**	81**	1							
V6 INT	.43**	.06	.33**	.43**	.36*	1						
V7 ADL	.30**	-	.41**	.49**	.44**	.60**	1					
V8 SRQ POWER status	.11	.01	.19	.41**	.29**	.28**	.24*	1				
V9 SRQ conflict	.08	-	-.10	-.06	-.09	.01	-.09	-.20*	1			
V10 SRQ Total	-.05	-	.62**	.40**	.59**	.11	.11	.38**	.28**	1		
V11 SDQ Child	.49	.05	-.07	.07	-.04	.30**	.19*	-.02	.29**	.001	1	
V12 no children	-.11	.03	.04	-.04	-.01	-.10	.07	-	.19	-.04	.15	1

V1= Parent SDQ Total
V2= Age of the sibling
V3= SHI Emotion
V4= SHI Custodial care
V5= SHI Total
V6= Parent rated INT
V7= Parent rated ADL
V8=SRQ Power
V9=SRQ Conflict
V10=SRQ total
V11=Child SDQ Total
V12=Number of children

Regression analysis is normally applied to datasets in which IVs are correlated with one another and with DV in varying degrees (Tabachnick and Fidell, 2001). Both ADL and INT were individually significantly correlated not only with parent-rated SDQ (0.30 and 0.43 respectively) but also with each other (0.60). Reflecting this, once INT was taken into account in the regression analysis ADL did not explain significant additional variance. Therefore, only disability characteristics (severity in terms of level of interference and activities of daily living) were included in the regression. Results from the linear regression (see table 9) revealed that 17% of the variance in sibling adjustment (as rated by their parents) could be explained by severity of disability however only the level of interference (not ADL) was significantly predictive of sibling adjustment ($p<.01$).

Table 9 Summary of linear regression analysis for severity of disability (activities of daily living (ADL) and level of interference (INT), predicting adjustment (parent rated total SDQ) (N=101)

Variable	B	SE	ß
Step 1			
ADL	.223	.260	.099
INT	.980	.322	.351*

Adjusted $R^2 =$ ·17 for step 1 *$p<.01$

Additional exploratory analyses

Some exploratory analyses were conducted to investigate the possible influences of siblings (Sib^{d}) attending a support group and type of disability on adjustment. In addition, the relationships between disability, gender, and sibling helping behaviour were explored.

Sibling's Attendance at a support group

The disability group was divided into those children who attend a sibling support group and those who do not. Mean parent rated SDQ scores were 8.17 (SD=7.13) for those attending a support group (N=12) and mean scores for those not attending were 11.73 (SD=6.92) (N=49). Results of a t-test revealed these differences were not significant, i.e. t(df=59)=-1.59 p=.12

Disability type

An exploratory analysis applying an ANOVA looked at type of disability and its impact on adjustment, quality of sibling relationship and sibling helping behaviour respectively. Groups were divided into physical disabilities/sensory impairments (PD) (N=21), learning disabilities/social communication problems (LD) (N=23) and 'mixed' (MIX) (N=17) which included siblings of children with both LD/PD. No significant differences were found between these groups in terms of the adjustment, sibling relationship and sibling helping behaviour (see appendix 7 for tables).

Effect of gender on helping behaviour

In order to explore whether girls tended to take on more helping roles than boys, and whether this tendency differed depending on whether or not they had a disabled sibling, a MANOVA was conducted with the four 'helping behaviour' subscales as DVs. Gender (male vs female) and Disability (disability vs no disability) were between-subjects factors.

Table 10 MANOVA comparing helping behaviour in male/female participants across groups.

	Males		Females	
	Disability	Control	Disability	Control
	N=20	N=13	N=26	N=24
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Multivariate	Λ=.942			
Emotional support	50.05 (15.73)	46.08 (14.17)	68.57 (17.68)	57.08 (15.51)
Custodial care	12.20 (4.03)	11.08 (2.46)	15.73 (5.03)	11.04 (3.65)
Tangible aid	11.10 (2.45)	11.85 (3.16)	14.42 (4.13)	12.29 (2.24)
Information	23.25 (6.40)	25.23 (7.91)	31.04 (9.01)	27.96 (8.91)
Total Help	94.23 (23.83)	108.37 (26.22)	96.60 (24.94)	129.77 (32.24)

*p< 05. **p=001

Results of a MANOVA show a significant multivariate effect caused by differences in subscales. For the total score, there was a main effect of gender (F = 14.13, p < .01) and a trend towards a main effect of Disability (F = 3.57, p = .06), but no GxD interaction (F = 2.28, ns). There were differences between subscales, with gender effects being found for Emotional Support (F = 16.27, p<.001), Tangible Aid (F = 6.99, p<.01) and Information-Giving (F = 7.84, p<.006) but not Custodial Care (F = 3.53, ns). There was a main effect of

Disability for Emotional Support (F = 4.46, p = .038) and Custodial Care (F = 9.75, p =.003) but not for Tangible Aid (F = 0.95, ns) or Information Giving (F = 0.09, ns). There was no significant GxD interaction for any of the subscales. Results therefore indicate that girls offer more emotional support, tangible aid and information giving. Siblings in the disability group offer more emotional support and custodial care. No interaction effect was found in total help scores indicating that girls help more generally, irrespective of disability and siblings help more if their brother or sister has a disability.

Discussion

This study examines the relationship between illness parameters, sibling helping behaviour and the sibling relationship to adjustment outcomes for siblings of children with a disability, as well as comparing their adjustment to siblings of children with no known disability. Results will be summarised and following this, possible interpretations of the current findings will be made. Strengths and limitations of this study will be discussed before consideration of the next steps regarding future research and clinical practice.

