

The Psychosocial Impact on Siblings of People with Lifelong Physical Disability: A Review of the Literature

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Abstract Adults with lifelong physical disability such as cerebral palsy are now likely to outlive their long time carers, typically their parents. Their siblings may then be called on to provide ongoing support, yet little is known about how this occurs or if the support offered is a function of earlier relationships. Therefore, we undertook a review of the literature to investigate the psychosocial impact on siblings when one has a lifelong physical disability. Computerized and manual searches identified 21 articles reporting empirical studies. These studies addressed the psychosocial impact of having a sibling with a physical disability. Only four articles were concerned with adult sibling relationships. An additional three articles relating to the adult sibling relationships of people with Down syndrome, autism and mental illness were included in an attempt to expand the adult perspective and identify if issues differed across different types of disability. The studies reviewed here highlight the need to expand sibling research to take a life span approach focussing on the views and experiences of the siblings both with and without disability. Increased understanding of siblings' hopes and expectations is imperative to ensure appropriate future support that includes a smooth transition from parents to siblings thus benefiting all stakeholders.

Keywords Siblings · Lifelong physical disability · Cerebral palsy · Psychosocial impact

The purpose of this review was to examine the research literature related to the psychosocial impact of having a brother or sister with a lifelong physical disability. Cerebral palsy (CP) is the most common cause of physical disability amongst children

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(Rosenbaum 2003). Therefore, this review has a particular focus on the siblings of people with CP. Psychosocial impact is defined as the effect of having a brother or sister with a physical disability on the psychological functioning of the non-disabled sibling. Psychological functioning incorporates emotional and social development, adjustment and self-concept. The impetus for this review is the emerging issue of people with lifelong physical disability outliving their long time carers/support providers who are usually their parents. Our particular interest is in the impact of having a sibling with a physical disability, implications on the adult relationship between the siblings with and without physical disability, and how these may affect future support.

When parents are no longer able to provide care to their offspring with physical disability, the specific ongoing support needs of this group make them particularly vulnerable to inappropriate placement in residential institutions, for example in nursing homes (Winkler et al. 2006). In addition to the personal trauma this may cause, supporting people in nursing homes is costly for the community. An alternative to institutional accommodation may be achieved with support from the non-disabled siblings to help their brother or sister with disability to remain living in the community. To date little is known about the likelihood of this happening or how it is best achieved (Dew et al. 2004). This is an important and largely unexplored issue that confronts an increasing number of older people with lifelong physical disability and their siblings.

Although some people with lifelong physical disability, such as CP, may experience a reduced lifespan due to severity of their disability and associated impairments, most people with CP have a typical life expectancy (Pellegrino and Dormans 1998). In 2003, Llewellyn and colleagues (2003) estimated that 9,000 parents over the age of 65 years in Australia were caring for an adult son or daughter with a disability living in the family home. In the case of caring for offspring with CP, this may involve a high level of physical care including lifting, transferring and positioning the person throughout the day and night and providing personal care including showering, toileting and mealtime assistance. These activities are additional burdens for parents as they age and become more frail (Hemsley and Balandin 2004). People with CP who are ageing may experience chronic health problems such as increased joint pain and decreased mobility (Balandin and Morgan 1997; Murphy et al. 1995). In addition, many people with CP experience difficulty with communication and rely on parents to provide support in unfamiliar situations, for example in hospital (Hemsley et al. 2006). There is evidence that caregivers of people with more severe disability, who require high levels and intensity of support, experience greater negative impacts on their psychological and physical health than other caregivers (Raina et al. 2005).

Transitions of care can be complex for people with CP, as they age and non-disabled siblings may be regarded as the logical providers responsible for ongoing care of their sibling with disability (Rimmerman and Raif 2001). However, it is not known how the transition of care from parent to sibling is best managed. The role that siblings play in assisting a smooth transition of care is not well understood (Hemming et al. 2006), despite the sibling relationship being the longest and most enduring relationship throughout a person's lifetime (Cicirelli 1995).

Sibling relationships build on shared experiences and family values, with siblings often providing social, emotional and practical support to each other (Campbell et al.

1999). When one sibling has a disability however, the quantum and type of support may extend well beyond what is typically expected of a sibling relationship (Dew et al. 2004). Understanding this potentially more intensive sibling relationship will provide insights into how such relationships develop over time, and the benefits (and potential disadvantages) of the relationship to both parties. Such insights may inform health professionals and others how to provide effective support to both groups of siblings as they age.

Method

Inclusion Criteria

Articles needed to meet three criteria to be included in this review: (1) research participants identified as having a sibling with lifelong physical disability (e.g., CP¹), (2) focus on the psychosocial impact of having a brother or sister with a lifelong physical disability, and (3) published in English.

It can be argued that people with CP and their siblings face different issues from other groups of people with a lifelong disability due to the impact of their physical disability and also for some, their intellectual disability. In recognition of these differences, articles that addressed siblings of people with intellectual disability with no mention of physical disability were excluded (e.g., Cuskelly and Gunn 2003; Hannah and Midlarsky 2005; Orsmond and Seltzer 2000). Grossman's study (1972) was included as some participants had siblings with both intellectual disability and CP. An additional three articles relating to the adult sibling relationships of people with Down syndrome, autism and mental illness were included in an attempt to expand the adult perspective and identify if the issues differed across different disability groups.

