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Views of Teenage Children about the Effects of a Parent's Mobility Disability

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Abstract

Background—Few U.S. studies have explored how children experience a parent's mobility disability and its effects on their daily lives.

Objective—We aimed to engage youth ages 13–17 who had at least one parent with mobility disability in describing their perceptions of their parent's disability and its consequences for their daily and family life.

Methods—Participants videoed and photographed their experiences following general guidelines from the researchers about topics of interest. Participants made their own choices about what they submitted. We used conventional content analysis to identify broad themes.

Results—The mean (standard deviation) age of the 10 participants was 15.2 (1.9) years; 5 were male; 9 participants were white. All 5 girls submitted multiple self-focused (selfie) videos made in their bedrooms; the 5 boys submitted more diverse data files. Several broad themes or topics emerged including: the effects of timing and trajectory of the parent's disability; perceptions of early maturity and responsibility; fears and frustrations relating to the parent's disability; support and emerging resilience; and sense of social justice. Participants generally felt their parents' disability made them become – compared to their peers – more mature, responsible, capable of performing household tasks, and aware of disability civil rights.

Conclusions—Participants raised many issues that health care providers should be aware of when youth have parents with mobility disability. A parent's mobility disability may be associated

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with resilience but also may pose challenges for youth. More research is needed to understand better adolescent's experiences and how clinicians might best assist these youth.

Keywords

Disability; caregiving; child; parent

Introduction

Mobility disability – movement difficulties involving upper and/or lower extremities – is the most common disability type among all adult Americans. About 23.3% of noninstitutionalized, civilian U.S. residents ages 18 years old report chronic mobility difficulties affecting upper and/or lower extremity function.¹ Even among persons 18–44 years old, 5.5% report difficulties with lower extremity function.² Nonetheless, these individuals generally have similar goals for their lives, including parenthood, as do others.³ An estimated 164,000 American women with chronic mobility disability are pregnant each year,⁴ and these numbers are growing. However, relatively little is known about the daily lives of U.S. children whose mother or father has mobility disability or how this disability affects family life.

According to the 2011 *World Report on Disability*, “When adults acquire a disability, children are often asked to help. ... These increased demands on children may impair their education and their health.”⁵ Research, most extensively from the U.K.,^{6,7} Scotland,⁸ Wales,⁹ Australia,¹⁰ and Canada,¹¹ has explored caregiving by children of parents with disability. These studies generally suggest both positive and negative effects: children can feel closer to and more appreciated by their parents, but they may have worse physical and emotional health and educational performance than their peers. Children of parents with disability typically have more disadvantaged socioeconomic circumstances than their peers, complicating interpretation of these findings. The most comprehensive U.S. study of child caregivers found they lived in lower income households than other children, and 58% provided care for one or more activity of daily living.¹² Noting that their study provided an overview “but not the details,” the researchers urged qualitative studies to understand better child caregiver experiences.¹²

Despite questions specifically about child caregiving, a first step in understanding the experiences of having a parent with mobility disability is directly asking youth about their views. We therefore collected video, photographic, and audio data from youth ages 13–17 who had one or more parent with significant mobility disability. We aimed to hear from youth “in their own voices” about how their parent's mobility disability affects them, their views of their parent, and their daily and family lives.

Methods

The Massachusetts General Hospital (MGH)/Partners HealthCare Institutional Review Board (IRB) approved this research. To further protect participants, we obtained a Certificate of Confidentiality from the National Institutes of Health.

Designing Data Collection Guide

To inform our approach toward youth, we conducted 20 interviews with persons 21 years old who as children had a parent with significant mobility disability. As detailed elsewhere,¹³ one major finding from these interviews was the wide diversity of experiences. Gender concordance (discordance) between the child and parent with disability had important effects on both experiences and perceptions of the child, as did the timing of the parent's disability (earlier or later in the child's life).¹³ Based on these results we developed a brief open-ended guide, to focus youth participants on observations about general issues relating to their parent's mobility disability. We produced 3 versions of this guide (mother has disability, father has disability, both parents have disability). Table 1 shows the guide's content when the mother has mobility disability.

