Published in final edited form as:

Disabil Health J. 2016 April ; 9(2): 208–217. doi:10.1016/j.dhjo.2015.10.009.

Adults' Recollections and Perceptions of Childhood Caregiving to a Parent with Significant Physical Disability

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Abstract

Background—Caregiving roles of children < 18 years of age living with parents with health conditions or disability have been studied extensively abroad, but little U.S. research has examined the caregiving activities and perceptions of children with parents with significant physical disability.

Objective—To examine children's caregiving activities for their disabled parent, childhood perceptions of these activities, and adult views of this caregiving.

Methods—We conducted one-hour, semi-structured, open-ended interviews with 20 persons age 21 years who as children (age < 18 years) had a parent with significant mobility disability. We used conventional content analysis to identify themes.

Results—Interviewees' mean (standard deviation) age was 36.7 (13.8) years; 4 were male. As children, most interviewees assisted their disabled parent with activities of daily living (ADLs) and instrumental ADLs; some children provided more medical supports. Several parents, especially of older interviewees, did not seek their children's care. Interviewees reported both positive and negative childhood attitudes about caregiving. Roughly half recalled as children feeling proud, special, or otherwise positively toward caregiving activities, while about one-third viewed caregiving as just part of their daily reality (i.e., simply needing to be done). Approximately half remembered also feeling resentful, primarily from time demands, insufficient appreciation, and being different from their peers. Interviewees reported gender and cultural factors affecting their caregiving roles and perceptions.

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The Authors have no financial conflicts of interest.

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Conclusions—Children can provide significant care to parents with physical disability. Understanding better their roles and perceptions could suggest ways to improve these experiences for both child and parent.

Keywords

Disability; caregiving; child; parent

Introduction

According to the *World Report on Disability*, “When adults acquire a disability, children are often asked to help.”¹ Expectations about children’s household responsibilities and ages when these should start vary across cultures. Thus, studies of child caregiving must recognize diverse national social support and cultural contexts.^{2–5}

Child caregivers have been studied most extensively in the U.K.,^{2, 3, 6–18} Scotland,^{19, 20} Wales,^{21, 22} Australia,^{5, 23–26} and Canada.^{27, 28} These studies have found that child caregiving demands differ across health conditions necessitating caregiving (e.g., debilitating physical conditions, serious mental health illness, alcoholism). Fears of social service interventions and removal of children from homes prevent some families from seeking formal support services;^{7, 10, 12, 25} furthermore, disability can disrupt parental relationships, precipitating divorces and complicating custody decisions.²⁶ Caregiving involving toileting and bathing raises particular questions about gender concordance between the disabled parent and child. This research suggests that caregiving can have both positive and negative consequences for children: they may feel closer to and more appreciated by parents, but they may have worse physical and emotional health and educational attainment than their peers. However, interpreting these effects is confounded by child caregivers generally living in more socioeconomically disadvantaged situations than do other children.

It is unknown how many of America’s 74 million children – persons ages 0 to 17 years old – live with parents with significant physical disability. Few U.S. studies have examined child caregiving.^{29–32} Research involving U.S. child caregivers focuses primarily on specific contexts, such as family members with particular diseases, not physical disability.^{30–33} One U.S. study of 12 persons ages 23–58 years old found that childhood caregiving did not appear associated with negative adult mental health.³⁴ The most comprehensive U.S. study examined roles of children (ages 8–18 years) serving as caregivers in the home.³⁵ This 2003 survey estimated that 1.3–1.4 million U.S. children were caregivers and that 31% of these caregivers were only 8–11 years old.³⁵ Child caregivers lived in lower income households than other children, and 58% provided care for one or more activity of daily living. The survey’s authors noted that their “report provides an outline but not the details.”³⁵ Qualitative studies were needed to generate greater understanding of child caregivers’ experiences and response.

Our research aimed to explore the experiences and perceptions of childhood caregiving among U.S. children specifically with parents with significant physical disability. We conducted in-depth interviews with 20 adults (ages 21 or older) who grew up with one or

more parent with substantially impaired mobility. We asked adults not only to recall their childhood caregiving activities but also to describe their views – both as children and adults – of those experiences. Based on these interview findings, this paper describes childhood parental caregiving activities and childhood and adult perceptions of this caregiving.

Methods

The Massachusetts General Hospital (MGH)/Partners HealthCare Institutional Review Board (IRB) approved this research.