Search Procedures

We conducted electronic searches of four databases (PsycArticles; CINAHL; Medline and Web of Science) using the keywords 'siblings' and 'psychosocial' combined with each of the following; 'cerebral palsy,' 'physical disability,' 'disability,' 'handicap.' The keywords 'siblings and impact' and 'siblings and relationship' were combined with each of the descriptors above. The search extended from 1970 to 2008. We also hand searched the reference lists of the selected articles for additional references. Only peer reviewed published journal articles and published books were searched and included. Using these methods, 132 articles were identified of which 44 fit the criteria for inclusion. Twenty one articles, published between 1972 and 2005, reported empirical studies of the psychosocial impact on siblings of people with lifelong physical disability. Twenty three of the 44 articles were reviews and details of these are included in [Appendix](#).

¹ Cerebral Palsy is an umbrella term for a heterogeneous group of chronic non-progressive motor impairment syndromes (Stanley et al. 2000) characterised by disordered movement and posture and delayed motor development (Accardo et al. 1996).

Overview of Included Studies

Seventeen of the empirical studies were conducted with children or adolescents aged 3–18 years (Breslau 1982; Breslau et al. 1981; Coleby 1995; Cox et al. 2003; Dallas et al. 1993a, b; Dyson 1989, 1999; Dyson and Edgar 1989; Dyson and Fewell 1989; Harvey and Greenway 1984; Lobato et al. 1987, 1991; Magill-Evans et al. 2001; McHale and Gamble 1989; Nixon and Cummings 1999; Opperman and Alant 2003; Pit-Ten Cate and Loots 2000; Roe 1988) and four with adults aged 19 years and over (Begun 1989; Burton and Parks 1994; Davis and Salkin 2005; Grossman 1972). One study (Begun 1989) included participants aged 12–69 years with a mean age of 30.1 years. It was therefore included with the adult studies. Thirteen studies specified that some participants had a sibling with CP and two of these (Dallas et al. 1993a, b; Davis and Salkin 2005)² focused exclusively on the siblings of people with CP. Details of the empirical studies included in this review are summarized in Table 1.

Due to the very small number of adult sibling relationship studies (four) in this review, we have included in the discussion three additional adult studies of people with a brother or sister with an intellectual disability (Flaton 2006; Orsmond and Seltzer 2007; Seltzer et al. 1997). These articles were included as they raise important issues which may also be relevant to people with physical disabilities around the future support provided by siblings.

Of the studies conducted with children aged 3 to 18 years, two relied solely upon mothers as informants (Breslau 1982; Breslau et al. 1981) and ten included both parents (usually mothers) and siblings (Coleby 1995; Dyson 1989, 1999; Lobato et al. 1987, 1991; Magill-Evans et al. 2001; McHale and Gamble 1989; Nixon and Cummings 1999; Opperman and Alant 2003; Roe 1988). Of these ten, two gathered additional information from the children's teachers (Coleby 1995; Roe 1988).

Participants of nine studies were solely the siblings of people with lifelong physical disabilities (Begun 1989; Burton and Parks 1994; Cox et al. 2003; Dallas et al. 1993a, b; Davis and Salkin 2005; Dyson and Fewell 1989; Grossman 1972; Harvey and Greenway 1984; Pit-Ten Cate and Loots 2000). Dallas et al. (1993a, b) used observations of pre-school children and four studies involved children in pre-adolescent or adolescent years (Cox et al. 2003; Dyson and Fewell 1989; Harvey and Greenway 1984; Pit-Ten Cate and Loots 2000). Four studies focused on adults (Begun 1989; Burton and Parks 1994; Davis and Salkin 2005; Grossman 1972).

Results

Data Collection

The research methods and data collection tools used in each study are detailed in Table 1. Seventeen of the 21 research teams used standardized instruments to collect their data (e.g., Breslau et al. 1981; Harvey and Greenway 1984; Roe 1988). Sixteen studies incorporated control groups of participants who had siblings without a

² The two articles by Dallas et al. 1993a, b) report on different aspects of the same study. For the purposes of this review they are treated as one study referenced by both articles.

Table 1 Literature on psychosocial impact with siblings of people with life long physical disabilities

Study details authors/ study aim	Age range (years)	Disability	Method	Informant/s	Findings	Total nos./ control group nos.	Nos. CP, N/A= not specified
Grossman 1972. Exploratory study into the psychosocial implications for siblings of having a disabled brother or sister	18–25 College students	Retardation	In-depth interviews	Siblings	Psychosocial impact on siblings varied depending on a variety of cultural, social, and psychological factors	83/66	20
Breslau et al. 1981. Psychological functioning of siblings	6–18	Serious impairment	Psychiatric Screening Inventory (Langner et al. 1976)	Mother	Siblings of children with physical disabilities were at no greater risk of severe psychological impairment than the control group.	239/ 1,034	79
Breslau 1982. Impact of birth order and age spacing on psychological functioning of siblings	6–18	Congenital disability	Psychiatric Screening Inventory (Langner et al. 1976)	Mother	Younger male siblings of children with congenital disability are more likely to be psychologically impaired than their older brothers or older or younger sisters.	237/248	77
Harvey and Greenway 1984. Self concept of child with physical handicap and their non-disabled sibling compared to control group	9–11	Physically handicapped	Piers–Harris Children’s Self Concept Scale (Harter and Pike 1983; Piers and Harris 1969)	Siblings	The presence of a physical handicap resulted in lower self-concept for both the child with the disability and, to a lesser extent, their closest age sibling compared to the control group	33 matched sib pairs/18	19
Lobato et al. 1987. Psychosocial characteristics and functioning: empathy; verbalised affect towards parents/siblings; understanding of disability terms; perceived self competence and acceptance	3–7	Handicapped	Stanford-Binet Intelligence Scale (Form L-M); The Pictorial Scale of Perceived Competence and Social Acceptance (Harter and Pike 1983); Family Role Play Assessment (Lobato 1981, 1985); Empathy/Interpersonal Awareness Scale (Borke 1971). The Child Behavior Checklist (Achenbach 1981); Home Routines checklist (based on Schwirian 1976)	Siblings and mothers	No significant differences in the psychosocial characteristics of siblings of children with or without disability	24/22	7