Summary of findings

In contrast to predictions, siblings in the disability group did not report greater adjustment difficulties than siblings in the control group. In comparing their ratings with normative data on the SDQ, children did however report more peer-related problems. In line with previous findings, parents rated greater adjustment problems of siblings in the disability group. These parents rated greater adjustment difficulties across all areas measured: emotional problems, conduct problems, hyperactivity and peer relationships, suggesting parents have concerns regarding their child's adjustment not only in terms of internalising behaviour as previous research has predominantly found. Neither parents nor children reported a significantly different level of pro-social behaviour between the two groups (control and disability). Although it was hypothesized that they may demonstrate greater pro-social behaviour due to a possibly more elevated ‘helping role’, this was not found to be the case. Current findings are consistent with research that has found a discrepancy between parent and child ratings of adjustment, with parents reporting greater adjustment problems (Cuskelly, 2004).

Results indicated that Siblings in the disability group (Sib^d) rated having greater status and power compared to their brother or sister (IC^d). This is in line with previous findings (e.g. Dallas, Stevenson & McGurk, 1993; Farber & Jenne, 1963; Stoneman, 2005). The relationships were not significantly different for warmth and closeness, which is in contrast to the hypothesis that there would be greater warmth between brothers and sisters in the disability group. Conflict was lower between siblings in the disability group. This finding was inconsistent with previous research reporting greater conflict between siblings when one child has a disability (e.g. Brody, Davis and Crapps, 1988).

Corresponding with previous research, siblings of children with a disability were found to take on a more helping role and in line with previous research this was mostly in terms of emotional support and custodial care (Midlarsky, 2005).

In examining whether demographic factors, disability parameters, the sibling role and relationship influence adjustment, it was found that the only significant predictors were disability severity (effect on activities of daily living (ADL) and level of interference (INT)). These two predictors were highly intercorrelated, and once INT had been taken into account the effect on ADL did not explain any additional variance in sibling adjustment.

Exploratory analyses revealed that those siblings of children with a disability who attended a support group did not show better adjustment than siblings without such support. However, with the relatively small sample here - only 12 out of 61 siblings attended a support group – the study may have lacked the power to detect an effect. In comparing the adjustment, sibling relationship, and sibling helping behaviour of sib^d according to disability type (physical, learning, mixed) no significant differences were found. This suggests that the experience of a sibling with a disability may have many similarities across types of disability. Helping behaviour comparing male and female siblings in the control and disability group showed that girls help more generally, irrespective of whether their brother or sister has a disability. Although female siblings help more in general and siblings of children with a disability help more, an interaction effect of gender by group was not found.

Interpretation of findings

Possible explanations for the discrepancy in parent-child reports include under-reporting by the child participants of their adjustment problems. This is consistent with views that these children may want to appear to be the 'good' or 'easy' child (Seligman, 1983). Alternatively, they may see their siblings' problems as much bigger and therefore have a greater tolerance of any problems they may experience. Possibly, parents may be more anxious and therefore sensitive to the possibility of adjustment problems and may over report difficulties. Relative to normative data, parents of children with a disability rated non-disabled siblings as having elevated adjustment problems whilst those who did not have a disabled child rated their children as being better adjusted than average. Parents' ratings were moderately correlated with the children's own ratings, to the same degree whether or not the family included a child with a disability, and so it seems unlikely that there were any systematic biases (e.g. produced by anxiety) in the ratings given by parents for children with a disabled sibling. This suggests that parents may have a similar level of agreement with their children's subjective adjustment regardless of whether they live with a sibling who has a disability.

This research supports previous findings of increased adjustment problems in children who have a sibling with a disability as reported by parents (e.g. Sharpe, and Rossiter, 2002). However, problems highlighted in previous research have generally been regarding emotional difficulties (Howe, 1993). Conduct problems have also been identified, although this is less frequent. For example in a study investigating siblings of children with either cystic fibrosis, spina bifida or cerebral palsy, the siblings were found to be at greater risk of delinquency and fighting (Breslau, Weitzman & Messenger, 1981). In contrast with our findings, hyperactivity has been identified in the literature as being lower in siblings of children with disabilities (Hastings, 2006). This may be in part due to the disabilities represented in their study being Down's syndrome and autism which have both been associated with higher levels of hyperactivity (Hastings, Beck, Daley, & Hill, 2005). Type of disability may therefore be important in considering how siblings respond. It could be that where higher levels of hyperactivity exist in the index child, parents may see a greater contrast with the sibling. Hyperactivity could also be a greater problem at certain ages and so may have been be less apparent in the research by Hastings (2006), which had a sample covering a broader age range. This is in line with other research findings that, despite elevated levels of internalising and/or externalising problems in siblings of children with disabilities (Fisman et al., 2000; Coleby, 1995, Cuskelly & Dadds, 1992; Nixon & Cummings, 1999) the scores of the majority of siblings did not fall into the clinically significant range. This may be reassuring to parents, and suggests that many siblings may not need substantial input from health and other professional services. Nevertheless, in the present study SDQ ratings by parents indicated that almost half of the children with a disabled sibling did fall into the clinical range whereas this was the case for only 9% of children without a disabled sibling. Similarly, Ross and Cuskelly (2006) also found that although the mean levels of internalising and externalising behaviour scores were within the normal range for siblings of children with autistic spectrum disorder, 40% of the siblings were reported by their mother to have significant adjustment problems. Thus even though the majority of children appear to cope reasonably well, there is a sizeable minority for whom the presence of a disabled sibling is associated with the appearance of significant levels of disturbance, and for these children – whose needs may often be overlooked in the context of those of the disabled child - it is important to identify whether there are useful forms of professional support which could help their adjustment.