Participant Recruitment

We sought interviewees who: were ages 13 to 17 at the time they participated; had at least one parent with mobility disability involving either upper or lower extremities; and, to facilitate in-person consent procedures, lived within easy driving distance of Boston. We aimed initially to recruit 30 English-speaking child participants, recognizing that parents might speak another language. We planned to recruit by contacting staff and posting IRB-approved flyers throughout MGH-affiliated pediatric practices and the Boston Center for Independent Living (nonprofit disability advocacy and support organization).

After 12 months of recruitment efforts, we only had 4 consented subjects. We therefore obtained IRB approval to also recruit from another Boston children's hospital and major rehabilitation hospital. Ultimately, we recruited through: asking pediatricians in various hospital- and community-based practices, including in racially and ethnically diverse communities; contacting adult members of a disability support group at the rehabilitation hospital; networking within local disability advocacy, disability sports, and other community organizations, including churches; and advertising the study on www.clinicaltrials.partners.org.

Nevertheless, we experienced considerable difficulties identifying potential participants. Because of project deadlines and financial constraints, we ceased recruitment after 22 total months.

Data Gathering Procedures

We obtained written informed consent during face-to-face encounters of study staff with the parent and child. We then loaned child participants iPod Touch devices to make audio and/or video recordings that reflected their own styles. Although the guide offered ideas about topics, participants had freedom to take their own approach in generating data. Participants returned the devices by pre-paid mail when they decided they had completed their task. Both child and parent received a \$50 gift card for participating. One researcher typed transcripts verbatim from the digital recordings.

Analysis

To protect confidentiality, we used pseudonyms for all participants and slightly altered defining family characteristics. All researchers repeatedly and independently reviewed both video and photographic data and the typed transcripts and generated their own ideas about important themes using conventional content analysis.¹⁴ Researchers shared their ideas during meetings; we reached consensus through discussion. All researchers had participated in the earlier study of adult interviewees (see above).¹³ As a final step, we considered how the youth themes related to the views of adults. We present selected quotations that exemplify each theme, changing defining family characteristics to protect confidentiality.

Results

We identified 12 potential candidates who met eligibility criteria and, during the screening call with the parent, agreed to participate. We subsequently could not schedule meetings to administer informed consent with 1 candidate. We obtained informed consent from 11 candidates, and 10 completed the study.

Table 2 presents characteristics of the 10 youth participants and their parents with disability. Mean (standard deviation) age was 15.2 (1.9) years; 5 were male; 1 was Black and 9 White; no participants were Hispanic. Seven were gender concordant with their disabled parent. Three participants were only children; among the 7 participants with siblings, 5 were the eldest child. The parents of 3 participants were divorced, and 6 were unemployed because of their disability. The most common cause of parental disability was spinal cord injury (SCI), followed by stroke and below-the-knee amputation.

Table 3 describes the data provided by each participant. All 5 girls made multiple selfie videos in their bedroom; 2 girls also made videos involving family members. In contrast, the 5 boys submitted diverse data files. Jack submitted only audio recordings responding explicitly to the questions in the guide, while the other 4 boys provided selfie videos, videos of activities or conversations with their parent with disability or other family members, and photographs. The total number of minutes of audio or video recordings ranged from 8–24 minutes for the girls and 2–41 minutes for the boys.

Given the data diversity and small number of cases, our analysis identified very broad themes, as described below.

Effects of Parent's Disability Timing and Trajectory

Among the 10 parents, some became disabled before their child's birth or early in their child's life and at the time of the study had stable functional impairments that were substantially accommodated (e.g., prosthesis after leg amputation, wheelchair use with SCI). In contrast, others had progressive disorders or sudden conditions (e.g., stroke) later in their child's life; one was improving, while others remained the same or slowly worsened. Some parents had acute complications (e.g., pneumonia) requiring hospitalization. Not surprisingly, the differing timing and trajectories of the parent's disability affected how children perceived the disability and its effects on family life.