Table 1 (continued)

Study details authors/ study aim	Age range (years)	Disability	Method	Informant/s	Findings	Total nos./ control group nos.	Nos. CP, N/A= not specified
Roe 1988. Examine the needs of the brothers and sister of disabled children	7–14	Disabled: Physically, multiply; ID	Coopersmith Self-Esteem Inventory (Coopersmith 1984); Intention to Behave Altruistically Scale (Roe 1986); Measure of Family Cohesion (Cooper et al. 1983). Child and Adolescent Adjustment Profile (Ellsworth 1981); Behavioural Measure of Altruism; Interview	Siblings, Parents, Teachers,	Siblings of children with disabilities feel more isolated both within and outside their families than children in the control group	29/29	N/A
Begun 1989. Lifespan perspective to explore qualitative aspects of sibling relationships involving developmentally disabled people	12–69	DD	Sibling Relationship Questionnaire adapted from Furman and Buhrmester (1985)	Siblings	Sibling relationships where one sibling has a disability are positive but nonintimate	46/0	N/A
Dyson 1989; Dyson et al. 1989. Psychological predictors of self-concept, behaviour problems and social competence of older siblings of children with DD; compared to matched siblings of non-disabled children	8–15	DD; MR; physical; sensory; speech disorders; LD hyperactivity	Piers-Harris Children's Self Concept Scale (Piers and Harris 1969). The Child Behavior Checklist (Achenbach 1981); Demographic form; The Family Support Scale (Dunst et al. 1984); The Questionnaire on Resources and Stress-Short Form (Friedrich et al. 1983); The Family Environment Scale Form R (Moos and Moos 1981)	Siblings, Parents	Individual differences in adjustment were more significant than whether the participants had a sibling with a disability or not. Therefore having a sibling with a disability is not alone a sufficient factor affecting a child's adjustment	55/55	N/A
Dyson and Fewell 1989. Investigate self concept in siblings of handicapped and non-handicapped children. Mediating effect of sibling and familial characteristics e.g. gender, type of handicap and socioeconomic status	7–14	Handicapped: speech disorders; DD; physical/ behaviour disorder; MR	Piers-Harris Children's Self-Concept Scale (Piers and Harris 1969)	Siblings	Siblings of children with disabilities do not differ from children in the control group in self-concept	37/37	N/A

<p>McHale and Gamble 1989. Sibling adjustment and psychological wellbeing: comparison with control group</p>	<p>8–14</p>	<p>Disability</p>	<p>Harter's Perceived Competence Scale (Harter 1982); Childhood Depression Inventory (Kovacs 1981); Revised Children's Manifest Anxiety Scale (Reynolds and Richmond, 1979); Sibling Inventory of Behavior (Schaeffer and Edgerton 1981). Background characteristics of family; Connors' Parent Rating Scale (Goyette et al. 1978); Sibling Inventory of Behavior (Schaeffer and Edgerton 1981)</p>	<p>Siblings, Mothers</p>	<p>Siblings of children with disabilities reported more caregiving, maternal negativity and poorer adjustment. These items were associated with adjustment</p>	<p>31/31</p>	<p>14</p>
<p>Lobato et al. 1991. Examine similarities and differences between siblings of disabled and non-disabled children in their behavioural interactions with their mothers</p>	<p>3–7</p>	<p>Handicapped</p>	<p>Home videotaping of play sessions coded for Nurturing Behavior, Aggression and Commands/Directives</p>	<p>Siblings and mothers</p>	<p>Few differences were found between the sibling groups in the quantity or quality of their interactions with family members</p>	<p>20/20</p>	<p>7</p>
<p>Dallas et al. 1993a. Examine children with CP's interactions with their siblings. Two articles from same study: I. Influence of severity of disability, age and birth order. II. Interactional Structure</p>	<p>2–13</p>	<p>Cerebral Palsy</p>	<p>Home observations of play: drawing; block puzzles; free play. Coded for direct; cooperates; aggression; absorbed; mobility</p>	<p>Siblings (Mothers present and asked not to intervene)</p>	<p>Compared to the more egalitarian interactions in the control dyads, children with CP were more passive and less assertive than their nondisabled siblings who took control of the interactions regardless of birth order</p>	<p>64/64</p>	<p>64</p>
<p>Burton and Parks 1994. Assessed differences among self-esteem, locus of control, and career aspirations</p>	<p>18–23</p>	<p>Disability</p>	<p>Sibling Demographic and Background Questionnaire; Self-Esteem Scale (Rosenberg 1965); Internal-External Locus of Control Scale (Rotter 1966); Sibling Evaluation Questionnaire (unvalidated)</p>	<p>Siblings</p>	<p>Siblings of people with disabilities reported similar levels of self-esteem and higher levels of internal locus of control than the control group</p>	<p>30/30</p>	<p>N/A</p>

Table 1 (continued)

