

Relationships Between Adolescent Children and Their Siblings with Cerebral Palsy: A Pilot Study

Abstract:

Purpose: To observe children's (aged 9–18) interactions with, and perceptions of, their siblings with cerebral palsy, how these perceptions and interactions impacted on their life, and the implications of their perceptions and interactions for family intervention.

Method: Participants in the study included four children between the ages of 9–18 years, who had a sibling with cerebral palsy, no more than two years older or five years younger than the child being interviewed. The participants consisted of one female older than her sibling with cerebral palsy, one female younger than her sibling with cerebral palsy, one male older than his sibling with cerebral palsy and one male younger than his sibling with cerebral palsy. All children with cerebral palsy were male.

Results: A thematic analysis of the data revealed the most striking emergent themes as acceptance, wishing, helpfulness, responsibility friendship, and resilience.

Conclusions: It was concluded that siblings of children with cerebral palsy should be included in family intervention as children act as facilitative role models for their siblings with disabilities and may aid their sibling in the intervention process.

It is not always easy having a brother with cerebral palsy, many things take much more time, patience and effort, but when you interact with them you see that there is a specialness about them, a sense that they are an angel sent here to teach you something, that there is more to life than your own selfishness and what you deem to be important. (A child whose brother has cerebral palsy)

Sibling relationships are extremely important as some of the most powerful bonds and human interactions are between siblings because they act as surrogate parents, informal teachers and friends (Davidoff, 2006).

Living with a child with cerebral palsy involves tackling a vast range of problems, such as physical, cognitive and behavioural (Finnie, 1997). Many families do not receive help in dealing with the emotional aspects of having a child with cerebral palsy (Finnie, 1997), and these emotions will impact on the other family members, such as the siblings of the child with cerebral palsy. Having a sibling with a developmental disability is a risk factor for sibling adjustment problems (Sharpe & Rossiter, 2002, cited in Lobato and Kao, 2005). "In many families, the amount of time devoted by parents to the

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one child with cerebral palsy may lead to problems with siblings" (Schleichkorn, 1993, p.114).

Stress, however, is not always the case, and positive experiences arise from having a sibling with cerebral palsy. Literature has shown that having a sibling with disability can be both rewarding and stressful and that it may have positive and negative affects for the child without disability (Gallagher & Powell, 1989). Positive aspects which have been reported are that siblings report satisfaction in learning to live with and cope with the demands of a child with disability and joy and pleasure at the smallest accomplishments of the child with cerebral palsy. The siblings also reported subsequent feelings of compassion and warmth for all people with disability.

As siblings play a facilitative role in cognitive and social development of their siblings (Gallagher & Powell, 1989), it is important for practitioners to understand how the sibling of the child with cerebral palsy feels toward their sibling and what emotions they may feel, having a sibling with disability. Older siblings play an important role in facilitating communicative competence of the younger child (Norman-Jackson, 1982, cited in Gallagher & Powell, 1989) and closely-spaced siblings provide stimulation that facilitates language development in young children (Nelson & Bonvillian, 1978, cited in Gallagher & Powell, 1989). Many siblings of children with disabilities assume the role of an older child, regardless of their age (Dallas, Stevenson & McGurk, 1993). Because many therapists use a family-systems theory approach to intervention, understanding the role of the siblings of the child with cerebral palsy is essential.

Family size, socioeconomic status and parental attitudes and expectations affect how the sibling reacts to their sibling with cerebral palsy (Gallagher & Powell, 1989), and the temperaments of the children are more important than the type of disability. Studies suggest that the more severe the disability, the more adversely affected the sibling of the child with cerebral palsy (Gallagher & Powell, 1989). Age influences how the sibling of the child with cerebral palsy is affected; as the child with cerebral palsy grows older, their siblings are likely to experience more difficulties (Gallagher & Powell, 1989).

Siblings who are older than the child with cerebral palsy are usually more well adjusted than siblings who are younger; the older a sibling is, in relation to the child with cerebral palsy, the better adjusted they seem to be.

South Africa is a country with diverse cultures and many different socioeconomic classes and class impacts on the responsibilities of the sibling of the child with cerebral palsy. Poorer families do not have the financial resources for additional caregivers and so a sibling may have to take on this responsibility of caring for their sibling with cerebral palsy (Gallagher & Powell, 1989). With more than nine Indigenous cultural groups in South Africa and several colonial groups including the Dutch, British and Indian cultures, South Africa has a vibrant and complex range of cultures. Each culture views differently the responsibilities of siblings of children with disabilities and how the family reacts to the child with disability.