The comparisons regarding the quality of the sibling relationship between the groups showed more similarities than differences between these groups. This was true with the exception of a significant difference in the power and status of the sibling and the level of conflict. Compared with children whose sibling was not disabled, children with a disabled brother or sister perceived themselves to have a greater degree of elevated power and status relative to their sibling. This is in keeping with the predictions made. Conflict, on the other hand was lower in the disability group, which is in contrast with previous findings (e.g. Brody, Davis and Crapps, 1988). A possible explanation for this could be that conflict has greater meaning in families with a child with a disability. For example, Nixon and Cummings (1999) devised hypothetical situations of everyday examples of family conflict. Siblings of children with a disability reported higher levels of anxiety and sadness and responsibility in response to these hypothetical conflicts. It may be that conflict has a greater consequence in terms of increased feelings of guilt. In order to reduce those feelings they may attempt to fight less with their brother or sister. Alternatively, they may report less conflict as 'remembering' less conflict reduces their distress. Stoneman and Brody (1993), in a study of 67 same-gender school age sibling pairs, found that when siblings had quite low activity levels, conflict was lower. The difference in findings in this study may be a consequence of the disability types included in this sample. It may be that less conflict has been found in this study due to the high proportion of index children who experience physical limitations, and therefore possibly lower activity levels.

As expected, siblings in the disability group do appear to offer more help to their brothers or sisters especially in terms of emotional and custodial care. Previous research has suggested that when a sibling has a more severe disability, the burden of care for their brother increases which in turn leads to more adjustment problems (Damiani, 1999). However, unexpectedly, helping behaviour did not seem to be related to adjustment. Possible reasons for this may include the protective factors such as support and coping resources, or the higher levels of helping behaviour being carried out by girls. The age of the sibling, birth order, gender, family size was not associated with sibling adjustment. This supports some previous research which has also shown little effect of these variables (e.g. Eisenberg, Baker, & Blacher, 1998; Gold, 1993; Hannah & Midlarsky, 1999; Mates, 1990; McHale, Sloan, & Simeonsson, 1986; Roeyers & Mycke, 1995). However, others have found these to be influencing factors, such as the protective nature of a large family size (Kaminsky & Dewey, 2002). This study confirmed the strong associations found between disability severity and adjustment. More specifically, severity indicated by limitations in the level of interference with other parts of life (e.g. ability to learn), affected sibling adjustment. This has been most often reported as a top predictor of adjustment.

Exploratory analyses comparing disability types indicated that the type of disability did not affect sibling adjustment. Additionally support group attendance was not associated with differences in adjustment within the disability group. Evans, Jones and Mansell (2001) examined the effectiveness of a programme designed to support siblings of disabled children with learning disabilities and challenging behaviour. Results showed that siblings attending the group increased their knowledge about learning disabilities, involvement with their disabled sibling, and their own self-esteem. Parents also reported an improvement in family relations. However, in a study investigating the psychological adjustment of siblings of children with ASD, knowledge of their brother or sister's disorder was found to be unrelated to adjustment as measured by the child behaviour checklist (Achenbach, 1991). In this study an effect of support group attendance may have been undetected because of low statistical power, with only 12 of 61 siblings attending such a group. 'Support' comes in many different forms and may also benefit siblings indirectly. For example, siblings may benefit from parents receiving support. Future research could more clearly define support and investigate further the relationship between this and sibling adjustment.

Furman and Buhrmester (1985) identified factors that determine the quality of sibling relationships. Factors addressed in this study were, sibling warmth/closeness, power/status, conflict and rivalry. In comparing siblings of children with disabilities to those of typically developing children, there were some differences between groups. However, some of the differences found were in line with previous findings (Dallas, Stevenson & McGurk, 1993; Farber & Jenne, 1963; Stoneman, 2005) with greater power rated by siblings in the disability group. Other findings did not support previous research findings (e.g. Stoneman, 2001) as differences in warmth and closeness between groups were not significant. Other aspects of the relationship showed contrasting findings to previous research (e.g. Brody, Davis and Crapps, 1988) as conflict was unexpectedly lower between siblings in the disability group.

Aspects of the sibling relationship may be influenced by 'disability', but how the relationship is influenced appears to vary across studies. Incorporated in Furman and Buhrmester's model is the influence of characteristics of individual children (cognitive, social and personality) on the quality of the sibling relationship. Disability may be linked to these characteristics. However, these were not explicitly measured in this study. Further research looking at how disability might influence individual characteristics may help to unravel the differences in sibling relationships between those of typically developing children and sibling dyads where one child has a disability.

This study did find some differences in the sibling relationship between groups. However, against predictions, the relationship was not found to be associated with adjustment outcome of the partaking siblings. In this study the TSCM was not fully supported. Mean scores were significantly different between the two groups regarding the sibling relationship (conflict and power/status), sibling helping behaviour (emotional support and custodial care) and functional impairment. The only clear predictor of adjustment problems (as rated by parents) was the presence of a disability and disability severity (level of functional interference). This does not support a mediating effect of these factors on the relationship between disability and adjustment. However, a shortcoming is that this study did not fully explore the TSCM, for example it did not address coping as a mediator. Furthermore, demographic characteristics are incorporated in the TSCM, however there was no significant impact of demographic characteristics (age, gender, family size) on adjustment. This may be due to the limited variation in demographic characteristics within and between groups. In this sample, the majority of families were UK born and white. Other limitations and strengths of this study will now be considered.

Strengths and Limitations

This study extended further research by looking at how differences in the sibling role and relationship may link to sibling adjustment. However, although the sibling relationship was explored in this study, the management of this relationship by parents was not. Parents' perspectives may be helpful; for example the way parents manage their children may affect the self-esteem of their children. It could be that rather than the sibling relationship influencing adjustment, lowered self-esteem may increase vulnerability to adjustment difficulties as a number of studies have shown that siblings of CWD are at greater risk of lower self-esteem (e.g. Engstrom ,1992; Ferrari, 1987; Spinetta & Deasy-Spinetta, 1981 & Vance, et .al., 1980).