Study details authors/ study aim	Age range (years)	Disability	Method	Informant/s	Findings	Total nos./ control group nos.	Nos. CP, N/A= not specified
Coleby 1995, How children are affected by having a sibling with a disability	School-aged	Multiple disabilities	Social Behaviour Assessment Schedule (based on Platt 1985); Burden of care questionnaire (Pahl and Quine 1985). Child Behaviour Questionnaire for Completion by Teachers (Rutter 1967 Scale B Interview); Self-report measure of chronically manifested anxiety "What I think and feel" (Reynolds and Richmond 1978); Voeltz Scale (Voeltz 1980)	Parents, Teachers, Siblings	The 'burden of care' experienced by the mother had a significant positive correlation on the adverse effect on the siblings of children with severe disabilities	41/41	N/A
Dyson 1999, Comparison of psycho-social functioning and family psychological correlates over time	11–18	DD; MR; physical and sensory handicaps; speech disorders and LD	Piers-Harris Children's Self Concept Scale (Piers and Harris 1969), The Child Behavior Checklist (Achenbach 1981); Demographic form; The Family Support Scale (Dumst et al. 1984); The Questionnaire on Resources and Stress-Short Form (Friedrich et al. 1983); The Family Environment Scale Form R (Moos and Moos 1981)	Siblings, Parents	Having a sibling with a disability is not, alone a sufficient factor affecting a child's adjustment. Psychosocial functioning of siblings both with and without a sibling with a disability is related to family psychosocial factors e.g. family functioning, parental stress and family social support	37/34	N/A
Nixon and Cummings 1999, How having a sibling with a disability predicted children's reactions to everyday stress of family-related conflict	7–15	Disability	Laboratory tests—exposure to conflict stimuli; Results according to emotional distress (Grych and Fincham 1993); cognitions—perceived threat, involvement and responsibility; coping strategies—involved coping or avoidance. O'Leary Porter Scale of marital hostility (Porter and O'Leary 1980); Beck Depression Inventory	Siblings, Mothers	Siblings of children with disabilities were more sensitive to everyday family stresses and displayed more adjustment problems than control group participants.	30/30	6

<p>Pit-Ten Cate and Loots 2000. Experiences of siblings of children with physical disabilities</p>	<p>10–19</p>	<p>Physical disability</p>	<p>(Beck et al. 1961); Child Behaviour Checklist (Achenbach and Edelbrock 1983) Global Family Checklist; Sibling Relationship Interview; Coping Response Inventory—Short Form (Moos 1993); Interview The Family Assessment Device version 3 (Epstein et al. 1983); The Life Satisfaction Survey (Chubon 1995); Multidimensional Scale of Perceived Social Support (Zimet et al. 1988). The Future Questionnaire (Arnold and Chapman 1992). Demographic Variables</p>	<p>Siblings</p>	<p>43/0</p>	<p>11</p>
<p>Magril-Evans et al. 2001. Comparison of family function, life satisfaction, and social support for adolescents with CP; their families with control group</p>	<p>13–15, 19–23</p>	<p>Cerebral palsy</p>	<p>Sentence-completion instrument—18 open-ended statements of real or hypothetical stressful situations (adapted from Walker 1988)</p>	<p>Children with CP; Parents and Siblings, Child with CP, Mothers</p>	<p>90/75</p>	<p>90</p>
<p>Cox et al. 2003. Determine the coping responses to daily life stressors of children who have a sibling with a disability</p>	<p>6–18</p>	<p>Multiple disabilities: developmental; communication; Down syndrome; Sight and hearing; autism</p>	<p>Parental Questionnaires designed for study: professional support services used by family, diagnosis of child with a disability, information given to siblings re their brother/sister's disability, family adaptation to having a member with a disability. Structured interviews with pre-formulated, open-ended questions re stress and adaptation</p>	<p>Siblings</p>	<p>46/0</p>	<p>N/A</p>
<p>Opperman and Alant 2003. Coping responses of adolescent siblings</p>	<p>12–15</p>	<p>Severe disability</p>	<p>Parental Questionnaires designed for study: professional support services used by family, diagnosis of child with a disability, information given to siblings re their brother/sister's disability, family adaptation to having a member with a disability. Structured interviews with pre-formulated, open-ended questions re stress and adaptation</p>	<p>Parent, Siblings</p>	<p>19/0</p>	<p>5</p>
<p>Davis and Salkin 2005. Relationship between sibling with a disability and non-disabled sibling</p>	<p>53</p>	<p>Cerebral palsy</p>	<p>Case study: Co-constructed narrative</p>	<p>Siblings</p>	<p>1/0</p>	<p>1</p>

physical disability (e.g., Dyson and Edgar 1989; Lobato et al. 1987; McHale and Gamble 1989). Thus, researchers attempted to adopt robust methodologies. However, in relying upon standardized instruments there is a danger of response error whereby the choice of instruments or questions influenced the results. For example, instruments measuring behaviors such as anxiety, depression or aggression may result in increased reporting of these behaviors (Bryman 2001). To overcome this, some researchers adopted a mix of standardized instruments along with semi-structured interviews with parents and/or the siblings in order to triangulate results and include qualitative data (e.g., Opperman and Alant 2003; Pit-Ten Cate and Loots 2000; Roe 1988).

Standardized tests were used in all but two of the childhood studies (Dallas et al. 1993a, b; Lobato et al. 1991) in order to gather data from mothers and from siblings of people with lifelong physical disability. However, there was little consistency in the measures used with the exception of five studies. Dyson (1989, 1999), Dyson et al. (1989), Dyson and Fewell (1989) and Harvey and Greenway (1984) used The Piers–Harris Children’s Self Concept Scale (The way I feel about myself) (Piers and Harris 1969) to measure the children’s self reported self concept. Dyson (1989) and Lobato et al. (1987) measured behavior problems and social competence of the siblings in their studies using the parent completed Child Behavior Checklist (Achenbach 1981). Otherwise across the remaining studies 14 different measures were used with parents and 22 with siblings. The use of so many instruments makes it difficult to compare and contrast the results between studies.