Blake, Jack, Sara, and Seth had always known their parents with disability well-accommodated by wheelchair or leg prosthesis. They described little if any negative impact on their daily lives. “Their disabilities are completely normal to me,” said Jack, whose mother and father both had SCI. Sara’s mother also had SCI: “It’s what I grew up with so I don’t really know any different.” In a video, Seth asked his younger sister whether she would prefer that their father “have a normal leg” rather than the prosthesis. “No,” she answered, “because his robot leg makes him specialer than he could be if he didn’t have the robot leg.”

Other participants reported more complicated and sometimes contradictory views of their parent’s disability, especially if the participant remembered the parent as able-bodied. Justin, the youngest participant whose mother had had a stroke, submitted videos of him being interviewed by his parents and of Justin doing small activities with his mother. Justin was often tearful and frequently equivocated about his feelings towards his mother’s disability. When his father asked if “we are better off or worse off as a family,” Justin replied, “Probably both ... in some ways it’s easier and other ways a lot harder.” His father later asked, “Do you think you have as much of a mother as other kids?” Justin responded, “Probably not.” Amanda also voiced complex feelings. On the one hand, her mother “does all these crazy things that you would never picture a person in a wheelchair being able to do, but she just goes and does them.” However, as described below, Amanda’s mother’s repeated hospitalizations for infections upended this portrait of being without limits.

In Bridgit’s case, exposure to illnesses in others accentuated her reaction to her father’s stroke. “I’ve lost a lot of people in my life, and I’ve lost them early on, so I’ve always kind of been depressed,” Bridgit said. Her father’s stroke “cemented it.” In her selfies, Bridgit was frequently tearful, looking down as she spoke: “I’m not going to lie: things are terrible. I can’t talk to him like I used to. ... I used to wonder if it would have been easier if he had died. And I hate myself for thinking about that, but I think with a death, it’s easier to move on in a way.”

Perceptions of Early Maturity and Responsibility

Several participants reported feeling more mature than their peers or bearing more responsibility because of their parent’s disability. Emily’s mother has progressive neurodegenerative disease and uses a wheelchair:

“One of the positive things that I’ve gotten from having a mother with a disability is it makes me more self-aware ... I learned really fast what I needed, how to provide it for myself and how to provide it for others. ... I’m really glad that I have that, because it means that in a way I’m like five steps ahead of a lot of my peers.”

According to Emily, “One of the common misconceptions is that I take care of my mom, but it’s completely wrong. She definitely takes care of me. But all kids should help out their moms.”

Some participants saw their parent modeling how to strive and achieve. On his prosthetic leg, Blake’s father was an accomplished athlete. “You just got to do things that will make you better and push yourself hard,” Blake observed. “That’s what he always tells me to do ...

that's what I really like about him." Talia described her father, post-stroke, helping her with spelling lessons. "It was so hard and ... he said don't give up, just keep trying." Talia felt this exhortation went beyond learning to spell: "It's like he meant more than that, don't give up, keep trying no matter how much someone wants to push you down."

Sometimes participants expressed more nuanced views of their responsibilities, nonetheless viewing them as "normal." "I do more work around the house than I see what my other friends do," said Amanda. "For me, doing all this work is pretty normal ... [but] seeing my friends not doing this stuff is weird. And sometimes it just really sucks having her in a wheelchair because I feel like I don't get to have as many experiences like my friends have." Emily admitted to sometimes being annoyed when "I get settled all cozy in my nest and ... [my mother] needs something like juice ... I have to get up and do it. And it gets irritating, but it's normal."

