

Growing up with cerebral palsy: perceptions of the influence of family

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Abstract

Background Cerebral palsy (CP) is a non-progressive condition present from birth or infancy that includes various neurological patterns of dysfunction. It is characterized by abnormal motor control and/or posture and can involve communication difficulties. Children and youth with CP face multiple social and developmental challenges during their formative years including mild to severe physical limitations, poor socialization, limited recreational activities, and stigmatization. Families play a key role in supporting adaptation to CP. The purpose of this paper was to explore women's perceptions of the ways their families contributed to their overall quality of life with CP.

Methods Drawing on data from a qualitative study of eight women with CP, the purpose of this analysis was to examine perceptions of the ways in which their families and individual family members contributed to participants' overall quality of life and adaptation to CP. Respondents ranged in age from 22 years to 55 years and had varied forms of CP. The study was based on a feminist biographical approach, which combines biographical methods with feminist principles.

Results Participants provided considerable, rich contextual data on their family life and the pivotal role family played. The analysis identified four themes related to supportive family roles: (1) being an advocate, and teaching advocacy; (2) promoting inclusion and acceptance; (3) integrating therapy into daily life; and (4) the importance of siblings as friends and mentors.

Conclusions Health-care providers can contribute to the family's ability to facilitate quality of life by providing guidance on how to be advocates and teach advocacy, including the child with CP in family activities, accessing therapy and incorporating beneficial therapies at home, and promoting healthy sibling relationships.

Keywords

cerebral palsy, childhood disability, family support, qualitative research method

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Introduction

Cerebral palsy (CP) is a non-progressive condition present from birth or infancy that includes various neurological patterns of dysfunction. It is characterized by abnormal motor control and/or posture and can involve communication difficulties (Turk *et al.* 2001; Wichers *et al.* 2005). CP is the most common physical disability of children, with approximately 10 000 new cases each year in the USA (Cerebral Palsy Fact Sheet 2012).

Worldwide incidence varies by country but is approximately two cases per 1000 liveborn children (McAdams & Juul 2011).

Children and youth with CP face challenges not encountered by children without disabilities (Harrison 2003), including mild to severe physical limitations, poor socialization, limited recreational activities and stigmatization (Pimm 1996; Lepage *et al.* 1998; Green 2003). These challenges are compounded when children with disabilities are raised in a family with able-bodied

members who do not share their challenges (Olkin 2006). However, family members can mentor or support the child in dealing with these challenges.

There is a paucity of research on how those with CP or other physical disabilities interpret family influences. Past research on families (parents and siblings) of people with physical disabilities focused on family stress or parenting styles (Knaf *et al.* 1996; Goldbeck 2006; Gannoni & Shute 2009), and discovered social isolation, feelings of incompetence, lack of knowledge, authoritarian parenting and maladaptive child behaviour increase parental and family stress (Sen & Yurtsever 2006; Woolfson & Grant 2006; Butcher *et al.* 2008; Ketelaar *et al.* 2008). In particular, maternal stress is affected by poor spousal support, high family needs, and low family adaptability (Glenn *et al.* 2009). However, families with the ability to manage stresses of raising a child with CP positively had a direct benefit on both the physical and psychological health of the caregiver, primarily the mother (Raina *et al.* 2005). Issues affecting families of those with physical disabilities are important to understand, not only from the perspective of parents and siblings, but also from the point of view of the person with CP in order to identify factors supporting and improving their lives.

Health outcomes for youth and young adults with CP and other disabilities are often related to one's self-esteem and quality of life (Young *et al.* 1997). For example, women with disabilities have lower levels of self-esteem when compared with women without disabilities and to men with disabilities (Nosek *et al.* 2003; Hughes *et al.* 2005; Duvdevany 2010), putting them at greater risk for impaired social functioning and lower quality of life (Rosenbaum *et al.* 2007; Varni *et al.* 2007; Russo *et al.* 2008). Because females with CP are more vulnerable for poor outcomes it is important to explore their life experiences to identify factors improving outcomes.

The data for this article come from a larger qualitative study in which women with CP shared their experiences of living and growing up with CP. Although participants were not asked specific questions about the role of family in their lives, the use of the feminist biographical method allowed them to discuss topics of importance and provided detailed accounts of the importance and influence of family members. Therefore, the purpose of this paper is to explore women's perceptions of the ways families contributed to their well-being.