Study Participants

We sought interviewees who: were at least 21 years old at the time of the interview; when younger than 18 had had at least one parent with a physical disability; and during the interviewee's childhood, the disabled parent had used ambulation or wheeled mobility aids (cane, crutches, walker, manual or power wheelchair, or scooter) or had significant arm difficulties. We started recruitment by contacting organizations serving persons with disabilities, MGH colleagues, social networks, and personal contacts. However, this approach generated only about a dozen individuals to contact, all of whom agreed to participate. To broaden our search, we advertised the study on www.clinicaltrials.partners.org, a Partners Web site that lists studies soliciting participants for research being conducted by investigators at Partners institution. This listing is available to the public and also sends weekly broadcast emails to all MGH employees. Six participants responded to this announcement.

We speculated that interviewing siblings could offer productive insights. When appropriate, we asked interviewees whether they would ask their sibling(s) if we could contact them about participating in a separate interview. We asked four women interviewees to check with their brothers; one brother agreed. We asked one male interviewee to ask his two brothers if they would participate; one brother agreed. We asked one female interviewee to ask her sister to participate; the sister agreed.

Interview Protocol and Procedures

We designed a semi-structured, open-ended interview protocol for this study. The protocol (available upon request) covers nine broad topic areas. Table 1 shows the questions concerning: childhood caregiving activities of interviewee for disabled parent; interviewee's perceptions of caregiving activities during childhood; and current perceptions of childhood caregiving activities. The protocol provides probes after main question to further guide questioning, if necessary; many probes were based on findings from research from abroad (see above). In each interview, questions varied somewhat depending on interviewees' specific circumstances, in particular whether the disabled parent was still living and timing of the parent's disability during the interviewee's childhood. Given the open-ended responses, interviewees' answers to individual questions sometimes covered other topics. The interviewer kept careful mental notes of topics covered, returning to the protocol as appropriate to ensure all issues were covered.

After obtaining verbal informed consent, X.X.X. (study principal investigator) conducted and audiotaped all 20 telephone interviews, which averaged one hour and occurred from September 2013 to May 2014. Participants received a \$50 gift card in thanks. A professional transcription service typed transcripts verbatim from the digital audio recordings. All names are pseudonyms; we change certain small details to protect participants' confidentiality.

Analysis

The analysis reported here examine responses relating to specific caregiving activities and perceptions of these activities, during childhood and now looking back as adults. We used conventional content analysis³⁶ as our analytic method. To specify codes for sorting the texts for analysis, L.I.I., who had conducted all the interviews, recommended a list of codes. After reading the transcripts, all authors met to review these codes, recommending revisions. A.J.W. and A.A.B then coded the same several transcripts to generate this revised coding list. Afterward, A.J.W. and A.A.B used these codes with NVivo 10 (QSR International) qualitative analysis software to sort the transcript texts. Finally, L.I.I. went sequentially through each of the 20 interview transcripts to ensure that all relevant texts had been coded by A.J.W. and A.A.B

We present selected quotations that exemplify each of the three analyses described below: childhood caregiving activities, childhood views of caring for their disabled parent, and adult views of caring for this parent. Below, we sometimes provide approximate proportions of participants reporting specific experiences or attitudes. We recognize that interviewees do not represent of the general population, and we do not intend these estimates to imply population prevalence of these caregiving experiences. We provide these numbers to indicate clearly how often interviewees reported specific experiences or views rather than relying only on general terms such as “many,” “several,” or “a few.”

Results

Table 2 presents characteristics of the 20 interviewees. Mean (standard deviation) age was 36.7 (13.8) years. Most interviewees were female, white, well-educated, and Massachusetts residents. Half were gender concordant with their disabled parent (e.g., female interviewee with disabled mother). Half of disabled parents were still alive at the time of the interview. The most common causes of parental disability were polio or post-polio syndrome and multiple sclerosis (Table 3). More than half of disabled parents used manual or power wheelchairs during the interviewee's childhood.

Childhood Caregiving Activities

Reported childhood caregiving activities for disabled parents fell into five broad categories (Table 4).

Assistance with Activities of Daily Living

Almost half of interviewees reported having assisted their disabled parent with one or more basic activity of daily living (ADL): feeding, bathing, dressing, toileting, or moving around the home. The extent and nature of help varied by the parent's impairments or needs. For

example, Astra's (age mid-30s) mother, disabled by polio, could independently use the toilet and bathe herself, once Astra had turned on the water. But with her mother's limited hand dexterity, Astra "had to help her dress herself ... anything that she can't do with her hands. So tie her shoes, button her pants, zip them, and change her pads, put her deodorant on ...". In contrast, Monica's (age mid-20s) father was quadriplegic from a spinal cord injury (SCI) several years before she was born:

Probably about the age of five, I started learning how to be a caregiver, even just doing simple things like giving him a drink, feeding him, preparing food. Then, as I would get older, I learned to help him brush his teeth and wash his hands, get him dressed, like get his shirt on, and help him with shaving. Then when I got a little older, I would help by emptying his leg bag, and ... I learned how to secure the wheelchair in the van. Pretty much, anything I was capable of, I was doing.

