

Adolescent Perceptions on the Impact of Growing Up With a Parent With a Disability*

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Over the years, a significant amount of research has been conducted on the effects disabilities have on parents, however, there has not been much research conducted on the subject-matter from the perspective of the child. The focus of this study was to investigate the overarching themes expressed by individuals who grew up with a parent with a disability; self-perceptions, relationships, and skillfulness. Within this two-phase study, participants were distributed YCPS (the Young Caregivers Perception Survey) as well as a revised version, the YCPS-R through an online SONA system at a Northeastern university. Consistent findings in this study revealed that participants reported that they had perceived higher levels of independence and overall responsibilities to the family as compared to their friends or other children with parents who are not disabled. Participants also reported high levels of support from siblings, relatives, and friends, as well as felt as though they were able to ask for help from others.

Keywords: parental disability, adolescent caregivers, young caregivers, adolescent perceptions

A disability is defined as a significant impairment within an individual that limits his or her ability to perform major life activities (such as working, managing a home, or personal care) due to a physical, mental or emotional health problem (Olkin, Abrams, Preston, & Krishbaum, 2006). Over the years, a significant amount of research has been conducted on the effects disabilities have on parents, however, there has not been much research conducted on the subject-matter from the perspective of the child. A young caregiver is a child (age ranging from 5 to 25 years old) that have more responsibilities and engage in caregiving tasks depending on the severity of the parent's disability (Doutre, Green, & Knight-Elliott, 2013). In various research articles, it has been noted that young caregivers are a hidden population because of the possibility of receiving stigma and some do not identify as caregivers due to family norms.

The limited research that has been conducted in this area has shown that children of parents with disabilities face different risks and situations when compared to children being raised by nondisabled parents. The published research that has been done with young caregivers was in other countries, beyond America. Joseph, S. Becker, F. Becker, and Regel (2009) identified that child caregivers have six types of care they participate in which include; domestic tasks, general care, emotional support, intimate care, child care, and

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miscellaneous tasks. Researchers Harstone, Bergen, and Sweetgrass (2010) stated that children can be affected socially, physically, and emotionally throughout their development and into adulthood.

Joanne Riebschleger (2004) had found that children who have parents with a mental disability often report feelings of sadness and worry within both the home and school settings. These children describe their parents "bad days" as times that they will attempt to avoid and ignore their parent, or engage in caregiving behaviors in order to alleviate symptoms that their parents may be expressing (Riebschleger, 2004). Youth may experience stress, stigma related to their parent's disability, experience interpersonal difficulties, and other conflicts that has the possibility of impacting their development (Pakenham & Cox, 2012). Within the realm of physical disabilities it has been found that indirect effects greatly influence a child's developmental experience, which includes: lower levels of reported activities with friends outside of school and family activities involving non-family members, transportation difficulties, and poorer overall parental health than parents without illnesses or disabilities (Olkin et al., 2006). Children who care for parents with physical disabilities and intellectual disabilities have more intimate responsibilities, such as personal hygiene tasks that the parent cannot do themselves (Harston et al., 2010).

While some researchers have explored the impact of children who have parents with mental or physical disabilities, few studies have focused on the impact of parental disability and development tasks in childhood. Also, while this research illustrates the initial stages of a movement toward the child perspective, there is little information exploring this issue within the populations of the United States. The focus of this study is to investigate and explore the overarching themes expressed by individuals who grew up with a parent with a disability; this research is more interested in the impact on development.

Phase I

Method

The current research is the initial phase of a two-part study. Within this phase, a pilot study was conducted in which participants consisted of 72 college students. This sample had included 42 females and 30 males (58.33% and 41.67%, respectively). Participants were of Caucasian (55), African American (13), Hispanic (3) and Asian (1) descent. Of these participants, all were undergraduate level students including 21 Freshmen, 27 Sophomores, 15 Juniors, and 9 Seniors.