It is within this background that the researchers set out to investigate children's perceptions of how their sibling with cerebral palsy impacted on their lives.

Method

The purpose of this pilot study was to observe children's (aged 9-18) interactions with, and perceptions of, their siblings with cerebral palsy, how these perceptions and interactions impacted on their life, and the implications of their perceptions and interactions for family intervention.

Participants

The sampling method of this study was convenience sampling. Permission from the Gauteng Department of Education was obtained for Forest Town School and for Frances Vorweg School. The principals of the schools were given the inclusion and exclusion criteria and were asked to identify eligible families. Each eligible family was given an information sheet with contact details describing the goals of the project with an emphasis on voluntary participation and withdrawal at any time. Confidentiality was guaranteed, with assurance that recordings would be destroyed after the project was completed.

Inclusion criteria included:

- The children from a family must have a male sibling with cerebral palsy, no more than 2 years of age older or five years younger, than the child being interviewed.
- The child with cerebral palsy must be a male; this will employ consistency of siblings with cerebral palsy throughout the pilot study and will eliminate the involvement of gender of the sibling with cerebral palsy impacting on the results of the study.
- The participants must belong to a middle socio-economic status class. This will eliminate the impact of socio-economic status affecting the results of the study.
- The family must consist of two parents, as to exclude perceptions relating to single parent families.
- Children with a sibling with moderate-severe cerebral palsy will be included in the study, as to obtain deeper insight into the perceptions and interactions of children with their sibling with cerebral palsy.
- Proficient English speakers, as the researcher speaks English as her first language.

The final participants were the families of four children between the ages of 9-18 years, who had a sibling with cerebral palsy, no more than two years older or five years younger than the child being interviewed. The participants consisted of one female, aged 18 (older than her sibling with cerebral palsy); one female, aged 9 (younger than her sibling with cerebral palsy); one male, aged 18 (older than his sibling with cerebral palsy) and one male; aged 9 (younger than his sibling with cerebral palsy).

Design and Data Collection

A qualitative design was used which involved interviewing four families' children regarding their perceptions of, and interactions with, their siblings with cerebral palsy. The interview lasted about 45 minutes. The questions in the interviews (see Appendix 1) remained open-ended to minimize coercion or shaping of responses by the researcher and to maximize validity

(Breakwell, Hammond & Fife-Schaw, 2000). The children were interviewed without their parents in the room. A video recorded observation of the participant and their sibling with cerebral palsy at snack time, was recorded and observed, with the use of a checklist, which took about 30 minutes and a kinetic family drawing, of the family at supper time, was drawn by the sibling of the child with cerebral palsy. This aided in determining the reliability of the themes that emerged from the interviews and took about 15 minutes to complete. The checklist consisted of points that the researcher wanted to gain information on (Breakwell et al., 2000, p.228). The kinetic family drawing is a widely-used method of evaluating the child's perceptions of their family context (Carlson, 1990; Marijcke, Veltman & Browne, 2003). Obtaining all the information took about 1 hour and 30 minutes to complete.

Data Analysis

The data collected were transcribed and thematic analysis was conducted according to the method of Llewellyn, Cutler and Stein, (2000). Thematic analysis of the kinetic family drawing and analysis of the video-recorded observation of the child and his sibling with cerebral palsy were both done independently by two of the authors in order to assess inter-rater reliability. The data were combined from the three research tools—interview, observation and kinetic family drawing

Validity

Validity was ensured during this pilot study by the researcher via different methods of data gathering (interview, observation, kinetic family drawing) and by asking the significant other (in this study, the mother) if the data obtained was a true reflection of the child and their sibling with cerebral palsy. The data obtained from the three research tools were systematically cross-checked to ensure the validity of the themes being generated (Strauss and Corbin, 1990).

Ethical Considerations

Ethical consent was obtained from the Ethics Committee at the University of the Witwatersrand, South Africa. Permission from the Gauteng Department of Education

was obtained for Forest Town School and for Frances Vorweg School. Once families deemed eligible by the principal expressed interest in participating, they were given an information sheet as described above. Those who wished to participate signed consent and assent forms. Because children cannot provide valid consent, their parents had to consent to their children participating (Greig & Taylor, 1999). The children also signed an assent form which detailed in simple terms what the pilot study was about, asked if they were willing to participate and mentioned their choice to participate or not in the study (Greig & Taylor, 1999).