Marc's (age early 40s) mother was severely disabled by multiple sclerosis (MS) but typically had home aides assisting her seven hours daily. His father worked long hours, which often left Marc and his younger brother home alone with their mother.

I'm 16, 17 years old ... and there's nobody around to help my mother. ... All of a sudden, I was helping my mom go to the bathroom. ... I'd have to help her pull down her underwear and her pants, and ... then she could hardly even wipe herself. And then I would have to help her get up and pull her clothes up. Or sometimes she would get stuck in the shower, and she couldn't get her legs over the tub.

Assistance with Instrumental ADLs

Roughly three-quarters of interviewees reported assisting their disabled parent with instrumental ADLs (IADLs), including cooking, cleaning, shopping, doing laundry, paying bills, and fetching items to help the parent perform IADLs. Examples of IADL assistance include Eliza (age late 20s), whose mother's leg was severely injured in early life:

We had a lot of chores, actually. Probably the one that I did as opposed to my brother was help with meals ... From a really young age, I was involved in meal preparation, even if that just meant fetching a can from the cupboard ... We would also do the laundry ... and standard chores ... like cleaning.

Similarly, Amin (age early 40s), Marc's younger brother, recalled doing chores before his mother's MS progressed: "We'd come home, we'd do our schoolwork, and then we'd do the chores around the house ever since we were little kids." After his mother developed MS, Amin "had to do the food shopping, and I had to do the cooking with her ... [and] paying the bills."

Activities Related to Medical Needs

About one-quarter of interviewees assisted their disabled parent with medically-related needs, including helping with leg braces or complicated devices (ilizarov apparatus, Table 3) and other tasks. Amin's mother periodically received home intravenous infusions to treat her MS. "They sent visiting nurses," Amin recalled, "but they can't be there all day. So I used to help her with the IV, connecting it, and flushing her arm, her port for her after the treatment." Amin's older brother Marc remembered, "At first, I ... was a little squeamish

about it, and I was just like, ooh, needles. And I would get a little light-headed if I saw a nurse giving her an IV.” Amin handled this task: “I just had the nurses watch me. I was nervous at first, but you know, it doesn’t bother me to do stuff like that.”

Kat (age late 20s) was 12 years old when her father became quadriplegic from SCI. After he returned home from hospital, the family talked openly about what was required to care for him: “that wasn’t shielded from me.” Preventing pressure ulcer development was critical, Kat remembered:

I used to switch places at night sometimes [with] my stepmom ... They have ... two adjacent hospital beds ... Some nights my stepmom would go sleep in the guestroom or my room, and I would sleep in the [hospital bed] on her side and turn my dad ... at like 2:00 in the morning ... just to let my stepmom get a full night’s sleep.

This effort lasted for two years, until Kat’s father regained some arm strength.

Other Types of Assistance

Several interviewees described providing other types of assistance, including caring for younger siblings and simply being present in the home so the disabled parent was not left alone. Gabriela’s (age mid-30s) mother, who had emigrated from Latin America, had severe rheumatoid arthritis. When she was 16, Gabriela’s stepfather left her mother. “At that point I ... stepped up to take care of the family because my mom really fell apart,” Gabriela, who has two brothers, recounted. “Feeling that you’re a child and to have the responsibility of your parent, that feels hard. ... There’s this whole thing in our culture, too, where if you’re the oldest, especially the oldest female, you’re in charge.”

Beka (age early 30s) understood from an early age that her father could not protect her physical safety as other fathers could. Walking with forearm crutches because of polio, Beka’s father nonetheless had a job that required frequent overseas travel, and he sometimes took his young daughter with him.

This is just a very foggy memory ... I know he had me on very good voice command ... For example, we traveled in Venice when I was ... maybe 2 years old. ... He obviously couldn’t hold my hand and make sure I didn’t like run into the canals or anything. But I think you grow up with this understanding that like my parent can’t chase me, ... so I just didn’t go.

Beka aimed, by her good behavior, to help her disabled father fulfill his parental role as protector.

Disabled Parent Did Not Want Child’s Assistance

Finally, about one-quarter of interviewees reported their disabled parent rarely sought their child’s assistance and viewed child caregiving as inappropriate (none of these were among the sibling pairs interviewed). The three oldest interviewees reported this parental attitude, attributing it to social norms: disability was hidden, and as few persons as possible were asked for help. However, Marjorie (age mid-30s) and her two younger siblings had similar experiences with their father, severely disabled by MS:

My mom kind of covered for my dad ... They were very like attentive to making sure that nothing about our lives as kids changed. ... We went to school, did our activities, had our friends ... Over time, my dad was like in bed and wasn't getting out of bed ... We would ... jump into bed and ask him to help us with our homework. But they really normalized it in the way that in retrospect to me is pretty surprising that they pulled it off ...