This was a cross-sectional study, which has its limitations regarding increasing the understanding of the dynamic nature of the illness and the adaptation process. This study therefore did not intend to draw conclusions regarding factors relating to changes over time and was limited in the extent causal assumptions could be made. Longitudinal research is essential to increase understanding and to make firmer conclusions.

Exploratory analyses addressed 'type of disability' in a basic way by dividing groups into three: 'learning disability', 'physical disability' and 'mixed (LD and PD)'. This analysis indicated that these groups did not differ significantly in their sibling role, relationship, and sibling adjustment. This suggests that further research may be able use siblings who have brothers or sisters with a variety of conditions within one group. Clinically, interventions may be able to be applied to siblings of children with a variety of needs. However, this non-significant finding comparing disability types is tentative given the small sample size. It would have been interesting to consider the importance of type of disability in a much larger sample size. A common criticism in this area of research is the low numbers of participants (e.g. Sharpe and Rossiter, 2002). Unfortunately it was more difficult to obtain participants than was anticipated. Several steps were taken to maximise responses, this included: (1) Providing online and paper versions of the questionnaire, so offering a preferred choice to respondents. (2) Ensuring the questionnaires would take no longer than 30 minutes to complete (parents less than 10 minutes, child questionnaires took an average of 20 minutes to complete). (3) For paper copies, freepost reply envelopes were provided or could be directly returned to the class teachers. (4) Reminder letters were sent out, with a letter sent directly to the child when parents had completed their part of the study. (5) Sensitive information was kept to a minimum. In a review (Edwards et al., 2002), a number of these factors increased questionnaire response rates.

The majority of parent respondents were mothers, despite asking for responses from either parent. This limits findings to the perception of the mother. However, previous studies may be skewed according to source of information they have received. For example, a number of studies have used only mothers as informants (e.g. Breslau, et. al., 1981; Breslau and Prabucki, 1987 ; Lobato. et. al., 1987, & Villiams, et. al.,1993). A strength of the study was the use of more than one source (parent and child) so that the relationships between variables are less likely to be exaggerated as a result of a shared measurement variance.

Future research

To ensure sufficient numbers and power it was deemed important to constrain the number of questionnaires, which would increase likelihood of participation as well as minimising the number of variables in order to increase the power of statistical analysis. In a larger study, with fewer constraints, it would be useful to explore the effect of other factors on the disability-adjustment relationship. For example, to consider the variations in sibling adjustment, it may be worthwhile exploring their perceptions of the positive contributions their brothers or sisters with disabilities make to their lives, such as increased sensitivity, opportunities to learn about difference, and developing an attitude about not taking life for granted (Taunt & Hastings, 2002). Few studies have addressed this, but this may act as a protective factor for adjustment difficulties. There is a need for research to address siblings' own perceptions of positive contributions, and for investigation of the functional significance of these perceptions for adjustment if they exist (Hastings & Taunt, 2002).

It has been argued that 'our knowledge of what young carers do and how they differ from other children, is extremely limited and without this information, practice recommendations will be based on guesswork and prejudice' (Olsen, 1996). This study has helped increase our understanding of what siblings may actually do and how this may then affect them. Siblings of children with disabilities offer increased levels of emotional support and custodial care, but in this study these factors do not appear to impact on sibling adjustment as measured by the SDQ. These findings need replicating. It would also be interesting to use the same cohort in future research, or look at older siblings' perceptions as when they are older they may have greater insight into their situation. Current findings have implications regarding considering siblings in clinical practice, which will now be discussed.

Clinical implications

Clinical implications include support of previous findings of an elevated risk for adjustment problems in siblings of children with disabilities. Needs of siblings therefore need to be considered. In the exploratory analysis support group attendance did not make a difference in terms of sibling adjustment. However, low sample size may have meant that potential benefits of attending a sibling support group may not have been detected. Further research needs to be carried out in order to consider the impact of support group attendance on sibling adjustment. Severity of disability was the greatest predictor of adjustment difficulties in terms of functional impact and this suggests that clinicians should be aware of potentially greater needs for siblings when their brother or sister faces more everyday challenges, regardless of how much they appear to 'help' as this may not be the best predictor of adjustment.

Conclusions

Current results are in line with existing literature in terms of replicating previous findings that siblings of children with disabilities are at risk for psychological adjustment problems as indicated by their parents. However, self-report did not suggest such differences, this too is in line with research indicating discrepancies in parent-child reports, with parents reporting more adjustment problems. This research also indicates that the majority of siblings who have a brother or sister with a disability *don't* fall into a clinical range of adjustment problems. Interventions may therefore only need to be directed at siblings of children with more severe difficulties that interfere with everyday functioning as it seems these siblings are more likely to have adjustment problems at a clinical level. The findings also support previous research indicating that siblings of children with disabilities engage in more helping behaviour, particularly in terms of custodial care and emotional support. Differences were also found regarding the quality of the sibling relationship. As expected, power differences were greater in the disability group, with siblings in the disability group being more powerful than siblings in the control group. These findings also support the importance of disability severity as measured in terms of level of interference caused by the disability in their daily lives as a predictor of adjustment.

However, these findings are in contrast to research, which has found greater conflict in families with a child who has a disability. The reverse was found in this study, with greater conflict between TD sibling dyads. The level of conflict was related to the level of power, more power meaning less reported conflict. Information was gained from more than one source. This enabled differences in perceptions to be found when being reported by parent or child.

It also adds to the literature by supporting previous findings of greater helping behaviour in the disability group but that this may be less important than might be assumed in determining adjustment differences. This study adds to the current literature in that it supports research emphasising the importance of disability severity in identifying greater risk of adjustment difficulties.