Clearly, adopting a smaller range of standardized measuring instruments within sibling research would assist researchers to compare results and identify variables which may impact the most on the psychosocial development of siblings of people with lifelong physical disabilities. This may have important consequences for the development of sibling support programs. The two childhood studies, which did not include standardized instruments, incorporated observations of pre-school children playing and interacting with their siblings with a disability and/or their mothers (Dallas et al. 1993a, b; Lobato et al. 1991). In both studies the researchers identified that mothers played a more active role in directing the interactions between siblings where one has a disability compared to the control groups. Researchers also indicated that both younger and older non-disabled siblings with a brother or sister with a physical disability are more likely to take the dominant role in the relationship. These studies offer valuable insights into how siblings interact from a young age and raise questions about how this may translate to their relationship as adults. Observations are useful with very young participants, however those who are older are able to articulate their perceptions of their relationship with their siblings.

The use of interviews (e.g., Davis and Salkin 2005; Grossman 1972), sometimes supplemented by standardised tests (e.g., Opperman and Alant 2003; Pit-Ten Cate and Loots 2000; Roe 1988), allowed adolescent and adult sibling participants to describe their experiences and feelings in their own words rather than fit within a prescribed category. Using this method provided researchers with rich descriptive material to analyse qualitatively to provide insights into participant’s experiences.

Discussion

Results of the studies reviewed here highlight two issues that are interlinked. The first of these is the age of the sibling participants. Seventeen of the 21 studies were focused on child (aged 2–18 years) sibling relationships with only four focused on adult (19 years and over) sibling relationships. This over-representation of studies with children highlights a lack of knowledge about the experiences of adult siblings of people with lifelong physical disability. This includes a lack of information on how the psychosocial impact of disability in childhood affects the adult sibling relationship.

The second issue is the identity of the primary informant in each study. In the studies of children, parents, especially mothers, were the primary informants although in some studies (e.g., Dyson 1989; Lobato et al. 1987; McHale and Gamble 1989) additional information was sought from the siblings themselves usually using standardized instruments. Sharpe and Rossiter (2002) have argued that using mother informants created a negative bias. Results of the studies reviewed here support this argument. When the siblings were the primary informants (e.g., Burton and Parks 1994; Cox et al. 2003; Grossman 1972) they were more positive in their reports about their relationships with their sibling with disability than mothers. This highlights the importance of talking to siblings directly. An additional issue is the need to ensure that the sibling with a disability is included in research into the sibling relationship.

The sibling with a disability was included in only five of the 21 studies reviewed here (Dallas et al. 1993a, b; Davis and Salkin 2005; Harvey and Greenway 1984; Lobato et al. 1991; Magill-Evans et al. 2001). In three of these this was by observation of disabled and non-disabled pre-school siblings' interactions (Dallas et al. 1993a, b; Lobato et al. 1991). Only two studies (Davis and Salkin 2005; Magill-Evans et al. 2001) included the views of the sibling with physical disability. The researchers in both studies highlighted that there were similarities in the way both the person with CP and their non-disabled brother or sister viewed both themselves and their relationship. The authors of these studies identified the need for more research which includes both the siblings with and without disability.

Age of Participants and Primary Informants

Childhood Studies

The reason for the predominance of research with children may be researchers' hypothesis that the relationship between children with a disability and their non-disabled sibling/s is non-normative and is likely to have a negative effect on the development of the non-disabled sibling (e.g., Lobato et al. 1987; Opperman and Alant 2003). However, Cox et al. (2003) demonstrated that having a sibling with a disability also has a positive impact on the non-disabled sibling (e.g., Cox et al. 2003). There is also evidence that there are no differences in the psychosocial impact of siblings between those children who had a sibling with a disability and those children in control groups whose siblings did not have a disability (Breslau 1982;

Breslau et al. 1981; Dyson 1989, 1999; Dyson and Edgar 1989; Lobato et al. 1991; Magill-Evans et al. 2001; Pit-Ten Cate and Loots 2000).

Breslau et al. (1981) and Breslau (1982) reported that siblings of children aged 6–18 years with severe congenital physical disability had no significantly greater risk of having a severe psychological impairment than siblings of a non-disabled child. Likewise, in examining the variables of self concept, social competence and behavior, Dyson and colleagues (Dyson 1989; Dyson and Edgar 1989; Dyson and Fewell 1989) reported comparable results on all variables between the children (aged 7–15 yrs) in their study and control groups. Based on the Piers–Harris Self Concept Scale, the mean self-concept score of 62.5 for the total group is in the top range of normative data. When comparing the variables of family functioning, life satisfaction, and perceived support on a group of family members (including siblings aged 13–15 years) with a sibling with CP and a control group, Magill-Evans et al. (2001) identified little difference between the two groups. Similarly, observing the interactions between 3–7 year old children (with and without siblings with disability) and their mothers, Lobato et al. (1991) reported no significant difference in the quantity and quality of interactions between the two groups. However, female siblings interacted significantly more often than male siblings with their sibling with disability. In addition, children who had a brother or sister with a disability were significantly more likely to engage in parallel and social play than the children in the control group. Reporting on their interviews with 43 pre-pubescent and adolescent children, Pit-Ten Cate and Loots (2000) noted that having a sibling with a disability did not increase the likelihood of these children having psychosocial problems. These studies indicate that having a sibling with a disability does not predispose children to psychosocial problems.

Mother Informants

Almost all the studies on the impact of having a brother or sister with a lifelong physical disability on a non-disabled child relied upon parents, especially mothers as the primary informant. Mothers consistently have more negative views than the siblings themselves about this impact (Sharpe and Rossiter 2002). Turnbull et al. (1993) suggested that this may reflect the stresses and strains of mothering a child with a disability and the guilt associated with lack of sufficient time or energy to give to sons or daughters who do not have a disability.