Marjorie's mother performed all caregiving tasks for her husband, then and now.

Childhood Views of Caring for Disabled Parent

Interviewees' recollections of their childhood feelings about caring for their disabled parent varied widely, most falling into four broad categories. Importantly, most individual interviewees described both positive and negative childhood attitudes. About a quarter expressed virtually uniformly positive childhood perceptions of caregiving, while none voiced consistently negative recollections.

Proud, Special, Caring, and Protective

About half of interviewees recalled feeling proud, special, caring, protective, or otherwise positively as children about care they provided their disabled parent. As Kat, whose father has SCI, said, "I really liked feeling important because I could do things for my dad that made me feel amazed." Emily (age mid-20s), whose mother has MS, acknowledged, "Me and my sisters definitely had to grow up a lot ... faster than a lot of my friends. We definitely had to clean the house and ... make dinners and do a lot more things ... than any normal kid would probably do at our age." But Emily took pride in her performance. "It did make me feel competent. I did like the idea that I was maturing a lot faster than my friends, and that I had probably a lot more responsibility than they had up ... through high school."

Some interviewees described positive childhood attitudes toward caregiving as early manifestations of their characters, sometimes presaging adult career choices (e.g., Emily is a nurse). Molly (age early-20s) recalled caring for her mother after she had surgery.

I wanted to take care of her, as almost a replacement for when she was not in tiptop shape to take care of me. ... When I was really little, maybe 5 or 6, my mother ... came home from ... surgery. ... I don't know why this was my first instinct, but I thought she needed something to eat. And I was so tiny that I couldn't reach anything except the bag of salad ... at the bottom of our refrigerator. ... She was so nauseous, but she ate it just because she felt so bad that I was trying to take care of her. So this has always been a tendency in me.

Molly now works for an employment organization for persons with disabilities.

Matter-of-Fact, Realistic, and Normal

About a third of interviewees described childhood caregiving in matter-of-fact terms, as "normal" (e.g., because they had always known their parent as disabled) or as something that simply needed to be done. "I grew up with it, seeing it since I was born," recalled Monica, whose father's SCI predated her birth by several years. "To me, it was all normal. And as I began to start learning how to help, it was almost like a natural type thing to do."

“We always had chores,” recounted Allison (age late 20s), Emily’s older sister. “Vacuuming, or putting away the dishes, or cleaning the kitchen, or putting dinner in the oven, folding the clothes. ... I didn’t see it as something that I had to do for my mom,” who has MS. “... It was kind of like a collective effort of all of us together.” Edward (age late 40s) did not mind fetching things for his father, disabled from polio. “It was never any ... real friction or tension. It was just easier for me to do a flight of stairs than him.”

Providing intimate ADL care to his mother, severely disabled by MS, made Marc uncomfortable, but he ultimately was realistic. “Here’s my mom, ... nude and helpless. And I’m like 17 years old, and I’d have to help her with these things,” Marc remembered. “I was embarrassed. And then after a while, I was just like, ‘She’s my mother, I have to help her, she has no choice in this.’ And it’s just the way it is.”

Resentful of Demands and Time Required

Roughly half of interviewees described negative childhood views of caregiving, primarily involving time demands, feeling insufficiently appreciated, and seeming different from their peers. “I recall many times as being very frustrated that I had to do something where he couldn’t just do it himself,” said Monica, describing her quadriplegic father. Monica recalled “just ... wanting to be a child.” As a teenager, Monica voiced frustrations about assistance requests: “I would yell at him. Yeah, we would fight. ... We butted heads a lot.” As a teenager, Marc also “had a lot of built-up anger.” His mother’s situation contributed to this emotion: “I didn’t know how to deal with it or talk to anyone about it.”

“When I was younger I was ... very much interested in pleasing my parents,” recounted Eliza, whose mother’s leg was severely impaired. “As I got a little bit older, [I] started to feel like this isn’t fair ... and got a little bit wiser to the fact that other kids didn’t have to do as much as I did, and started to see helping out with dinner as a hassle.” According to Eliza:

I didn’t feel like I had a choice ... I felt like this was something that I had to do, and there was ... no way out of it. And that’s what made it a burden ... I felt like I had ... more responsibilities in general than other people my age, ... who didn’t know how to do laundry when they were ... 7 years old, which was ... routine for us. ... My mom and I would fight occasionally ... raise our voices. And I would ... tell her that I didn’t want to do something, and she would say, ... “I really need help with this, or we can’t eat dinner.” ... I would eventually do it pretty much every time, whatever she asked ...