Table 1

Sample Questions from YCPS

Self-Perceptions
"I feel as though I am a stronger person because of my childhood experiences with my parent(s) with a disability(s)."
"Compared to my friends, I feel I learned more ways of how to take care of myself."
Relationships
"I was able to ask help from others."
"My relatives were supportive."
Skillfulness
"Compared to my friends, I was taught a variety of life skills earlier in life."
"Compared to my friends, I cooked meals often as a child."

The study was available through a Northeastern university's online SONA system where a surveymonkey.com direct link was provided for participants to follow. After filling out an informed consent

participants were asked to respond to the questionnaire that was available to those who had grown up with a parent who had a disability. YCPS consisted of 60 items that reflected three individual areas: self-perceptions, relationships and skillfulness, regarding their experiences with their parent(s) who has a disability(s). This survey overall consisted of closed-ended (Likert Scale; ranging from strongly disagree to strongly agree) questions and open-ended questions. SPSS analyses were conducted in order to observe descriptive statistics and the measurable trends of these students who have completed childhood and adolescent development.

Results

It was found that students had reported that mothers (41) had disabilities more frequently than fathers (33). Physical disabilities were reported most frequently, followed by mental disabilities and finally intellectual disabilities (42; 29; 9, respectively). In regard to the age at which the children learned of their parent's disability, it was observed that the modal frequencies were at ages 10, 13, and 12 (13, 8 and 6, respectively). The parents' marital status was measured through the categories; married, single, divorced, remarried, and deceased. The results yielded 34, 20, 18, 5, and 1, respectively. All but eight students had lived with their parent who had the disability.

In this research, 24 of the participants agreed that they had made family decisions as children, while 32 disagreed. Within the sample, 37 participants stated that they had worried about their family's financial situation, as opposed to 26 who did not. Subsequently, 38 participants felt as though they could ask for help from others, while 15 others did not. Additionally, 50 participants perceived as though they had acquired a number of life skills earlier than their peers, while only 5 participants disagreed. Overall, 46 participants, as opposed to 10 other participants felt that they became stronger individuals because they had a parent with a disability.

Phase II

Method

The 60 question, YCPS was revised in order to improve data collection and observations. This revision had consisted of removing the neutral category in closed-ended questions. Within this study, the YCPS-R was conducted on a northeastern university student population. Overall, the sample consisted of 90 students, which included: 58 women (64.44%) and 32 men (35.56%) who completed the entirety of the survey. Participants were of Caucasian ($n = 74$), African American ($n = 12$), Hispanic ($n = 2$) and Asian ($n = 2$) descent. Of these participants, all were within the undergraduate level including; 43 Freshmen, 29 Sophomores, 11 Juniors and 7 Seniors.

The study was again available at a Northeastern university's online SONA system in which a direct link was provided to surveymonkey.com for participants to follow. The students who met the criteria of having a parent with a disability completed an informed consent form before taking the survey. As in the previous pilot, the YCPS-R was employed in order to assess overall trends within this current sample of students who had a parent(s) with a disability(s), SPSS analyses were conducted in order to observe the descriptive statistics and measurable trends of individuals who have completed childhood and adolescent development.

Results

In this phase, when asked to define the term "disability", several participants identified it along the lines of, "Something that impacts a person's abilities, movements and activities", as well as "Something that

hinders someone's ability to function or complete day to day tasks". These findings were congruent with the overall definition utilized in this study. Unlike phase I, more fathers ($n = 60$) were reported as having a disability than mothers ($n = 33$). Mental disabilities (49) were the most prevalent, while physical disabilities (32) and intellectual disabilities (15) were less prevalent. Children learned of their parent's disabilities primarily through being told directly by their parents themselves or a close relative (e.g., Grandmother). The modal ages at which they learned of their parent's disability were 10 ($n = 14$) and 13 ($n = 9$); the mean age was 11.15. When measuring the parents marital status, it was observed that 45 were married, 23 single, 16 divorced, 5 remarried, and 3 were deceased. All but fourteen students had lived with their parent who had the disability.