Methods

The study was based on a feminist biographical approach, which combines biographical methods with feminist principles. The biographical method uses a hermeneutical approach in

investigating life history narratives and includes written textual depictions (autobiographies, diaries, letters and other personal documents) revealing the participant's personal character and relationship with family, community and society (Denzin 1989; Erben 1996). As participants share narratives they often reflect on their past, present, and even future lives, their experiences, and the meanings of those experiences (Broch-Due 1992). Feminist researchers, such as Etter-Lewis (1991), Gluck and Patai (1991) and Minister (1991), embrace the biographical method and its focus on participants' life histories as an effective way to illuminate the meaning of women's lives (Smith 1994) and discover stories of the marginalized, the silenced or people made invisible in society (Denzin 1989; Kibele & Llorens 2012).

Such an approach allowed participants to tell their life stories and experiences with CP in their own words and in their own way. Numerous stories about family life, parents, siblings and extended families were shared and it is from this rich contextual data the influence of family in the lives of women with CP was discovered.

Sample criteria and recruitment

Inclusion criteria were women with CP over the age of 18 who had a communication skill level appropriate for conversation. Three study participants had speech impairments, but were understandable. Sampling continued until repeated patterning was well established (Leininger 1994), with eight women participants.

After approval by two institutional review boards, community-dwelling women with CP who met inclusion criteria were invited by flyers distributed by health-care providers, community agencies and others with CP to contact the investigator if interested. Potential participants contacted the researcher by telephone or e-mail after learning about the study and, if agreeing to participate, gave informed consent.

Participants ranged in age from 22 years to 55 years with a mean of 36.88 years (SD = 12.98). Four participants had spastic quadriplegia, two had athetoid CP, one had spastic diplegia and one had spastic left hemiplegia. Two participants were married and living with their husbands. One participant lived with her adopted daughter. Two participants lived alone and had care attendants as needed. One participant lived with roommates. The youngest two participants, aged 22 and 24 years, still lived with their families. One participant worked full time, two worked part-time, three were seeking employment and two were still in college.

Data collection

Consistent with the feminist biographical method, data were gathered through audio recorded unstructured interviews, and participants' personal writings. The data for this article come from the first of two interviews ranging from 45 min to 135 min each. The first interview began with the question, 'Tell me about your life and growing up with CP'. The purpose of the first interview was to allow participants share life stories in their own words and discuss topics of interest and importance. The participants, therefore, controlled topics and sequencing of the first interview. The second interview consisted of specific questions participants answered, not included in these data.

Data analysis

Analysis of interviews was ongoing throughout and after the data collection. Themes were identified within each participant's narrative and triangulated with written texts if provided (one woman provided an autobiography and another provided a series of poems), and compared across all participant narratives (Ayres 2000; Ayres *et al.* 2003). Codes were utilized to identify themes occurring within each participant's transcription and across all participants' transcriptions. Research team members reviewed codes of each manuscript and themes to assure quality and consistency.

Methodological rigour

This study used McLeod's (1994) criteria for ensuring methodological rigour which include: clearly identifying study aims and methods; acknowledging participants' societal or cultural backgrounds; delineating and providing specific exemplars substantiating themes; and triangulating data from other sources, such as participants' written texts. Societal and cultural backgrounds were acknowledged during the interview process, and participants were encouraged to relate their backgrounds to life experiences. Written autobiographies and poems shared by some participants added another level of understanding to their narratives.

Results

Most participants began with narratives about their birth stories and progressed through childhood, adolescence and adulthood. It became clear there were many commonalities and differences among the women's lives.

Themes and subthemes

Key themes describing pivotal family roles perceived by participants as important to their overall quality of life and adaptation to CP were identified: (a) being an advocate, and teaching advocacy; (b) promoting inclusion and acceptance; (c) integrating therapy into daily life; and (d) the importance of siblings as friends and mentors. These themes were relevant to all participants, regardless of perceived family support.

Being an advocate, and teaching advocacy

Advocacy, the act of supporting, encouraging and promoting the rights of others (Fry *et al.* 2011), was described by participants as ensuring their physical, emotional or educational needs were met. Seven participants described two types of family advocacy: (a) family members as advocates, and (b) teachers for participants to learn the importance of self-advocacy.

Family members as advocates

Family members acting as advocates included parents, siblings and extended family members. Examples included parents interceding with school personnel when the participant was mistreated by peers or denied the opportunity to enroll in a specific class. Extended family negotiated a way for a participant to receive therapy not available in the participant's hometown: 'I had another aunt in another big city so I went there for the summer so I could have speech and physical therapy.' Participants described their advocates as 'vocal', 'on the warpath' and 'a positive force', and identified advocacy as not only an active role needed to reach a goal, but also a way in which family members made them feel valued.