Furthermore, Eliza was “pretty studious,” and she felt that these tasks “got in the way of me ... being able to do my homework.” In contrast, she thought her brother used chores “as an excuse for not doing his homework.”

Gender-based Discomforts and Expectations

Interviewees indicated that gender-based sensitivities and expectations played large roles in childhood caregiving attitudes. For example, even at age 7, Gabriela knew that, for using the toilet or bedpan, her mother “would need a female to do it. ... It would be me.” Kat “would have done anything for her father” after his SCI, but her father drew the line at intimate

ADLs: “I did everything that was like not embarrassing for my dad, so anything that happened where he was clothed I was a part of. ... He was still proud.” Like his brother Marc, Amin was uncomfortable performing intimate ADLs for his mother: “I wouldn’t be able to wash her private areas. That’s just a little too weird for a son to have to do to his mother to think about.” But at times he had no choice: “There were a couple of times where she fell in the shower and [paid assistants] couldn’t get her up, and I had to help with that. That was a little awkward. You don’t want to see your mother nude and stuff. But you can’t leave her sitting there.” Unlike Marc, though, who became angry, Amin recalled, “I didn’t mind. ... It was difficult at first to deal with that, but I got over it, and it didn’t bother me too much after that.”

Some interviewees suggested that gender-based dynamics related to family culture. Gabriela’s mother, who had emigrated from Latin America, needed help with cooking and cleaning. But Gabriela suspected a secondary motivation: “It was very cultural ... You have to raise your daughters to be able to run a household, is the way that she would put it.” Caroline’s (age early 20s) parents had emigrated from Vietnam. Her father, disabled by polio, frequently asked Caroline to fetch items for him.

I don’t know if that was because it was hard for him to get around – I’m sure it was. But I used to think it was like maybe cultural – like the Vietnamese males and then the females. ... I felt that it was important to show respect to my dad – yeah, I think I felt that it was important to do these things because I was his daughter

Adult Views of Caring for Disabled Parent

Ten interviewees’ disabled parent had died (Table 3), introducing sometimes complicated feelings into answers about adult views of childhood caregiving. In addition, many interviewees described adult perceptions of having had a parent with a disability, not commenting specifically about caregiving. Monica’s statement exemplifies this type of response; “Growing up with a disabled father, I had ... values that were instilled in me where others who haven’t had that experience ... can be not as compassionate to others who are not considered normal.” Recognizing these complexities, adult views of childhood caregiving fell into four broad categories.

Caregiving Helped the Child Too

More than half of interviewees described their childhood caregiving as having helped them too in a variety of ways. Some interviewees praised practical skills they had learned, such as cooking (e.g., good preparation for Amin’s food service job), doing laundry (something college peers knew nothing about), “multi-tasking,” “juggling responsibilities,” and “being patient.” Nearly half indicated childhood caregiving informed adult careers and activities, including health care professions and disability advocacy. For example, “Definitely it all dates back to my mother,” said Emily, whose mother has MS. “That’s why I went into nursing, because I loved caring for her.” Kat is developing a Web site with resources to assist persons with SCI, like her father, and their families. Monica works with philanthropies supporting persons with SCI: “Moving forward, I can help others ... My experience has taught me a lot of different things. So what can I do now to better the lives of others who are going through the same thing?”

For some interviewees, caregiving roles benefited other aspects of family life. For example, Allison, Emily's older sister, noted, "It made my family a lot closer." When asked what she would tell children in a similar situation, Allison, a second-grade teacher, replied:

These are the cards that you were dealt. ... I know it might be difficult, but you're going to look back on it, and you're going to be proud, I guess, of all the help that you ... have done at home. It makes you feel more like a helpful person. It ... puts different things in perspective for you. ... Yes, it may be a little bit different from your friends. However, everybody has some sort of problem or hurdle that they're trying to overcome in their own personal lives.

Age, Knowledge, and Experience Give Perspective

Most interviewees who reported negative childhood perceptions of caregiving described changes in attitudes that came with age, knowledge, and experience. In particular, specific information about diseases and disorders, including MS, SCI, and stroke, helped now adult children understand better the extent, causes, and implications of their parent's physical impairments. For example, Mary (age early 20s) practices nursing on a hospital's neurology service. "I was pretty selfish," she recalled; her father had a stroke when she was in her mid-teens. "... I was kind of brushing it off like, 'No, you're fine.' And not really respecting the fact that he just went through this major thing, and his world is flipped upside down." Similarly, Monica, who described "butting heads" with her late father when he requested help, now sees things differently: "I feel guilty in the sense that he had to be strong enough to ask for help because he was not capable. But yet he probably felt the huge burden on his daughter and wife that he had to continually ask for help ..."