Fears and Frustrations About Parent's Disability

Some participants voiced fears about their parent's disability or related health problems. Their comments raised questions about supports for the child, emotionally and for daily needs. For example, Amanda's mother had a SCI when she was very young. Her earliest childhood memory was "the first day when I went to go see my mom in the hospital. ... I remember being so scared and wanting to cry and trying to be brave ..." Since then, her mother has required periodic hospitalizations. Amanda noted, "You sort of get used to going to the hospital all the time." Nonetheless, during her mother's most recent admission:

"I had a really, really bad panic attack, and I was crying, and I didn't know who to call, and I just had to deal with it on my own. ... I was so sure she wasn't going to come home ... She always says she's not going to leave me, but I'm always so scared one time she's not going to be able to keep her promise."

Other participants expressed frustrations relating to their parents' disability. In one video, Andrew walked on a woodland path alongside his father, who rode his power wheelchair. "It's a good thing he didn't bring his manual chair," Andrew observed, "because we would have to push him up if he got tired and lazy." Talia put her feelings into context: "It's hard at times because like my mom gives [my father] showers, and she'll tell me I have to wait till she's done giving him his shower, and I don't get attention. ... But I don't want to be selfish because my dad needs ... more help than I do."

Support and Emerging Resilience

Many participants' comments suggest an emerging resilience and protective factors. These participants found meaning in their parent's disability, lived full lives with their parent, and were supported by their communities. In her final selfie, Amanda shifted from asserting she was "on my own" during her mother's hospitalizations to acknowledging "you [can call] my entire neighborhood my family, because that's what they are to me. They would do anything for me in a second" – including invitations to stay with them. "It's really nice to have a family that's not actually related to me ..." Other participants also described non-family members providing support. Bridgit reported her father had several paid personal care

assistants, including “Nona and Nancy. Nancy has been like an aunt to me, and Nona has kind of been like an aunt ...”

Amanda said that her experiences with her mother’s inpatient stays “helped me figure out what I want to do with my life.” From “going to the hospital all the time, ... I decided to go into nursing.” Blake’s father “pushes me to get good grades, ... to do good in school.” Blake aspires to “go through all the stages that [his father’s] been through and do as good as him – or better.” Emily observed: “I’m really lucky because I had a mom who made sure she taught me [to take care of myself] even though she wasn’t like capable of doing it ... That’s probably the greatest thing that my mother has taught me, besides loving myself.”

Sense of Social Justice

Several participants recognized discriminatory attitudes toward persons with disability, as well as their legal rights. Some participants appeared to be becoming disability advocates. Blake noted “some people are always staring at [dad’s prosthetic] leg and ... some people are scared of it and like look away.” For Blake, however, “he’s just a normal dad ...” Amanda focuses on accessible parking spots. “It gets me every time when we see people park in handicap spots that can walk and are fine. We get so upset.” Her mother has argued with drivers who park in these spots without obviously needing them. “She’s just really comfortable with her disability, and ... it’s sort of great.” Despite “probably stereotyping,” Amanda thinks that “people who don’t have parents in wheelchairs probably don’t see an issue with people parking in handicap spots when they are not in a wheelchair.”

Emily, a high school senior, had highly developed views on disability rights, albeit recognizing “if I hadn’t been raised by a mother with a disability, I don’t know if I would get it.” Emily recounted numerous impediments her mother confronts daily, reporting her mother would likely be unable to attend her high school graduation because of access barriers. To reach the ceremony, her mother would have to be carried, and “my mom hates being carried. It’s humiliating for her, but she does it because she loves me.”

Emily expressed particular outrage over an incident several years earlier when she dialed 911 because her mother had burned herself in a cooking accident. “My school apparently freaked out at my mother when they found out about this. [They said] that’s too much responsibility, wah wah wah! Excuse me! ... I’ve been able to call 911 since I was very little because mom always hurts herself, kids hurt themselves ...” Emily felt that by their early teens youth should be able to call 911 for emergency help. “I doubt they would have freaked out if my mother had been able-bodied.”