This study attempted to gain more knowledge about how or why some siblings of children with disabilities adjust well and others do not. This study revealed a more complex picture than the TSCM model is able to explain. It would be helpful for future research to consider other factors that may influence adjustment.

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Appendices

Appendix 1: British Journal of Clinical Psychology Guidelines for Authors

Notes for Contributors

The British Journal of Clinical Psychology publishes original contributions to scientific knowledge in clinical psychology. This includes descriptive comparisons, as well as studies of the assessment, aetiology and treatment of people with a wide range of psychological problems in all age groups and settings. The level of analysis of studies ranges from biological influences on individual behaviour through to studies of psychological interventions and treatments on individuals, dyads, families and groups, to investigations of the relationships between explicitly social and psychological levels of analysis.
The following types of paper are invited:

- Papers reporting original empirical investigations;
- Theoretical papers, provided that these are sufficiently related to the empirical data;
- Review articles which need not be exhaustive but which should give an interpretation of the state of the research in a given field and, where appropriate, identify its clinical implications;
- Brief reports and comments.

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5,000 words, although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Reviewing

The journal operates a policy of anonymous peer review. Papers will normally be scrutinised and commented on by at least two independent expert referees (in addition to the Editor) although the Editor may process a paper at his or her discretion. The referees will not be aware of the identity of the author. All information about authorship including personal acknowledgements and institutional affiliations should be confined to the title page (and the text should be free of such clues as identifiable self-citations e.g. 'In our earlier work...').

4. Online submission process

1) All manuscripts must be submitted online at http://bjcp.edmgr.com .

First-time users: click the REGISTER button from the menu and enter in your details as instructed. On successful registration, an email will be sent informing you of your user name and password. Please keep this email for future reference and proceed to LOGIN. (You do not need to re-register if

your status changes e.g. author, reviewer or editor).
Registered users: click the LOGIN button from the menu and enter your user name and password for immediate access. Click 'Author Login'.

2) Follow the step-by-step instructions to submit your manuscript.

3) The submission must include the following as separate files:

- Title page consisting of manuscript title, authors' full names and affiliations, name and address for corresponding author - Editorial Manager Title Page for Manuscript Submission
- Abstract
- Full manuscript omitting authors' names and affiliations. Figures and tables can be attached separately if necessary.

4) If you require further help in submitting your manuscript, please consult the Tutorial for Authors - Editorial Manager - Tutorial for Authors
Authors can log on at any time to check the status of the manuscript.

5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate page. The resolution of digital images must be at least 300 dpi.

For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions:

Structured abstracts –

The British Journal of Clinical Psychology

Authors should note that all papers submitted to the *British Journal of Clinical Psychology* must include structured abstracts. Papers will not be considered for publication unless they have a structured abstract in the correct format.

Articles containing original scientific research should include a structured abstract with the following headings and information:

Objectives State the primary objectives of the paper and the major

hypothesis tested (if appropriate).
Design Describe the design of the study and describe the principal reasoning for the procedures adopted.
Methods State the procedures used, including the selection and numbers of participants, the interventions or experimental manipulations, and the primary outcome measures.
Results State the main results of the study. Numerical data may be included but should be kept to a minimum.
Conclusions State the conclusions that can be drawn from the data provided and their clinical implications (if appropriate).
Review articles should include a structured abstract with the following headings:
Purpose State the primary objectives of the review.
Methods State the method used to select studies for the review, the criteria for inclusion, and the way in which the material was analysed.
Results State the main results of the review.
Conclusions State the conclusions that can be drawn from the review and their clinical implications if appropriate.

- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.
- SI units must be used for all measurements, rounded off to practical values if appropriate, with the Imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations etc for which they do not own copyright.

For Guidelines on editorial style, please consult the *APA Publication Manual* published by the American Psychological Association, Washington DC, USA (http://www.apastyle.org).

6. Brief reports and comments

These allow publication of research studies and theoretical, critical or review comments with an essential contribution to make. They should be limited to 2000 words, including references. The abstract should not exceed 120 words and should be structured under these headings: Objective, Method, Results, Conclusions. There should be no more than one table or figure, which should only be included if it conveys information more efficiently than the text. Title, author and name and address are not included in the word limit.

7. Publication ethics

Code of Conduct - Code of Conduct, Ethical Principles and Guidelines
Principles of Publishing - Principles of Publishing

8. Supplementary data

Supplementary data too extensive for publication may be deposited with the British Library Document Supply Centre. Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the Editor together with the article, for simultaneous refereeing.

9. Post acceptance

PDF page proofs are sent to authors via email for correction of print but not for rewriting or the introduction of new material. Authors will be provided with a PDF file of their article prior to publication.

10. Copyright

To protect authors and journals against unauthorised reproduction of articles, The British Psychological Society requires copyright to be assigned to itself as publisher, on the express condition that authors may use their own material at any time without permission. On acceptance of a paper submitted to a journal, authors will be requested to sign an appropriate assignment of copyright form.

11. Checklist of requirements

- Abstract (100-200 words)
- Title page (include title, authors' names, affiliations, full contact details)
- Full article text (double-spaced with numbered pages and anonymised)
- References (APA style). Authors are responsible for bibliographic accuracy and must check every reference in the manuscript and proofread again in the page proofs.
- Tables, figures, captions placed at the end of the article or attached as separate files.

Journal of Pediatric Psychology

MANUSCRIPT PREPARATION

Instructions to Authors

The main emphasis of the journal is on original research. Analytical reviews of research, brief scientific reports, scholarly case studies, and commentaries are also considered for publication. The Web site (http://www.jpepsy.oxfordjournals.org) includes book reviews in addition to general information on the journal. Submissions are welcomed from authors in psychology and other disciplines serving children and families.