For several interviewees, these attitudinal changes in adulthood represented substantial shifts. For example, Marc became estranged from his mother at age 18 and did not see or speak to her for many years. Becoming a parent contributed to his changing views:

... It's silly holding a grudge like this. It's senseless. She's my mom, she has MS. I'm fortunate enough to be walking around normal and being able to take care of myself. And I would think of being her and not being able to take care of myself. Or think about what if my kids didn't call me or didn't want to see me. And it was really bad. So I decided, slowly, I'm going to have a relationship with her again.

Marc started visiting his mother, then living in a nursing home, seeing her frequently until her death several years later.

Effects of Caregiving as Adults

Some interviewees were still actively caring for their disabled parent or had provided care after childhood until their parent's death. Those experiences sometimes solidified positive aspects of caregiving. For example, Emily still lives with her parents: "I know I'm needed at home. ... It would be hard for my father to ... care for my mother just them two alone." Emily admitted that she might have moved out if her mother was not disabled, but she added, "I love being here with my parents. ... It's helpful for me, too. ... I just like being here to help out at the house."

A few interviewees who had not performed caregiving as children found that caregiving as adults offered benefits, especially to themselves. Tom (age mid-50s) exemplifies this pattern. When he was 18 years old, his mother, who had MS, “threw me out ... I didn’t do much around the house, and I was ... smoking a lot of pot ... and just being a kind of irresponsible kid.” When he was in his mid-20s, his mother’s MS progressed, and she – always “fiercely independent” – needed assistance:

She definitely felt humbled by it, by needing to have my help. And I think for me it was definitely ... taking on a bigger responsibility or growing up or feeling like, wow, ... I really need to step in here and got to be there for her in this way. And I guess it felt good for me to be able to do that for her. almost like washing away some of the stuff in the past ...

Family Relationships Are Complicated

Finally, several interviewees had very complicated relationships with their disabled parent, which began as children and continued as adults. Caregiving may have contributed to these complexities but also likely did other important factors, including personality clashes and socioeconomic stresses. As one example, Gabriela knew of her mother’s “very rough childhood” in Latin America, and she “just wanted to make ... her [mother’s] adulthood better.” Gabriela lived at home during college specifically to care for her mother, even though she felt that time spent caregiving compromised her college grades. She also worked three paying jobs to cover college and family household expenses. Gabriela (age mid-30s) subsequently earned her doctoral degree and has a professional job. Nonetheless, she still lives with and cares for her mother. Sometimes Gabriela thinks, “What am I doing? ... I’m just letting ... my life pass and I’m not ... seriously pursuing a relationship. ... But then there’s ... this fear in me that if she were to see me in a relationship, that she would give up.”

Discussion

An overarching theme from our interviews with 20 adults is a virtual truism: families vary widely, as do specific caregiving experiences of children with parents with physical disabilities. Factors that interviewees indicate affected their childhood caregiving include: preferences of the parent and child; extent and nature of the parent’s physical disability; availability of other formal and informal caregivers throughout the day; gender dynamics; perceptions of familial cultural expectations; and immediacy of need. Many interviewees recalled both positive and negative perceptions of caregiving as children.

“Young carers” have been studied extensively outside the U.S. Our findings are largely consistent with studies from the U.K. and other Commonwealth countries mentioned above, including the range of caregiving tasks, concerns relating to gender discordance between parent and child, and the potential for children holding both positive and negative perceptions of caregiving. It was outside our scope here to look at other consequences, such as implications for children’s physical and emotional health, education, and effects of one parent’s disability on seeking formal caregiving services or family dynamics (e.g., divorce).

Our results are also consistent with one U.S. study that surveyed 51 adult Midwesterners about childhood caregiving activities, albeit not specifically for parents with physical disability; cancer, stroke, and cardiovascular disease were the most common reasons parents needed care.²⁹ As children, these 51 adults also performed ADLs, IADLs, and medical tasks, and described mixed childhood perceptions about their experiences. One notable finding was that school life sometimes suffered – although school also provided welcome breaks from caregiving responsibilities. As adults, views also varied, including positive (e.g., nurtured good personal qualities, career motivation) and negative effects (e.g. unresolved anger, guilt, fears of having parent’s disease).²⁹

Our inclusion of three sibling pairs offered interesting and unique insights into various family members’ responses to caregiving. The sisters provided almost identical reports about family dynamics and perceptions of caregiving (both as children and adults); the brothers offered similar factual reports about caregiving but different reactions to these experiences; and the brother and sister pair differed both in experiences and responses, partially because of their wide age differences (i.e., their father was less physically impaired during the brother’s childhood). With only three sibling pairs, these results suggest only that such interviews are possible and might uncover differences among siblings, which are worth exploring further as gender, birth order, and time may affect experiences. Thus, sibling studies might be a fruitful area for future research.