Family members as teachers of advocacy

Family members also taught participants how to advocate for themselves. Sometimes advocacy was modelled: 'My mother is a strong fighter. She won't take no for an answer. She instilled that in me. That courage to fight'. One respondent quoted her sister as saying, 'Never be ashamed of who you are and what you need help with. Don't ever take any crap from anyone'. Participants who learned self-advocacy as children used the skills as adults in academic and employment settings.

One father modelled the steps of advocacy after his daughter was not allowed to use a floatation device in a public pool. First, he validated there was a law forbidding the use of floatation

devices in public pools. Then he researched the steps needed to change the law. Finally, by following the steps to change the law, the law was changed. Years later his daughter used similar steps to address an injustice faced in college. She acknowledged self-advocacy is not easy, but learned from parents: 'I'd say that I've been taught from my parents from a very young age that I need to advocate for myself and the importance of doing that. And I think I do a fairly good job of it'. She linked her ability to self-advocate to successful completion of her undergraduate and graduate programmes, and continued to use those skills when looking for employment.

The participant whose family did not advocate for her nor teach her to advocate for herself described difficulties using her wheelchair on rainy days:

I was a clerical aide for teachers. I struggled to walk, use my arms. I did not have endurance. I shared a tiny work area with another lady. There was no way to unload my chair if it was raining, or to load it after school. The principal said that I could not leave the chair at school. There was no covered walkway when it was raining, and it was hard to get the chair out of the car in the rain. So when it was raining, sometimes I'd just leave it in the car and have to work without it. I noticed that at the high school, the kids in [wheel] chairs on rainy days had people holding umbrellas for them, but no one would do that for me. This has all made me very depressed. The world doesn't make things accessible. You're trying to fit in, and you're trying to live your life, but they don't let you.

One participant never described an experience of advocating for her rights or needs. Instead, she described struggling and becoming depressed, and viewed her world in negative terms.

Promoting inclusion and acceptance

Being included in activities was important. Family members contributed to a sense of inclusion by treating participants as a regular part of the family and making sure participants were included in family activities. Most participants echoed the words of one woman who stated, 'I felt very accepted by my family'. One participant, the youngest of nine children, described how she was a part of family activities:

Well, there were obviously things I couldn't do. But, at least with my family, I know that they made an effort to give me a wide range of experiences. For instance, all the rest of my family is very active, very into sports and things like that. And hikes. So like with hikes, they would just . . .

When I was very young, they would put me in a backpack. After that they would kind of just put me on their back and switch through all my brothers. They tried to allow me to go on the hikes and see the things that they really appreciated.

Participants reporting supportive families said they were treated normally. 'But my family treated me just like anybody else'. Being treated just like anybody else included doing chores and being disciplined. When one participant tried to take a toy from her younger sister by invoking her CP, her father immediately interceded stating, 'I don't ever want to hear that as an excuse again'. She said, 'And that's just kind of their philosophy – that just because I was disabled didn't mean that I could use it to my advantage'.

In contrast, one participant never felt accepted by her family. When school experiences were particularly difficult, she would come home and cry. Unlike other participants, whose families made them feel loved and understood, this participant stated, 'I don't think that my stepmom, that she understood. And I guess my dad didn't either'. Through the interviews, this participant described a family that didn't care if she were upset or spent hours alone in her room.

Integrating therapy into daily life

Childhood interventions, including physical and occupational therapy, are frequently prescribed for children with CP. Obtaining therapy can, however, be time-consuming and costly. Indeed, families played a pivotal role by placing a high priority on accessing therapy sessions and integrating therapy into the home: 'My dad would do this thing called wheelbarrow where he would hold my legs and I would walk around on my hands'.

Accessing therapy

Physical, speech and occupational therapy sessions were an integral part of supportive families. In most cases, as soon as parents knew their daughter had CP, they sought appropriate therapy. In fact, therapy was such an important part of one family's life that each participant's siblings, at one time or another, wanted to be a physical therapist. However, therapy, helpful as it was, was not always fun. One participant felt she never had time to play, because she was always in therapy. Another participant's family addressed therapy as a time for friendships: 'I was always allowed to take two friends with me to therapy. And they would play around and they would think that it was a cool place'. A different participant lived in a remote rural town that could not

meet her therapy needs. Therefore, during summer, she lived away from home with aunts who supervised her speech therapy. Accessing therapy was also not easy. It was often expensive and time-consuming. However, no participant described any parental complaints about providing therapy. In fact, they acknowledged parents worked hard to provide them with every opportunity to benefit from therapy.

However, one family did not access therapy for their daughter: 'I have a lot of frustration and sadness because I read of things therapy offers CP patients today that I did not have a chance to benefit from'. She not only resented missing therapy, which she felt might have increased her ability to walk, but also her family's lack of concern and caring for her needs.