Discussion

The 10 participants provided diverse portraits of the experience of living with parents with significant mobility disability. One overarching theme that emerged was how the parent’s adaption and accommodation to disability shapes their child’s perceptions and experiences. The themes emerging from the interviews fit well within Roland’s Family–System Illness Model.¹⁵ This model builds upon a developmental perspective where three interconnected threads evolve over time: the illness (here, disability), individual, and family. The model

recognizes that psychosocial demands of disability change as the disability moves through phases. These changes occur simultaneously as family system dynamics change because members are moving through life cycles. This situation produces periods where the demands and strengths of a family fit well together and other periods where families are more vulnerable. In this study, we saw cross-sections of these dynamic systems that were in different parts of their evolutionary process.

Participants whose parents have well-accommodated, clinically stable underlying conditions and whose outcomes seemed clear expressed comfort with their parent's disability, treating it as "normal" and not significantly affecting their own lives. They have had time to adjust their family dynamics to the relatively stable demands of disability – sometimes having grown up with the disability and viewing it as the "normal" state. In these instances, the three levels – disability, individual, and family – cycles are in harmony. In contrast, participants whose parents had progressive or poorly-accommodated disability noted conflicting emotions, sometimes including fear and depression. These same emotions appear when an individual's own sense of self is fragile or family systems disruption runs high, reflecting the interrelations between disability, individual, and family. Factors associated with participants' resilience included: making meaning out of their parents' disability for their own life, living full lives with their parent with disability, and having a sense of self within a larger community.

Unique characteristics of each participant provided sources of both vulnerability and resilience. These youths were not passively experiencing their parents' disability. Rather they actively used internal and external resources to shape their understanding of their parents' disability and how it affects them. This also occurs among youth whose parents have psychiatric disability;¹⁶ although these youth face challenges, they are not solely "at risk." As Emily observed, she had to learn much faster than her peers how to provide for herself and what she needed to do to help out within her family. She therefore saw herself as "five steps ahead a lot of my peers."

Several important considerations for health care providers caring for teenagers whose parents have mobility disability emerged from these interviews. Most notably, when a parent has a new disability, ongoing progression of existing disability, or acute complications related to disability, youth may be at risk of feeling vulnerable. Youth may require not only emotional support but also attention to meeting daily living needs, especially if they live with a single parent. Similar concerns have been raised about children of wounded military veterans or children whose parents have developed serious illnesses, such as cancer,^{17–20} although less research has examined how parental illness might affect children in positive ways.²¹ Recommendations and programs exist for addressing the concerns of children when parents develop cancer.^{22–28} Especially in early teenage years, anything that makes youths feel "different" can present challenges and raise concerns about bullying.

However, a major message from our study is that health care providers should treat youth with parents with mobility disability just as they do other youth, while simultaneously being aware of the often-evolving situation, checking in with youth to explore any worries, and providing support as needed. Clinicians should avoid making erroneous assumptions about

the effects of disability on the parent, child, and daily life. Stereotyping and stigmatizing the parent with mobility disability may lead to faulty premises that could make youth feel their situations or they themselves are fundamentally misunderstood or underestimated. Emily, in particular, stated this concern clearly: in the 911 call incident, she felt her mother had been explicitly criticized by school officials who thought Emily was burdened with too much responsibility related to her mother's disability. Several participants noted that one benefit of having a parent with mobility disability was their heightened maturity compared with their peers and ability to take responsibility.

Typical themes of developmental stages and youth-parent interactions in adolescence (e.g., separating from the nuclear family, attaching to peers) came through the participants' reports, as we would expect in a family system model. Even when their parent's disability presented an unresolved crisis, self-perceptions extended beyond being the child of a parent with disability. As among other youth moving into early adulthood, these adolescents were finding ways of separating from their nuclear families, developing their sense of self, relating more strongly with their peers, and moving from concrete terms to incorporating abstract thinking. Participants reported hiding romantic relationships, comparing with peers, and deciding on vocations. Being attuned to youths' development, family lifecycle, and parents' disability can facilitate proactively identifying possible concerns and potential strategies for overcoming challenges and finding resilience.