Our study shares the limitations in generalizability of other qualitative interview studies. In particular, we had difficulty recruiting males and racial and ethnic minorities. Two of three women interviewees who asked their brothers to participate in the study reported that their brothers found talking about the topic too emotionally difficult. We reached thematic saturation on some topics, primarily the major caregiving tasks. However, with our 20 interviewees, we could not capture fully the variability of family, cultural, and other influences on child caregiving experiences. In addition, we did not have large enough numbers to compare two important subgroups, defined by whether or not the parent was disabled from the child’s earliest memories or how the child’s developmental stage affected their experiences. We also were unable to validate our results by recontacting interviewees or by peer debriefing.

Nonetheless, our study suggests that – similarly to their international peers – American children often provide important and sometimes essential caregiving to parents with physical disability. Additional research is required to examine whether caregiving affects children’s educational achievement and social or emotional development and what intrinsic and extrinsic protective factors promote positive experience with caregiving activities. Our finding that many interviewees felt more mature and capable of handling daily tasks (e.g., cooking, laundry) than their peers suggests that effects of child caregiving are nuanced, with beneficial components. In the U.K., the 1995 Carers Act recognized important roles of so-called “young carers” as part of broader efforts to address unpaid caregiving.²² However, this stirred controversy in the U.K. disability rights community, with some disability advocates claiming that focusing on child carers tends to depict children as “victims” and their disabled parents as helpless or exploitative.³⁵ Shifting the focus onto families eased this controversy.

One particularly significant finding from both international and the limited U.S. research is that pediatricians and other health professionals often fail to recognize children in caregiving situations and thus do not ask probing questions about the physical, emotional, and developmental consequences.^{17, 18} Our study and international research suggest particular challenges for girls, especially in cultures where girls are expected to assume responsibilities for family caregiving tasks. For other boys and girls, depending on the circumstances, gender discordance with the parent with physical disability could pose problems, particularly when no other adults or caregivers are available in the home. Pediatricians should be vigilant about children's caregiving roles and the effects on the child and family dynamics, and they should assist efforts to obtain necessary formal caregiving supports.

Our results support the need for clinicians caring for parents with disability and children to recognize the roles and reactions of the child as caregiver. In particular, giving child caregivers and disabled parents safe opportunities to discuss and understand each other's perspectives and needs could improve experiences for both children and parents. Focusing on supporting all members of families where a parent has significant physical disability could most productively address caregiving needs, while benefitting both disabled parents and their children.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

The Eunice Kennedy Shriver National Institute of Child Health and Human Development funded this study (Grant No. R21HD073553-01A2).

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Table 1**Selected Questions and Probes from Interview Protocol****Caregiving activities for disabled parent**

I would now like to learn about ways that you – as a child¹ – helped your parent because of his/her disability. Did you provide any help to your disabled parent?

«IF DID NOT PROVIDE ANY CAREGIVING, ASK WHY. AFTER THAT DISCUSSION, SKIP TO SECTION E»

Before skipping – give examples as probes: preparing meals, taking to appointments, running errands, etc.

- 1 Please describe what kinds of things you did to help your disabled parent.

PROBES:

- Age at which started providing help; whether and how caregiving tasks changed with age
- Basic activities of daily living (feeding, bathing, dressing, toileting, mobility)
- Instrumental activities of daily living (e.g., preparing meals, doing household chores, shopping, telephoning)
- Transportation: driving parent, helping take public transportation

- 2 Did others in the household also help disabled parent? If yes, describe.

- What kind of activities did they mostly do
- Was there a division of labor by time or type?

Perceptions of caregiving activities during childhood

Now let's talk about how you felt about the help that you gave your disabled parent. We'll talk in a few minutes about how you feel about this now.

These next questions focus on how you felt when you were a kid.

- 1 Did you feel like you had a choice about whether or not you helped your disabled parent? Please describe.

PROBES:

- Attitude of other parent (if any)
- Attitude of disabled parent
- Expectations with or without any discussion with you
- Any negotiations about what you would versus would not do

- 2 Did your roles change as you got older?

- 3 When you were a child, how did you feel about the things that you did to help your parent?

PROBES:

- Proud, competent
- Make you special by having an important role
- Overwhelmed emotionally, like it was too much for you as a child
- Overwhelmed time wise, like it was too much with everything else that you needed to do (e.g., homework)
- Angry
- Embarrassed²
- Physically stressed: not strong enough to do certain tasks, was injured
- Different from other children
- Didn't think about it much

[Several questions on related topics, e.g., how parent reacted to child providing help, attitudes of child's friends]

- 7 When you were a child – again, we'll talk later about you as an adult – did you feel that helping your disabled parent was a good or a bad thing for you? Please describe why you felt that way.