Mothers reported that the 239 siblings aged 6–18 years of the children with disability showed more interpersonal aggression towards their peers compared with a control group of 1034 children without a sibling with disability (Breslau et al. 1981). Mother informants of a group of 24 younger children rated both brothers and sisters aged 3–7 years as significantly more aggressive, and brothers of children with disability as significantly more depressed than brothers in the control group (Lobato et al. 1987). In addition, the 41 parents of school-aged siblings interviewed by Coleby (1995) concluded that having a sibling with multiple disabilities had a negative effect on the psychological health and social contacts of the non-disabled siblings. Coleby linked this to “burden of care” (p. 424) and suggested that diminishing the daily “burden of care” on both the mother and the siblings (e.g., by regular use of respite care) would reduce this negative impact. On the other hand, it

can be argued that an early experience of “burden of care” may impact on adult siblings’ willingness to take on caring responsibilities for their brother or sister with a disability (Coleby 1995). Most research into childhood sibling relationships utilised mothers as informants with a resulting perception of negative impact of having a brother or sister with a lifelong physical disability on the psychosocial development of their non-disabled child. This contrasts with the self reports from adult siblings.

Adult Studies

The college-aged adult siblings who participated in Grossman’s study (1972) reported a range of positive impacts including: a greater understanding of people; more tolerance and compassion towards people in general; a heightened awareness of the consequences of prejudice; an appreciation of their own good health and intelligence; and a feeling that the experience had resulted in closer family ties (Grossman 1972). Twenty two years after Grossman published this research, Burton and Parks (1994) surveyed college aged siblings of people with disability and a control group. They examined self-esteem, locus of control and career aspirations. They reported similar positive results to Grossman (1972). Participants stated that having a brother or sister with a disability helped them to “be more responsible, be more tolerant, better see the good in others, develop a better sense of humor, and be more flexible” (Burton and Parks 1994 p.182). In conclusion, Burton and Parks identified no difference in self-esteem and career aspirations between the two groups of college-aged siblings. However, those with brothers and sisters with disability exhibited significantly higher internal locus of control than the control group. The researchers proposed that the experience of growing up with a brother or sister with a disability may improve the psychological strength of the non-disabled siblings. Higher internal locus of control and psychological strength may prove to be important components in the development of a supportive adult relationship that will be sustainable once parents are no longer able to provide care and support.

It is possible that young adults have had time to work through any negative feelings they may have had towards their sibling with physical disability as children and to develop a more positive view of their early experiences.

The young adults in these two studies demonstrated that the sibling relationship in adulthood is based on strong feelings of love and familial cohesion. However, these studies were conducted with *young* adults and there was little indication in the participants’ responses that they were contemplating providing care for their sibling with disability in the future when their parents are no longer able to do this.

In order to examine sibling relationships across the lifespan, Begun (1989) surveyed a broad age range of 46 sisters with a sibling with disability asking them about the qualitative aspects of their relationships (e.g., nurturance, competition, intimacy, and satisfaction). Begun received 46 completed surveys from respondents aged 12–69 years (mean age 30.1 years). Participants reported positive but non-intimate relationships with their disabled siblings. Using Miller’s (cited in Begun, p. 567) term “affect neutrality,” Begun described the adult participants as having less competitive sibling relationships than the adolescent participants. According to Begun, this was due to older siblings being more involved in caretaking roles and

being less involved in normative sibling interactions. However, Begun did not discuss how a less intimate or competitive relationship in adulthood might impact on later life contact or involvement between siblings some of whom were in their 50s and 60s.

In contrast to this reported lack of intimacy, an intensely personal view of siblingship was provided by sisters Davis and Salkin (2005). Forty eight year old Davis is an academic conducting research into disability and 53 year old Salkin has cerebral palsy and a hearing impairment. Reflecting the issues facing middle-aged siblings, Davis stated that the motivation for this study was a concern for her and Salkin's future. "I...share...a concern about Kathy's future and an awareness as I was growing up that I might be assisting her when we got older" (Davis and Salkin 2005 p. 208). Davis and Salkin's parents were both dead at the time the article was written. The article revealed the complexity of the sibling relationship as both authors' dependence, independence, and interdependence was revealed. Throughout the narrative there is a tension between what each sister remembered about their childhoods. Davis acknowledged that this has little to do with Salkin's disability and much to do with being siblings. In the discussion Davis reflected "I see the striking difference between the dependent person I was afraid Kathy [Salkin] would be when I was a teenager and the independent person she actually is...you know, we are all mutually interdependent" (p. 230–1). The study is one of the few to give voice to the person with a disability and highlights the importance of siblings working together to understand each other and to co-construct their present and future relationship. In narrating their experiences of being siblings, Davis and Salkin (2005) offered valuable insights into the adult sibling relationship. The sisters' narrative examined many of the issues raised in previous research. These included: the dynamics between an older sibling with a disability and a younger, non-disabled sibling; the different perceptions of parental favoritism; the view of their family as different from other families; and the reactions of members of the public to people with disability. Finally, by including the views of the non-disabled and disabled sibling, the authors identified the importance of presenting both viewpoints in the relationship. Understanding both viewpoints is particularly important when supporting siblings through transitions of care. However, it must be noted that this study reports on one relationship and the issues raised by Davis and Salkin need to be explored with other sibling dyads where one sibling has a physical disability. Within the field of intellectual disability there are also few personal accounts of the experience of being an adult sibling of a person with a disability (e.g., Flaton 2006; Simon 2002). Both Flaton and Simon share similar positive feelings towards their sibling with disability yet neither include the sibling with disability's perspective.