If psychosocial problems arose in the children participating in the study, the researcher recommended to the parents that they seek professional advice from a qualified psychologist. The participating families and schools were given a summarized version of the final research report which removed identifying information.

Results

The overwhelming response was positive. The most striking emergent themes included acceptance, wishing, helpfulness, responsibility, friendship, and resilience.

Acceptance: All participants did not seem to think that there was anything unusual about their sibling with cerebral palsy.

"I think I'm pretty much fine with it because he's always been cerebral palsy and I've grown up with him like that so it just seems natural."

Wishing: All participants, although they accepted their sibling with cerebral palsy had at one time or another wished that their sibling could do the things they do such as walking and talking, feeding themselves and being unrestricted to do what they wanted.

"He can't walk and I can and he can't climb trees."

"I go out with my friends, you know walk around the shops and not be scared that my wheelchair is not going to fit through that gap and I can pretty much go anywhere around the house that I want to when I want to"

"I can feed myself...I can skip and I can climb a tree"

"I can do pretty much anything around the house and go anywhere I want"

"...sometimes I feel sad for him..."

"...I wish that he wasn't so restricted..."

"Sad. Because I wish that he could do the things I do"

Helpfulness: All participants needed to help their siblings with cerebral palsy and seemed to help them readily.

"I'll help him get dressed sometimes and get him what he wants. I'll help feed him..."

"I'll help bath him and he likes bathing so I'll play with his toys with him in the bath and dress him."

Responsibility: All participants showed a sense of responsibility. *"I help him feed himself and I get him juice when he's thirsty and I play with him when he's bored"*

"I cut up his food...change the DVD for him"

Friendships: All participants' friends were comfortable with the child with cerebral palsy.

"...most of them are good with him..."

"...I tell them that his muscles can't work properly"

They counted their sibling amongst their friends.

"Play, draw, play music, laugh, tell jokes, and eat"

"I watch DVDs with him and help him with his homework and listen to music"

"We take him to the zoo so that he can see animals; we take him to MacDonald's..."

Defense: They expressed frustration towards people who were inconsiderate towards their brothers.

"...and I also get annoyed when people stare at my brother..."

"...especially if we go out and there are stairs I tend to get quite angry with the people there for not making a ramp."

"...and when people park in the disabled parking, I get very angry."

All participants expressed love for their brother and did not mind helping their brother when he could not accomplish things on his own. Although participants wished that their brother could do some of the things that they could do, all accepted that their brother has cerebral palsy and they had adjusted to the reality.

Discussion

A family focused approach stresses the importance of interactions between the members of the family group, and the interrelatedness of all the family members. The siblings of children with disability are unique and vital components of such a family system (Gallagher & Powell, 1989).

Dormans & Pellegrino (1998) state that being a sibling of a person with disability they may have an increased maturity, sense of responsibility and a tolerance for being different. Cogher et al. (1992) state that when a child with disability requires a great amount of physical care, the siblings of the child may be given greater responsibilities than those usually given to children of the same age. Additionally, emotional support from friends plays a very significant role in adjustment to disability (Li & Moore, 1998).

Intervention is such a critical aspect of life for these children and it can be facilitated by including siblings as role models and communicators (Norman-Jackson, 1982, cited in Gallagher & Powell, 1989).

The primary aim of this pilot study was to investigate children's interactions with, and perceptions of, their siblings with cerebral palsy. The results indicate that siblings demonstrate not only high levels of resilience but maturity about their brother with cerebral palsy.

Siblings serve as developmental facilitators (Gallagher & Powell, 1989), and sibling relation-

ships can be powerful bonds (Davidoff, 2006). Multidisciplinary teams need to seriously consider the inclusion of siblings in any family assessment and intervention process. Having a sibling with cerebral palsy does have a complex range of impacts on a child's life and this pilot study highlights how it is a positive one.