Our findings also suggest that the barriers that impede parents with disability (e.g., lack of accessibility) may have consequences for the child (e.g., Emily's mother who might not attend graduation because the school was inaccessible). If health care deliver settings are not easily accessible, youth and parents may not receive needed care. Adults with mobility disability frequently encounter inaccessible facilities or medical diagnostic equipment^{29–31} and difficulty accessing care due to inadequate transportation^{32,33}—likely contributing to known health care disparities for adults with disability.³⁴ As appropriate in collaboration with parents' care teams, health care providers could help connect families to local resources that could circumvent barriers to accessing health care and other community activities, thus potentially reducing stress and improving wellness for both parent and child. Along with the youth and parents and with care to protect privacy, clinicians could reach out to schools to ensure that teachers and counselors are aware of special considerations raised by the parent's disability and identify school-based resources that might be helpful to the student (e.g., helping Emily's mother feel more comfortable and able to attend her graduation).

This study had important limitations, primarily relating to our difficulties recruiting study subjects. We did not have a unified data source from which to solicit participants (e.g., electronic health records about children did not systematically contain information about parental mobility disability). Despite recruiting from various sources, we were unable to meet our target sample size. With these small numbers, we could not reach thematic saturation except on general themes, notably the implications of the trajectory of the parent's mobility disability for youth. Our results may not generalize to other youth with parents with mobility disability, especially children in cultural or linguistic minority communities. We had also intended this project to explore the feasibility of using youth-directed video data in research (i.e., whether the youth would use the technology to produce data on our research

topic). Our approach generally worked well, although participants found modalities that best supported their self-expression, resulting in diverse submissions. However, conducting the qualitative analyses using these diverse data was challenging. More research must examine how to extract maximal information from these diverse data types, which sometimes carried powerful emotional content. By reporting primarily words, with limited comments about accompanying images, we have not done full justice to the rich data most participants provided.

This study offers a detailed look at the experiences of U.S. teenagers growing up with a parent with mobility disability. Allowing child participants to tell their stories in their own voices made the data seem uniquely authentic and real. Drawing inferences from our findings, health care providers may be well-positioned to offer important support for youth, especially when parents have new or changing mobility disability. These supports must recognize that some youth will already have responsibilities and competencies beyond those of their peers. Furthermore, the youth may be developing identities as strong social justice advocates, focused on advancing rights of persons with disability.

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Table 1

Video Guide: Mother Has Mobility Disability

Slide Title	Content
Introduction	<ul style="list-style-type: none"> • Thank you for doing this project. • We are trying to learn about what it is like for you – from your point of view – to grow up with parents with a disability. • Below you will find ideas for the kinds of things you might video or tell us about. This project is not about making the perfect video. It's about telling YOUR story and about how YOU feel
Remember	<ul style="list-style-type: none"> • Please remember that you are making a video for a research project • Ask permission to film people before you start. • You might be filming some sensitive situations. Please stop filming if anyone asks you to do so. • Do not share your videos with anyone other than the research team.
List of Possible Topics	
1.	<ul style="list-style-type: none"> • Introduce us to your family. • Tell us about who you live with. • Tell us what your family does together, even something simple like eating together or just hanging out.
2.	<ul style="list-style-type: none"> • Tell us about your mom. • Do you live with her? <ul style="list-style-type: none"> – If not, please tell us about where she lives and how often you see her. • Tell us about mom's disability. <ul style="list-style-type: none"> – What causes her disability? – What is hard or impossible for her to do because of disability? – Is her disability changing over time, such as getting better or getting worse?
3.	Tell us about how your mom helps you. <ul style="list-style-type: none"> • If you want, you can video times when she is helping you. • Or you can talk directly to the camera and tell us about how she helps you.
4.	Tell us how you help your mom because of her disability. <ul style="list-style-type: none"> • If you want, you can video times when you are helping her. • Or you can talk directly to the camera and tell us about how you help her.
5.	Tell us how you feel about how your mom's disability affects you. <ul style="list-style-type: none"> • If you want, you can talk directly to the camera about these feelings. • You probably have many different sorts of feelings. Some might seem good while others seem bad. Please share as many of these feelings as you can. • Remember, this is about you and how you feel – there is no right way of feeling.
6.	Tell us about whether her disability affects how you feel about your mom. <ul style="list-style-type: none"> • If you want, you can talk directly to the camera about how her disability affects your feelings about your mom. • As for #5, you probably have many different sorts of feelings. Please share as many of these feelings as you can
7.	What else is important for us to know about you and your family?