Consistent to phase I, it was found that 74 students believed that they were taught a variety of skills earlier in life, while 16 did not. Furthermore, 68 students felt as though they were taught more life skills than their peers, while 18 did not. Of these participants, 67 perceived as though they were taught to be more independent while 19 had disagreed with this statement. Subsequently, 61 participants perceived that they had learned more ways to take care of themselves while 25 disagreed. When asked whether they perceived as though they were more patient because of having a parent with a disability, 68 agreed to this question while 18 disagreed. Within relationships, questions consisting of support were asked, in which 65 agreed that they were able to ask for help from others while 21 disagreed. Overall, 68 participants felt as though they have become a stronger person from growing up with a parent who had a disability while 21 did not.

Overall, across both studies revealed consistencies regarding self-perceptions, relationships and life skills. Participants in each phase reported perceiving high levels of independence, however they also felt as though they were able to ask for help from others. Furthermore, participants perceived as though they had learned a number of life skills earlier than their peers or individuals with parents without a disability. Finally, consistent across both studies, participants felt as though they were stronger individuals based on their experiences of growing up with a parent with a disability.

Discussion

These results focus greatly on the perspective of the young caregiver. While Joseph et al. (2009) focused on various types of care, the current research focuses on three general areas: self-perception, relationships and skillfulness. The participants in this study felt a greater sense of independence, gained more life skills, and felt optimistic about their childhood experiences. The findings in this study were congruent with the research of Harston et al. (2010) and Riebschleger (2004) who found similar effects in young caregivers such as: increased independence and overall responsibilities to the family. In addition, these results support previous findings by Harstone and Charles (2012), who reported that young caregivers achieved various strengths from their childhood experiences which include: independence that helped them make better life decisions, the ability to find a positive within a negative experience, and greater personal skills.

It was observed within the first and second phases of the study that the participants felt they had support during their development. The participants also felt that they could ask for help from others if needed. The biggest supports that were found were siblings, friends, friend's parents, and neighbors. Harstone and Charles (2012), also found that young caregivers that felt a greater sense of support tended to have a better experience during their development. Additionally, Harstone and Charles (2012) reported that support from friend's parents helped in young caregiver's development.

The first and second phases of this study exhibits clear impacts on development based on perceptions about one's own family situation as compared to peers. The participants were asked several questions that compared their situation with their friend's. Participants reported that in comparison to their friends they attained more life skills due to their experience of having a parent with a disability and that they had a better understanding of how to take care of themselves. However, the results showed that they felt similar to their peers in relation to receiving attention from their parents, having the same amount of free time, having the same amount of household chores, and felt that their parents did not need more help than their peer's parents. The study found that the participants did not feel embarrassed having a parent with a disability, their parents did not get hurt in their household, and they were able to feel comfortable in their home.

While this research was a first step in exploring the overarching concepts of growing up with a parent with a disability, future research should take into account the following considerations. First, our overall sample included participants who have already completed childhood and adolescent development, rather than individuals currently undergoing adolescence and therefore may report retrospective information more so than prospective information. Furthermore, comparisons of results between those who are currently undergoing adolescence as well as those who have completed adolescence should be conducted. This would test the effects of those who are currently living with their parent who has a disability, as compared to those who may no longer live within their home. Future research should also include a question assessing the severity of the parents' disability. Finally, future research should explore various coping strategies that the children may have engaged in during their development. Previous research has shown that children who have parents with disabilities used activities outside of the home, prayer, journaling, taking walks, and even reducing their parent's behaviors as ways to cope with stress (Harstone & Charles, 2012).

The research supports the concept that children who grow up with a parent with a disability can have a different childhood experience. These experiences may be positive and contribute to the development of the child through a number of additional life lessons. Joseph et al. (2009), state that children who have parents with disabilities gain various skills throughout development which is congruent with our findings. Additionally Harstone, Bergen and Sweetgrass (2010), observed that children can be affected physically, mentally and emotionally in their development. Similar findings within this current study, in regards to questions on self-perceptions illustrated that the participants did not feel embarrassed having a parent with a disability. Finally, in contrast to results found by Pakenham and Cox (2012), most participants reported not being bullied because of their parent's disability. Overall, it was apparent that most participants were able to exhibit characteristics of resilience despite growing up with a parent with a disability.

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