Disability and Health Journal 9 (2016) 208–217

Disability and Health Journal

www.disabilityandhealthjnl.com

Research Paper

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 1-h, semi-structured, open-ended interviews with 20 persons age $\geqslant 21$ 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.

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

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.

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

The authors have no financial conflicts of interest.

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http://dx.doi.org/10.1016/j.dhjo.2015.10.009

It is unknown how many of America's 74 million children – persons ages 0–17 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, L.I.I. (study principal investigator) conducted and audiotaped all 20 telephone interviews, which averaged 1 h 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 analysis[36] 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.