Slide Title	Content
	<ul style="list-style-type: none">• Are there any other things that affect your family that are important?• How do these other things affect you?• How do these other things affect your mom because of her disability?
Thank you	Thank you for participating in this study! If you have any questions or need to talk to anyone at anytime, please call ...

Table 2

Study Participants

Pseudonym	Age ^a	Birth order	Parents' marital status	Income ^d	Current employment, parent with disability	Parent's disability and timing
Amanda	OT	Only child	Divorced	Low	Unemployed	Mother: spinal cord injury when Amanda was very young
Andrew	YT	Older ^b	Married	Middle	Contractor	Father: spinal cord injury, 8 years ago
Blake	YT	Older ^b	Married	Middle	Teacher	Father: below the knee amputation, before Blake was born
Bridgit	OT	Younger ^b	Married	Middle	Unemployed	Father: stroke, 6 years ago
Emily	OT	Only child	Divorced	Low	Unemployed	Mother: rare progressive neurodegenerative disorder throughout Emily's life
Jack	OT	Only child	Married	Middle	Mother: public agency staff Father: teacher	Mother and father: spinal cord injury, before Jack was born
Justin	YT	Older ^b	Married	Middle	Unemployed	Mother: stroke, 5 years ago
Sara	YT	Older ^b	Divorced	Low	Unemployed	Mother: spinal cord injury, before Sara was born
Seth	YT	Older ^b	Married	Middle	Works part-time	Father: below the knee amputation "many years previously"
Talia	YT	Youngest ^c	Married	Low	Unemployed	Father: stroke, 5 years ago

^aYT = younger teens, ages 13–15; OT = older teens, ages 16–17. To protect confidentiality, we do not report exact age.

^bOf two children

^cOf several children

^dAnnual income: low < \$20,000; middle \$20,000 – \$200,000

Table 3

Data Generated by Study Participants

Pseudonym	Medium	# of files ^a	# of minutes ^b	Brief description
Amanda	Video	4	15	Amanda took selfie videos talking in her bedroom with her dog on her lap.
Andrew	Video, photographs	12	3	Andrew made short videos showing activities involving his father and the rest of the family. He also submitted 4 photographs of him with his family.
Bridgit	Video	5	24	Bridgit took 3 selfie videos talking in her bedroom, one with her dog and cat. One video is taken in the car with her mother. One video is her and her sister.
Blake	Video, photographs	22	19	Blake took selfie videos talking about his father and made one video of him with his father. He also submitted 2 photographs: one of him with his father in the car and another of his father holding a basketball.
Emily	Video	8	23	Emily took selfie videos talking in her bedroom.
Jack	Audio	1		Jack answered the questions suggested in the interview protocol, as his girlfriend read the questions.
Justin	Video	5	41	Three videos show conversations among Justin and his parents. One video depicts his mother climbing stairs; another shows how Justin helps his mother with a task.
Sara	Video	5	8	Sara took selfie videos talking in her bedroom.
Seth	Video, photograph	4	2	Seth made one video talking to his sister about their father. He also submitted a photograph of his father, on a hike and one text file with 2 entries about his father.
Talia	Video	8	14	Talia took 5 selfie videos talking in her bedroom. The other 3 videos show Talia's father and discuss the consequences of his stroke.

^aNumber of separate files submitted by participant

^bTotal number of minutes of material across all submitted files