Manuscript preparation

Manuscripts (text, references, tables, figures, etc.) should be prepared in detailed accord with the Publication Manual of the American Psychological Association (5th ed.). There are two exceptions:
(a) The academic degrees of authors should be placed on the title page following their names, and
(b) a structured abstract of not more than 150 words should be included. The abstract should include the following parts:
Objective (brief statement of the purpose of the study);
Methods (summary of the participants, design, measures, procedure);
Results (the primary findings of this work); and
Conclusions (statement of implications of these data).
Key words should be included, consistent with APA style. Submissions should be double-spaced throughout, with margins of at least 1 inch and font size of 12 points (or 26 lines per page, 12-15 characters per inch). Authors should remove all identifying information from the body of the manuscript so that peer

reviewers will be unable to recognize the authors and their affiliations. E-mail addresses, whenever possible, should be included in the author note.

Original research articles should not exceed 25 pages, in total, including title page, references, figures, tables, etc. In the case of papers that report on multiple studies or those with methodologies that necessitate detailed explanation, the authors should justify longer manuscript length to the Editor in the cover letter.

Brief scientific reports should not exceed 12 pages, including a maximum of two tables and/or figures. This format should be considered for papers with scientific merit, but utilizing small samples or introducing new methodologies. It is also appropriate for reports of replication or application of an existing approach to a novel sample or problem.

Scholarly reviews should not exceed 30 pages total.

Case reports should not exceed 12 pages. Case reports are appropriate to document the efficacy of new treatment applications; to describe new clinical phenomena; to develop hypotheses; to illustrate methodological issues, difficult diagnoses, and novel treatment approaches; and to identify unmet clinical or research needs. Guidelines for case study submissions can be found in Drotar, D. La Greca, A., Lemanek, K. and Kazak, A. (1995). Case Reports in Pediatric Psychology: Uses and guidelines for Authors and Reviewers, Journal of Pediatric Psychology, 20, 549-565.

Commentaries should not exceed 4 pages, including references.

Commentaries are invited on all topics of interest in pediatric psychology.

The clinical relevance of research should be incorporated into the manuscripts. There is no special section on clinical implications, but authors should integrate implications for practice, as appropriate, into papers.

Authors should indicate in the Method section of relevant manuscripts how informed consent was obtained and report the approval of the study by the appropriate Institutional Review Board(s). Authors will also be asked to sign a statement, provided by the Editor, that they have complied with the American Psychological Association Ethical Principles with regard to the treatment of their sample.

Terminology should be sensitive to the individual who has a disease or disability. The Editors endorse the concept of "people first, not their disability." Terminology should reflect the "person with a disability" (e.g., children with diabetes, persons with HIV infection, families of children with cancer) rather than the condition as an adjective (e.g., diabetic children, HIV patients, cancer families). Nonsexist language should be used.

Manuscripts that do not conform to these guidelines will be returned to the authors for revision prior to peer review.

Manuscript submission is exclusively online. Authors are required to submit their manuscript online through the journal's online submission Web site. Submission is a representation that the work has not been published previously and is not currently under consideration for publication elsewhere. Authors should indicate in their cover letter that these conditions have been met. The relationship of the submitted manuscript with other publications or submissions of the author(s), if any, should be explained. The cover letter should also include a statement indicating that the paper has been seen and approved by all authors. The full mailing address, telephone, fax, and e-mail address should be included in the cover letter.

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New Editorial Policies 2007

Appendix 2: Journal of Pediatric Psychology Instructions for Authors

Please make sure to check the following guidelines: Editorial Policy, Authors' Checklist, Guidelines for Reviews, Mentoring Policy, Suggestions for Mentored Reviews, Descriptions of Special Sections, "People First."

Conflicts of Interest

At the point of submission, the *Journal of Pediatric Psychology's* policy requires that each author reveal any financial interests or connections, direct or indirect, or other situations that might raise the question of bias in the work reported or the conclusions, implications, or opinions stated - including pertinent commercial or other sources of funding for the individual author(s) or for the associated department(s) or organization(s), personal relationships, or direct academic competition. When considering whether you should declare a conflicting interest or connection please consider the conflict of interest test: Is there any arrangement that would embarrass you or any of your co-authors if it was to emerge after publication and you had not declared it?

As an integral part of the online submission process, Corresponding authors are required to confirm whether they or their co-authors have any conflicts of interest to declare, and to provide details of these. If the Corresponding author is unable to confirm this information on behalf of all co-authors, the authors in question will then be required to submit a completed Conflict of Interest form to the Editorial Office. It is the Corresponding author's responsibility to ensure that all authors adhere to this policy.

If the manuscript is published, Conflict of Interest information will be communicated in a statement in the published

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Author Self-Archiving/Public Access policy from May 2005

For information about this journal's policy, please visit our Author Self-Archiving Policy page.

Impact factor: 1.973

Editor-in-Chief

Appendix 3 Ethical approval

Dear Rachael

Re: Psychosocial adjustment of siblings of children with

Physical Disabilities (PD) / Learning Disabilities (LD)

The above titled application was approved by the School of Psychology

Ethics Committee on 31 October 2006.

Should you require any further information, please do not hesitate in

contacting me. Please quote reference CLIN/04/28.

Best wishes,

Kathryn

Miss Kathryn Smith

Secretary to the Ethics Committee

School of Psychology

University of Southampton

Highfield

Southampton SO17 1BJ

Tel: 023 8059 3995 Fax: 023 8059 2606

Email: kms@soton.ac.uk

Appendix 4: Letter to parents in the control group

Dear Parent or Guardian

RE: Sibling relationship study

I am Rachael Brown a Trainee Clinical Psychologist and I would like to ask you to take part in a study, gathering information about sibling relationships. The study involves asking you and your child to answer a number of multiple-choice questions.