- What were good things
- What were bad things
- Most of the time, how did you feel? Did this change as you grew older?

[Two other question modules about transition to adulthood and adult caregiving activities]

Current perceptions of childhood caregiving activities

Earlier, we talked about how you felt when you were a child about the help that you gave your disabled parent when you were a kid. Are your feelings about those experiences any different now that you are an adult?

«IF NOT DIFFERENT, SKIP TO SECTION H. IF DIFFERENT, CONTINUE»

- 1 Please describe the ways you feel differently now than when you were a child about the help you gave your parent when you were a kid.
 - Has that changes as the stages of your own life have changed?
- 2 Why do you think you feel differently now than you did back then?
- 3 When you became an adult, did you and your disabled parent ever talk about your childhood experiences helping him/her out?
 - Would that type of conversation help you?
 - If you have not had that conversation, what stops you from doing so?
- 4 «IF HAD OTHER PARENT» Did you and your other parent ever discuss your feelings about your childhood experiences as a caregiver? If yes, please describe these discussions.
- 5 «IF HAD SIBLINGS» Did you and your siblings ever discuss your feelings about your childhood experiences as a caregiver? If yes, please describe these discussions.
- 6 As an overall summary, how do you feel about your childhood experiences providing care to your disabled parent?

¹ Define child, if asked, as younger than age 18.

² Explore this issue in depth if there is gender discordance between parent and child and intimate caregiver tasks were performed.

Table 2
Characteristics of Adult Child Interviewee

n = 20

Characteristic	n
Age in years: mean (standard deviation)	36.6 (13.8)
Age category	
21 to 29 years	9
30 to 39 years	4
40 to 49 years	3
50 to 75 years	4
Female	16
White race	17 ^a
Not Hispanic	19
Education	
High school or equivalent	2
Associate's degree	1
College graduate	9
Master's degree	6
Doctoral degree	2
Marital status	
Unmarried	7
Has boyfriend or girlfriend	4
Living with partner but unmarried	2
Married	7
Number of siblings ^b	
Only child	5
One sibling	7 ^c
Two siblings	8
Birth order if one or more sibling (n = 15 interviewees)	
Older of 2 siblings	5 ^c
Younger of 2 siblings	2
Oldest of 3 siblings	3
Middle of 3 siblings	2
Youngest of 3 siblings	3
Gender concordance with disabled parent	
Interviewee female; father = disabled parent	7
Interviewee female; mother = disabled parent	9
Interviewee male; father = disabled parent	1
Interviewee male; mother = disabled parent	3

Characteristic	n
Interviewee lives in Massachusetts	16 ^d

^aTwo women self-identify as Asian and one as Black

^bWe interviewed 3 pairs of siblings: 2 sisters, 2 brothers, and 1 brother and sister

^cInterviewee's only sibling died in car crash that disabled the parent

^dOther interviewees lived in New Jersey, New York, or Pennsylvania

Table 3
Characteristics of Parent with Physical Disability

n = 20

Characteristic	n
Parent alive at time of interview	10
Father is/was disabled parent	8
Cause of disability	
Polio or post-polio syndrome	6
Multiple sclerosis	6
Spinal cord injury	2
Other ^a	6
Mobility aid use during interviewee's childhood ^b	
Cane	6
Crutches	4
Walker	2
Manual wheelchair	10
Power wheelchair	3
Leg braces, ilizarov apparatus ^c	4

^a Rheumatoid arthritis, stroke, Larsen syndrome, childhood injury with lower limb amputation, Arnold-Chiari malformation, long-term nutritional deprivation when young

^b Some parents used more than one type of mobility aid: as disability progressed, switched from ambulation aid to wheeled mobility aid; or used different devices in different contexts (e.g., cane for short distances, manual wheelchair for longer distances)

^c Ilizarov apparatus: external fixation device used to treat complex fractures or other problems of limb bones

Table 4

Themes Identified by Broad Topic Area

Childhood Caregiving Activities
Assistance with activities of daily living (ADLs)
Assistance with instrumental ADLs
Activities relating to medical needs
Other types of assistance
Disabled parent did not want child's assistance
Childhood Views of Caregiving for Disabled Parent
Proud, special, caring, and protective
Matter-of-fact, realistic, and normal
Resentful of demands and time required
Gender-based discomforts and expectations
Adult Views of Caring for Disabled Parent
Caregiving helped the child too
Age, knowledge, and experience give perspective
Effects of caregiving as adults
Complicated relationships are complicated