Home-based therapies

Therapy was not always provided in structured settings. One woman indicated, 'My parents were always making me do things like walk up the stairs ten times. My dad would do this thing called wheelbarrow where he would hold my legs and I would walk around on my hands'. It was not always easy for parents to encourage their daughters to undertake difficult things. When one participant was learning to walk, she fell and cut or bruised her face several times. Her mother bought her a helmet and continued to encourage her to walk around the house:

It was hard for my parents to let me try again; they wanted to throw their arms around me and keep me from trying. But they fought against that desire. It was more important that I learn to walk than that I not cry. They reminded themselves of this over and over again.

For one participant, home-based therapy included neighbours and others in her community. Although she did not comment on physical benefits of therapy, she mentioned the emotional benefits:

They did a therapy called patterning . . . where someone moved my right hand, another person moved my left hand, another person my left leg, another person my right leg. Just kind of get the feel of crawling. It's really interesting 'cause, even today, people will come up to me all the time and say, 'Oh, I used to help you with patterning'. That's kind of cool for me. It's just like this huge circle of people that I don't really know that care a lot about me.

Siblings as friends and mentors

Participants talked frequently about their relationships with siblings. When social exclusion limited interactions with peers,

siblings often filled the void for friends. They also mentored participants.

Siblings as friends

Relationships with siblings were important to participants; often they were their best friends, and in one case, her only friends: 'I didn't have any friends at home. I felt like I had no right to play. I was very angry. It was very lonely but my brothers played with me'. Even as adults, these brothers were close friends who visited often. Even though her disability limited interactions with other children, this participant viewed the relationship with her brothers as validating she was valued by someone other than her parents. As an adult she looks forward to their visits, because she knows that they will rekindle happy memories shared as children.

Many siblings treated participants the same as other siblings without CP, which often included fighting:

Growing up was typical. My brother is 3 years younger and my sister is 8 years younger. So my brother and I fought. I wasn't very big. He would pound me. I couldn't hit him hard enough to hurt so I would dig my nails into him.

Although fighting might be viewed as mistreatment, this participant viewed the relationship with her brother as a typical brother/sister relationship, validating her belief that she was a normal part of her family. Although she might be treated differently by peers, she never felt different around her brother.

The participant with the non-supportive family had little interaction with an older brother, and spent most of her time alone in her bedroom. She described her brother as being different: 'he's like totally the opposite – Mr. Life of the Party. He's all bubbly and I'm not that way'. With no friends at school or home, she never felt understood or valued.

Siblings as mentors

Siblings often served as mentors, through both their actions and words. Specifically, participants shared experiences where siblings showed them how to crawl, use a spoon, and even read.

One participant experienced a devastating emotional loss when a girl she thought was her best friend said they were not friends anymore. She was unwilling, to share this loss with her family, so she hid in her room so family members would not see her suffering. Her brother, with all the wisdom of a 16-year-old boy, forced her to tell him what was bothering her:

Finally he used his 8 years seniority and larger size to his advantage by threatening me. This worked. I broke down and told him, ending by screaming, 'There! Are you satisfied?' He waited a few minutes to let the atmosphere quiet. Then he said: 'You know Dorothy, the world is made up of two kinds of people. There are big people and little people. The little people are those who get up in the morning, get dressed, go to school or to work, come home, eat dinner, watch TV, and go to bed. They don't mean anything to the world and the world doesn't mean anything to them. You don't need to worry about them. It's the big people you need to worry about. They care about the world, and make decisions to try to make it a better place to live. They are successful in living and not just making a living. But you don't even have to worry about them because if they are truly big people they will have big enough hearts to love you and accept you as you are.'

She then explained, 'This little lecture had a strong effect on me. I stopped crying and began picking up the pieces of my world'. The words of her brother became a meaningful life lesson.

Discussion

Understanding the lifetime influence of families in the lives of women with CP is helpful to both health-care providers and parents of females with CP. Seven participants expressed hopefulness about their future and had goals for higher education. These participants described families who were willing to support their hopes and goals. The other participant, however, described a non-supportive family and did not foster hope for the future.

Benefits of having a supportive family were demonstrated most clearly by one participant whose family was not supportive. She could not recall her parents advocating for her needs or teaching self-advocacy. She did not believe she was a normal part of her family and had an almost non-existent relationship with her brother. In addition, she was often excluded from activities, and never received any therapy. As an adult, she continued to focus on negative aspects of life. This is consistent with research showing emotional abuse or insecure attachment during childhood can result in negative views of self and others in adulthood (Riggs 2010).