Although you may not directly benefit from this study, I feel there is not enough research that highlights the needs of siblings of children with disabilities and listens to their views directly. I am hoping that this project will help to raise awareness of issues that might inform ways that some siblings may be offered support. In order to understand more about these siblings needs, we need to gather information about all kinds of sibling relationships and gaining information from you would be extremely useful.

You (parent or primary caregiver) will be asked to answer some general questions about your family and the behavioural strengths and difficulties of the child that takes part in the study.

Your child will be asked questions regarding the needs of their brother or sister. Some questions may not seem relevant to you as we are asking questions about children of a variety of ages and needs. However, please answer all the questions as best you can. Please be assured it will take no more than 10 minutes to complete the parent questionnaire and about 20 minutes for your child to complete theirs.

The child completing the questionnaire should be aged between 11 and 16. If they have more than one brother or sister, please ask them to answer questions about the sibling who is closest to them in age. You could choose to complete the questionnaire online or answer a paper/pencil copy. Please indicate in the return slip which option you would prefer.

By completing and returning the questionnaire we assume you give your consent to take part in our study. Please be assured that any information you may provide will be treated as confidential. Any published results of this research project will not use your name or other identifiable information. Your participation is voluntary and you can decide to stop at any time.

If you want to know more about the study and would like a summary of this research project or have any questions please contact me (Rachael Brown) at rljb104@soton.ac.uk or via the school.

Many thanks for your consideration.

Rachael Brown
Trainee Clinical Psychologist

Please tick the appropriate boxes:

I do not agree to take part in this study ☐

I agree for my child and I to participate in this study ☐

Name of parent ________________________*(Please sign)*__________________

Please send me the online questionnaire to me. ☐

My email address is: ______________________________________

Or: Please send me a paper copy of the questionnaire to complete. ☐

Appendix 5: Letter to parents in the clinical group

SiReS

Dear Parent or Guardian

RE: Sibling relationship study

I am Rachael Brown a trainee Clinical Psychologist and I would like to ask you to take part in a study looking at the differences and similarities between brothers and sisters of children with and without disabilities in regards to relationships, feelings, and activities.

The study has two parts. In the first part you (parent or primary caregiver) will be asked to answer some general questions about your family and the behavioural strengths and difficulties of the child that takes part in the study. You will also be asked some questions regarding the needs of the sibling that your child is answering questions about (if you have more than 2 children this should be the sibling closest in age). Some questions may not seem relevant to you as we are asking questions about children of a variety of ages and needs, however, please answer all the questions as best you can. Please be assured it will take no more than 10 minutes to complete the parent questionnaire and about 20 minutes to complete the child questionnaire.

The second part involves asking your child to answer some questions about themselves and their relationship with their brother or sister (the questionnaire contains fairly straightforward multiple choice questions). The child completing the questionnaire should be aged between 11 and 16. If they have more than one brother or sister, please ask them to answer questions about the sibling who is closest to them in age.

You could choose to complete the questionnaire online rather than using a paper/pencil copy. For the computer-based version you will have to provide your email address and we will send you the web link and instructions. For the paper pencil copy these will be distributed via school. Please indicate in the return slip which option you would prefer.

Appendix 5: Letter to parents in the clinical group

By completing and returning the questionnaire we assume you give your consent to take part in our study. Please also indicate if you are happy for your child to complete the questionnaire (tick box). Please be assured that any information you may provide will be treated as confidential. Any published results of this research project will not use your name or other identifiable information. Your participation is voluntary and you can decide to stop at any time.

If you want to know more about the study and would like a summary of this research project or have any questions please contact me (Rachael Brown) at rljb104@soton.ac.uk or via the school.

We sincerely hope you will partake in our study.

Many thanks for your consideration.

Appendix 6: Questionnaire measure SRQ

UNIVERSITY OF DENVER
Department of Psychology
Frontier Hall
Denver, Colorado 80208
303-871-2478

Enclosed you will find a copy of the Sibling Relationship Questionnaire (SRQ). I would be pleased to have you use it, but I do have two requests.

1) You may only want to use certain scales. I do not mind this kind of reduction, but I would appreciate it if the scales that are used are kept intact (i.e., not reducing the number of items to one or two or rewriting specific items). These kinds of changes make it difficult to compare results.

2) I would appreciate receiving information about the results of your work.

I hope you find these scales useful. This letter gives you permission to use the questionnaire. Good luck with your research!

Sincerely,

Wyndol Furman, Ph.D.
Professor

ID # ______________________________ GROUP ____________

Sibling Relationship Questionnaire - Revised (Child) 3/90

My name is ______________________________(completed by)

The phrase “this sibling” refers to _______________ (completed about)

---

1. Some siblings do nice things for each other a lot, while other siblings do nice things for each other a little. How much do both you and this sibling do nice things for each other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
2. Who usually gets treated better by your mother, you or this sibling?	[ ]My sibling almost always gets treated better [ ]My sibling often gets treated better [ ]We get treated about the same [ ]I often get treated better [ ]I almost always get treated better
3. How much do you show this sibling how to do things he or she doesn’t know how to do?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
4. How much does this sibling show you how to do things you don’t know how to do?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
5. How much do you tell this sibling what to do?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
6. How much does this sibling tell you what to do?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH

7. Who usually gets treated better by your father, you or this sibling?	[ ]My sibling almost always gets treated better [ ]My sibling often gets treated better [ ]We get treated about the same [ ]I often get treated better [ ]I almost always get treated better
8. Some siblings care about each other a lot while other siblings don't care about each other that much. How much do you and this sibling care about each other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
9. How much do you and this sibling go places and do things together?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
10. How much do you and this sibling insult and call each other names?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
11. How much do you and this sibling like the same things?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
12. How much do you and this sibling tell each other everything?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
13. Some siblings try to out-do or beat each other at things a lot, while other siblings try to out-do each other a little. How much do you and this sibling try to out-do each other at things?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
14. How much do you admire and respect this sibling?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH

15. How much does this sibling admire and respect you?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
16. How much do you and this sibling disagree and quarrel with each other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
17. Some siblings cooperate a lot, while other siblings cooperate a little. How much do you and this sibling cooperate with other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
18. Who gets more attention from your mother, you or this sibling?	[ ]My sibling almost always gets more attention [ ]My sibling often gets more attention [ ]We get about the same amount of attention [ ]I often get more attention [ ]I almost always get more attention
19. How much do you help this sibling with things he or she can't do by him or herself?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
20. How much does this sibling help you with things you can't do by yourself?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
21. How much do you make this sibling do things?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
22. How much does this sibling make you do things?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH

23. Who gets more attention from your father, you or this sibling?	[ ]My sibling almost always gets more attention [ ]My sibling often gets more attention [ ]We get about the same amount of attention [ ]I often get more attention [ ]I almost always get more attention
24. How much do you and this sibling love each other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
25. Some siblings play around and have fun with each other a lot, while other siblings play around and have fun with each other a little. How much do you and this sibling play around and have fun with each other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
26. How much are you and this sibling mean to each other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
27. How much do you and this sibling have in common?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
28. How much do you and this sibling share secrets and private feelings?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
29. How much do you and this sibling compete with each other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
30. How much do you look up to and feel proud of this sibling?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH

31. How much does this sibling look up to and feel proud of you?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
32. How much do you and this sibling get mad at and get in arguments with each other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
33. How much do both you and your sibling share with each other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
34. Who does your mother usually favor, you or this sibling?	[ ] My sibling almost always is favored [ ]My sibling is often favored [ ]Neither of us is favored [ ]I am often favored [ ]I am almost always favored
35. How much do you teach this sibling things that he or she doesn't know?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
36. How much does this sibling teach you things that you don't know?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
37. How much do you order this sibling around?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
38. How much does this sibling order you around?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
39. Who does your father usually favor, you or this sibling?	[ ] My sibling almost always is favored [ ]My sibling is often favored [ ]Neither of us is favored [ ]I am often favored [ ]I am almost always favored

40. How much is there a strong feeling of affection (love) between you and this sibling?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
41. Some kids spend lots of time with their siblings, while others don't spend so much. How much free time do you and this sibling spend together?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
42. How much do you and this sibling bug and pick on each other in mean ways?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
43. How much are you and this sibling alike?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
44. How much do you and this sibling tell each other things you don't want other people to know?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
45. How much do you and this sibling try to do things better than each other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
46. How much do you think highly of this sibling?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
47. How much does this sibling think highly of you?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH
48. How much do you and this sibling argue with each other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY MUCH

Appendix 6: Questionnaires: Questionnaire on interference (INT) and Activities of Daily Living (ADL).

The following questions ask about your brother or sister and what needs they might have such as needing help with daily tasks.

How much are the following problems interfering with your brother or sister's life? For each type of problem, please tick the best answer-first box for 'no problem', second box if it is a minor nuisance only, or third box if the problem is greatly interfering in your brother or sister's life.

	No Problem	**A minor nuisance**	**Makes a big difference**
Physical problems interfering with everyday life, sport and so on.			
Teasing by other children.			
Learning problems			
Epileptic fits			
Emotional or behavioural problems			
Pain			
Does your brother or sister have any difficulty with the following everyday activities?			
	No Problem	**A minor nuisance**	**Makes a big difference**
Washing and bathing			
Dressing			
Eating a meal			
Continence			
Finding own way around without getting lost			
Walking ordinary distances without getting too tired			

Appendix 7: Exploratory analysis comparing disability types on the SDQ, SRQ and the SHS.

Table 9 Descriptive statistics and Analysis of Variance for parent rated SDQ

	LD N=23 Mean (SD)	PD N=21 Mean (SD)	Mixed N=17 Mean (SD)	df	F	p
Emotion	2.00(1.81)	3.42 (2.86)	2.65 (2.50)	2, 60	1.94	.15
Conduct	2.74 (2.14)	1.48(1.81)	2.18 (1.84)	2, 60	2.31	.11
Hyperactivity	4.30 (3.02)	3.42 (2.96)	3.82 (2.38)	2, 60	0.53	.59
Peers	2.13 (1.98)	2.52 (2.60)	3.06 (2.95)	2, 60	0.67	.51

*p<·05. **p=001

Table 10: Descriptive statistics and Analysis of Variance for SRQ

	LD N=20 Mean (SD)	PD N=20 Mean (SD)	Mixed N=13 Mean (SD)	df	F	p
Warmth	44.185 (9.13)	49.95 (11.08)	46.92 (10.39)	2,52	1.26	.29
Status	3.65 (4.31)	1.30 (3.91)	4.23 (4.71)	2,52	2.35	.11
Conflict	15.20 (4.51)	17.40 (6.04)	15.46 (5.24)	2,52	.98	.38
Rivalry	17.25 (2.71)	16.75 (3.27)	18.85 (2.37)	2,52	2.18	.12

*p<·05. **p=001

Appendix 7: Exploratory analysis comparing disability types on the SDQ, SRQ and the SHS.

Table 11 Descriptive statistics and Analysis of Variance for SHS

	LD N=18 Mean (SD)	PD N=17 Mean (SD)	Mixed N=12 Mean (SD)	df	F	p
Emotional support	56.77(17.34)	60.00 (20.32)	66.25 (20.32)	2, 46	.93	.40
Custodial care	13.78 (4.32)	13.64 (4.39)	15.83 (6.07)	2, 46	.86	.43
Tangible aid	11.72 (3.16)	13.12 (3.35)	13.33 (4.60)	2,46	1.91	.16
Information	25.89 (7.19)	27.12 (7.90)	31.50 (11.30)	2,46	1.59	.21

*p< ·05. **p=001