Limitations of the pilot study included the small sample of four families; ethnic and linguistic bias; response bias, observer effect and observer bias (Silverman, 1993). The sample was very small, involving only four families of boys with cerebral palsy. Sample selection was biased in terms of ethnic and linguistic competence for ease of questioning. The presence of the researcher may have influenced the responses from the participants: there could have been response bias, observer effect and observer bias, and an effect of the researcher on the setting, termed the "halo" or "hawthorne" effect (Silverman, 1993), wherein participants give socially desirable responses and where they may have denied the existence of negative feelings and accounts. The research design involved interviewing a participant about their sibling, which may have caused emotional stress to the participant which would not have been detected by the questionnaire. The authors recommend that future research seek larger and more representative samples and that repeated family interventions include the child with cerebral palsy.

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References

- Breakwell, G. M., Hammond, S., & Fife-Schaw, C. (2000). *Research Methods in Psychology* (2nd ed.). London: Sage Publications Ltd.

- Carlson, C. I. (1990). Assessing the family context. In C.R. Reynolds & R.W. Kamphaus (Eds.), *Handbook of psychological & educational assessment of children: Personality, behavior, & context* (p. 546–575). New York: The Guilford Press.
- Cogher, L., Savage, E., & Smith, M. F. (1992). *Cerebral palsy. The child and young person*. London: Chapman & Hall Medical.
- Dallas, E., Stevenson, J., & McGurk, H. (1993). Cerebral-palsied children's interactions with siblings – I. Influence of severity of disability, age and birth order. *Journal of Child Psychology and Psychiatry*, 34 (5), 621–647.
- Davidoff, L. (2006). The sibling relationship and sibling incest in historical context. In P. Coles (Ed.), *Sibling relationships*. London: Karnac Books, Ltd.
- Dormans, J. P., & Pelligrino, L. (Eds.) (1998). *Caring for children with cerebral palsy: A team approach*. Baltimore, MD: Paul H. Brookes Publishing Co.
- Finnie, N. R. (1997). *Handling the young cerebral palsied child at home*. (3rd ed.). London: Butterworth-Heinemann.
- Gallagher, P. A., & Powell, T.H. (1989). *Topics in early childhood special education: Families in special education*. Texas: PRO-ED, Inc.
- Greig, A., & Taylor, J. (1999). *Doing research with children*. London: Sage Publications Ltd.
- Llewellyn, G., Cutler, S.K., & Stein, F. (2000). Qualitative research models. In F. Stein & S.K. Cutler (Eds.), *Clinical research in occupational therapy* (4th ed.). California: Singular.
- Lobato, D., & Kao, B. (2005). Family-based group intervention for young siblings of children with chronic illnesses and developmental disability. *Journal of Pediatric Psychology*, 30, 678–682.
- Marijcke, W., Veltman, M., & Browne, K.D. (2003). Trained raters' evaluation of kinetic family drawings of physically abused children. *The Arts in Psychology*, 30(1), 3–12.
- Schleichkorn, J. (1993). *Coping with Cerebral Palsy. Answers to Questions Parents Often Ask* (2nd ed.). Texas: PRO-ED, Inc.
- Silverman, D. (1993). *Interpreting qualitative data. Methods for analyzing talk text and interaction*. London: Sage Publications, Ltd.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research. Grounded theory procedures and techniques*. California: Sage.

Appendix 1: Description of the Interview

Questions	Rationale
Tell me about your brother.	We wanted as much information as possible about the child with cerebral palsy.
How is your brother different from you?	We wanted to see how the individual perceived their sibling with cerebral palsy and how they perceived their brother to be different from them.
How do you feel about your brother being different?	We wanted to gain insight into the individual's emotions.
How do you feel when your brother can't do some of the things you do?	We wanted to gain insight into the individual's perceptions and emotions.
What are the things your brother can't do?	We wanted to gain insight into the individual's perceptions of their sibling.
What can you do that your brother can not do?	We wanted to gain insight into the individual's perceptions of their sibling and themselves.
What do you do to help your brother?	We wanted to gain insight into the individual's perceptions of their sibling and themselves and what they felt were their responsibilities towards their brother.

(continued)

<i>Questions</i>	<i>Rationale</i>
What sort of things do you do with your brother?	We wanted to gain insight into the individual's interactions with their brother.
What do your friends say about your brother?	We wanted to gain insight into the individual's perceptions and emotions.
What do strangers say about your brother?	We wanted to gain insight into the individual's perceptions and emotions.
Do people act differently to your brother than they do to you?	We wanted to gain insight into the individual's perceptions and emotions.