In a phenomenological case study, Flaton (2006) explored with one sibling (Anna) how having a brother with Down syndrome (Daniel) shaped her identity, experiences, and life choices. Anna reported that her identity was predominately formed by having a brother with Down syndrome. This included attributing her empathetic nature to her experiences with Daniel and testing the worth of potential friends against their willingness to accept Daniel. So close was Anna's bond to Daniel that after their mother's death she assumed the role of surrogate parent to him. Flaton suggested a number of issues for exploration in future research relating to if, how and why having a sibling with a disability changed the non disabled sibling's identity. The formation of identity may therefore have important ramifications for the

future support of the sibling with a disability. In contrast to this intimate view of a sibling relationship Seltzer et al. (1997) conducted a large quantitative study to identify the impact, closeness and well-being of siblings of adults with mental retardation or mental illness. Using self-administered questionnaires, Seltzer et al. (1997) compared the impact on lifestyle and psychological well-being of 329 siblings of adults with intellectual disability aged 21 to 63 and 61 adults with serious mental illness aged 26 to 60. They reported that the siblings of people with intellectual disability were overwhelmingly positive about the impact of their sibling relationship on their lives compared to the siblings of people with mental illness whose reports were predominately negative. Seltzer et al. (1997) suggested that this was due in large part to the nature of intellectual and mental disability. Intellectual disability is life long. Therefore, the siblings had grown up together and the non-disabled siblings had learned to cope with or adapt to their sibling's intellectual disability. In contrast, mental illness is an acquired disability often presenting initially in adolescence or young adulthood. Consequently, the siblings of people with mental illness need to adapt to changes in their sibling, often in the context of a mental health crisis. Importantly, Seltzer et al. (1997) concluded that "siblings who have a more positive view...may be quite willing and able to assume active, ongoing care giving roles" (p. 404). Reflecting on these findings, the siblings of people with lifelong physical disabilities share the childhood experiences of growing up with their sibling; they too may be prepared to take an active support role with their sibling with a disability in adulthood.

A third study of adult siblings of people with intellectual disabilities focused on the issue of how the type of disability may impact on the relationship between siblings. Orsmond and Seltzer (2007) used questionnaires to compare the instrumental and affective involvement of 154 adult siblings aged 21 to 56 years of 77 people with autism and 77 people with Down syndrome. The researchers reported that the siblings of people with Down syndrome had a closer relationship with and were more optimistic about the future for their sibling than those with a sibling with autism. Orsmond and Seltzer (2007) suggested that these differences may be attributed to the social impairment and repetitive and unusual behaviors typically exhibited by people with autism. They concluded that the siblings of people with autism may face greater challenges in taking on a future care giving role with their sibling when their parents were no longer able to fill this role. They posited that this was due to the non-disabled siblings of people with autism having less emotional closeness and more pessimism about their brother or sister's future than the siblings of people with Down syndrome. This study highlighted the differences in sibling relationships based in part on the type of disability experienced. Whereas, people with autism may require significant emotional and behavioral support, people with life long physical disabilities typically require a greater level of physical support. How non-disabled siblings, may view this requirement particularly if they are also (a) supporting aging parents, or (b) living in homes with access difficulties or (c) aging themselves requires further research.

Positive Sibling Informants

Irrespective of age, when the siblings were the primary informants they were likely to report a positive impact from having a brother or sister with a lifelong physical

disability (e.g., Pit-Ten Cate and Loots 2000). Nevertheless, it is worth noting Grossman's caution that people who volunteer as research participants may be more likely to report positive views than those who choose not to participate. Yet, 30 years on, there is a growing body of research which has demonstrated that direct contact with people with disability results in positive attitudes (Shelvin and O'Moore 2000), which helps account for the positive attitudes of siblings towards their sibling with disability. This is further supported by Cox et al. (2003) who, in explaining why most siblings aged 6–18 years in their study reported developing proactive strategies to deal with the daily stresses of living with a brother or sister with a disability, suggested that a high level of involvement and sense of responsibility translated into positive coping strategies for siblings. They termed this a "problem solving approach to daily life" (p. 409).

Although non-disabled sibling participants presented a positive view of their experiences overall, they highlighted difficulties including social isolation (Roe 1988), lower self esteem (Harvey and Greenway 1984; Roe 1988), adjustment problems (Nixon and Cummings 1999), communication difficulties (Magill-Evans et al. 2001) and limited family contact (Opperman and Alant 2003). Roe (1988) reported that the 29 non-disabled sibling participants felt socially isolated, had lower self esteem, and had more emotional and behavioral problems than a control group of participants without a sibling with disability. Roe linked these findings to one of cohesion in the family unit with more problems reported in families that described themselves as experiencing isolation. It is hardly surprising that the family unit figures largely in sibling research. Nixon and Cummings (1999) reported that siblings who had a brother or sister with a disability demonstrated more adjustment problems and had greater sensitivity to everyday family stresses than participants in the control group without a sibling with disability.

Similarly, Opperman and Alant (2003) reported adolescent siblings as saying that they had limited family interaction, a sense of guilt, and limited knowledge about their brother or sister's disability. Grossman's (1972) college-aged participants also had reported shame, a sense of being tainted or defective themselves, feelings of guilt for both their own good health and for having negative feelings about their disabled brother or sister. Opperman and Alant (2003) discussed the benefit of conducting longitudinal studies in order to better understand the impact of having a brother or sister with a disability throughout the siblings' life.