Although participants described instances of non-supportive behaviours by family members, the overall perception of their families was positive. Non-supportive behaviours included downplaying challenges, waiting a long time before providing

assistance, discouraging participants from setting high goals related to activities or education, and treating them differently. Supportive behaviours included consistent attempts by parents to be advocates, treat participants normally, inclusion in family activities, provide therapy and encourage positive sibling relationships. These behaviours contributed to participants' ability to recognize positive aspects of life despite occasional negative experiences. This is consistent with research that showing consistent parenting or supportive families, off-set negative experiences and promote resilience and life satisfaction (King 2003; King *et al.* 2003; Nosek *et al.* 2003; Callaghan 2006; O'Leary & Bhaju 2006).

This study demonstrates the important role of families in the lives of women with CP. It reveals strategies families and family members used to help participants learn to live with CP. Demonstrating and teaching advocacy was especially important. Although no participant described self-advocacy as an easy process, those able to speak up for themselves expressed more positive views of life than those unable to do so.

Being treated as a normal member of the family and included in family activities provided participants with positive experiences they continue to build on as adults. All participants except one described themselves as being treated as a normal family member or included in family activities. Although most participants viewed life in positive terms, the participant not treated as a normal family member focused on life's negative aspects. Even though research shows a child's adaptation to CP is multifactorial, family cohesion and inclusion are indicators of positive coping and self-determination (Newey 2008; Chiarello *et al.* 2009).

Physical, speech and occupational therapies were not cherished memories of most participants' childhoods. However, even as children they understood therapy was important. Participants also realized their families often made great sacrifices to provide either professional or home-based therapies. Knowing parents placed high importance on meeting needs confirmed participants' beliefs they were cared for and loved. This is in contrast to the participant who did not receive therapy. She grew up feeling uncared for and unloved, which made adulthood unfulfilling.

Siblings were important to all but one participant, as friends and mentors. Sibling relationships were especially important because participants felt understood and valued by someone other than a parent. Important sibling relationships continued into adulthood and provided participants with a broad support system. However, the lack of a loving sibling relationship for one participant left a void in her life. As an adult, she did not believe she could turn to her parents or her brother for help in times of

need. One study revealed young adults with disabilities with supportive sibling relationships have increased opportunities for autonomy (Kramer 2008). In another study, children and adolescents with intellectual disabilities with close, positive sibling relationships had fewer negative school experiences (Floyd *et al.* 2009).

Implications for parents and health-care providers

This study reveals the important role of families in the lives of women with CP. Participants shared strategies parents should use as they help a child adjust to growing up and living with CP. Health-care providers have an important role in assisting families support children with CP. They should encourage families to be advocates, model and teach advocacy. By being an advocate and teaching advocacy, parents enhance their child's ability to self-advocate when appropriate.

Health-care providers should also talk with families about treating the child with CP as a normal member of the family and help them develop strategies to do so. Normalization strategies include giving the child chores and providing appropriate discipline. Plans for including the child in family activities should be explored. If the child is small enough, a backpack can allow the child to be taken on hikes or other outings. Each family and child will have unique needs, but inclusion strategies should always be discussed.

In addition, health-care providers also need to teach families the long-term benefits of therapy. Including a friend during therapy can both encourage participation and promote friendships. Home-based therapies can encourage closer relationships with family members. Indeed, working as a team with physical, speech and occupational therapists, a primary care provider can assist families meet their child's needs.

Finally, supporting healthy sibling relationships has long-term benefits. Although a child should never be allowed to hurt or abuse a sibling with CP, it might be appropriate to allow roughhousing or wrestling within the bounds of safety. Promoting normal sibling interactions will help establish lasting friendships. It is also critical to talk to siblings of children with CP about the importance of establishing healthy relationships.

Limitations

The exclusion of non-verbal women from the study is a limitation. Although only one potential participant declined because of impaired speech, other non-verbal participants might not have received the recruitment flyer. The difficulty of interviewing women with incomprehensible speech is obvious. However,

the need to gain a fuller understanding of the experience of living and growing up with CP mandates their stories be uncovered. Of the eight participants, four had speech affected by CP, with two having almost incomprehensible speech. However, the time required to listen to these participants, learn their speech patterns and record their stories was well worth the effort.

Key messages

- Supportive families have a positive influence on those with CP during both childhood and adulthood.
- Having family members model advocacy prepares women with CP to advocate for themselves.
- Being included in family activities teaches girls with CP that they are accepted for who they are.
- Integrating physical, occupational and speech therapy into daily life has long-term benefits.
- Siblings who are friends and mentors in childhood, become life-time friends and mentors.

Conflict of interest statement

The authors declare that they have no conflicts of interest.

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