Siblings with a disability may experience similar difficulties to their non-disabled sibling. In one of the few studies to include children with disability as well as their non-disabled siblings (aged 9–11 years), Harvey and Greenway (1984) reported that the children with physical disability, and to a lesser extent, their siblings, experienced a lower sense of self worth, greater anxiety and a less integrated view of self than the control group.

More recently, Pit-Ten Cate and Loots' (2000) reported that the main difficulties experienced by non-disabled siblings were problems in communicating and participating in activities (e.g., playing sport or outdoor games) with their sibling with a disability. Pit-Ten Cate and Loots also discussed siblings' stress when coping with the reactions of members of the public towards their sibling (e.g., staring or making unpleasant remarks). The sibling participants expressed concern about the future and the health of their sibling with disability. These results point to potential

difficulties for relationships between siblings when one has a communication impairment. Shared experiences are important in building and maintaining adult sibling relationships (Connidis 1994). Consequently, it is important that the views of the sibling with a disability about their relationship with their non-disabled sibling/s are represented (Pit-Ten Cate and Loots 2000).

Summary

In summary, studies on the psychosocial impact of physical disability on siblings reviewed here raise some important questions which are, as yet, unanswered about how the sibling relationship may develop into adulthood. There is some indication that as children mature, the sibling relationship becomes less reciprocal and more focused on the non-disabled sibling assuming some level of responsibility for the brother or sister with lifelong disability (Dallas et al. 1993a, b). Nevertheless, underlying the relationship is love and solidarity which typifies many family relationships (Dew et al. 2004). There is also concern for the future which some participants expressed even as children (Pit-Ten Cate and Loots 2000).

Overall, when siblings themselves are asked about the impact of having a sibling with a lifelong physical disability they are mainly positive about the experience. As they grow older, siblings are able to reflect on and put their familial relationships into perspective. As adults they may also develop an appreciation of their siblings and a greater understanding of their parents' choices and constraints. In particular, the article by Davis and Salkin (2005) breathes life into the adult sibling experience. We can see how profoundly siblings affect one another. Being a sibling is indeed a family journey rather than a solitary one.

Although these studies provide us with greater insight into how the relationship may impact on the non-disabled sibling, what is missing is an understanding of the implications that this has for ongoing support offered by one sibling to another. Nothing is known of how the person with a disability may feel about their non-disabled sibling assuming a caring role and providing them with support and care once parents are no longer able to do this.

Conclusion

If psychosocial impact, particularly as a child, influences the development of the adult relationship between siblings with and without lifelong physical disability, then the literature reviewed here suggests this relationship may be different from typical adult sibling relationships. This may depend on the informant as mothers view the impact of disability more negatively than siblings. When standardized instruments are used to measure the impact on children, there is little difference between the siblings of children with physical disability and control groups without. The question of whether the positive or negative psychosocial impact of being the sibling of a person with a physical disability affects their involvement in the support and care of their sibling with a disability after their parents die remains unanswered. The view of the sibling with disability on this arrangement is not known nor is it clear what

policies and supports need to be available to ensure a smooth transition of care. In order to answer this increasingly pressing question, further research into how psychosocial impact influences the relationship between adults with a lifelong physical disability and their non-disabled sibling/s is urgently needed.

Researchers discussed the impact of mediating variables such as severity and type of disability (Begun 1989; Dallas et al. 1993a, b; Dyson 1989), family size (Breslau 1982; Coleby 1995; Dallas et al. 1993a, b; Dyson and Fewell 1989), birth order and gender (Breslau 1982; McHale and Gamble 1989), and socio-economic factors (Grossman 1972) on sibling relationships. However, there has been no definitive agreement about their impact and particularly how these variables may affect the adult sibling relationship. It is not possible to control all the mediating variables within a family. Nevertheless, it may be important for family members and service providers to acknowledge them in order to develop strategies to mediate negative impact and facilitate positive relationships between non-disabled and disabled siblings. This then is a further area of future study.

Longitudinal studies in which siblings with and without lifelong disability are studied across the lifespan will help identify both the impact on their psychosocial development and the nature of their relationship. This will facilitate the extrapolation of the likelihood of long term post parental support.

There is a need for qualitative research with current adult siblings of people with lifelong physical disability and importantly, including the sibling with lifelong physical disability. Such research would aid our understanding of the perspectives of siblings with and without disability and the roles they seek to fulfill in each others' lives. This in turn may facilitate discussion around later life support. For people with CP and complex communication needs, these discussions are timely as advances in augmentative and alternative communication (AAC) facilitate communication for people with little or no functional speech and assist them to give voice to their own issues and concerns.

Finally, understanding issues for adult siblings is important for policy and service development for organizations providing services to people with lifelong physical disability. Siblings are more likely than parents to provide emotional and instrumental support rather than affective (hands on) support (Bigby 2000; Campbell et al. 1999; Dew et al. 2004). The person with a lifelong disability may well live separately from their siblings but have sibling assistance in areas such as financial management, service negotiation, medical arrangements, and social and emotional support. Assisting organizations to plan effectively for the future, taking into account the needs and desires of the person with a lifelong disability and their family members, in particular non-disabled sibling/s may help support a good sibling relationship, reduce the involvement of service organizations and decrease the incidence of crisis intervention such as inappropriate placement in a nursing home.

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Appendix

Review Articles

1. Boyce, G., & Barnett, W. (1993) Siblings of persons with mental retardation: A historical perspective and recent findings. Chapter 7. In Z. Stoneman & P. Waldman Berman (Eds). *The effects of mental retardation, disability, and illness on sibling relationships: Research issues and challenges* (pp. 145–184). Baltimore: Paul H. Brookes
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