

Family Resilience in Families with Children Who are Deaf or Hard of Hearing

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Introduction

Hearing loss is one of the most prevalent disabilities present at birth in the United States with the Center for Disease Control (CDC) estimating one to two out of every 1,000 babies screened will be diagnosed with some degree of hearing loss (CDC, 2019). Hearing loss in childhood can affect language acquisition, psychosocial behavior, emotional development, the child's academic performance, and future employment opportunities (Garg & Gupta, 2015; Seewald & Tharpe, 2011; Smith, Bale, & White, 2005).

Families with children who are deaf or hard of hearing who are able to receive appropriate resources and support tend to fare better than those who do not (Fitzpatrick, Angus, Durieux-Smith, Graham, & Coyle, 2008). However, few studies have explored the concept of family resilience in this population. Family resilience is a rich and valuable topic to explore in documenting the experiences of families with children who are deaf or hard of hearing.

The purpose of this study was to document the perceived level of family resilience in families with a child who is deaf or hard of hearing. In this study family resilience is defined as the ability to cultivate strength and recover, gain strength, or bounce back to an acceptable level of family functioning after the stressor of the diagnosis of a chronic health condition in a child

Methods

This study is a mixed-methods triangulation design which incorporated the integration of results from both qualitative data from semi-structured interviews and quantitative data from questionnaires. Through the chosen methodology, the researcher obtained a more complete perspective of the experiences of the families raising a child who is deaf or hard of hearing. Families were recruited from those attending The Care Project retreat for families with children who are deaf or hard of hearing aged birth to three.

Parents were mailed a demographic questionnaire and the Family Resilience Assessment Scale (FRAS) before the retreat. They were provided with another copy if they wished to participate but did not bring their copy.

Parents who were willing, also participated in semi-structured interviews either at the retreat or were scheduled to complete this within a month after the retreat.

Descriptive statistics were run on the responses to the FRAS and the semi-structured interviews were analyzed utilizing the multi-step process described by Creswell (2014).

Quantitative Results

Seven families returned questionnaires. Participant ages ranged from 32 to 45 years, with a mean age of 36.8 ($SD = 4.26$). Half of the parents reported having finished a bachelor's degree, with 16% reporting having completed a high school diploma or equivalent, 16% a graduate degree, or a professional degree. All participants were married with none reporting a prior marriage. The majority of the parents reported their race as White (66%) with two parents reporting their race as Black and two as Hispanic.

The FRAS has six subscales: Family Communication and Problem Solving, Utilizing Social and Economic Resources, Maintaining a Positive Outlook, Family Connectedness, Family Spirituality, and Ability to Make Meaning from Adversity. Total responses to the FRAS are shown in Figure 1. Scores for the FRAS can range from 66 to 264 with higher scores indicating higher levels of perceived resilience (Sixbey, 2005). The parents in this study scored an average total score of 206.83 ($SD = 16.94$) with a range of 190 – 242. This indicates that the parents who responded have a high level of perceived resilience as measured by the FRAS. The parents in this study scored high in all six of the subscales indicating high levels of resilience in each area.

Family Resilience Assessment Scale Total Scores



Figure 1. Total scores for the FRAS as reported by the parents in this study.

Qualitative Results

Four families, five parents, participated in the semi-structured interviews. These interviews were transcribed by the researcher and then analyzed following the process of phenomenological reduction as described by Moustakas (1994). The semi-structured interviews progressed through four blocks of questions: family background, family interactions with and perceptions of The Care Project, family stress, and family resilience. The results reported in this poster are from the final question block.

Families recognized the importance of resilience in their journey with their child who is deaf or hard of hearing. When asked to provide their personal definition for resilience the families highlighted perseverance. The families' personal definitions of resilience are provided in Table 1. All parents agreed with the definition of resilience for the study, which they were shown after providing their personal definitions, but stated that it was important to think of resilience in an individual manner.

As one mother of an 18-month-old child expressed, *“Well you just keep on pushing through and like just does nothing going to get us down.”*

The mother of three children who are deaf or hard of hearing stated in her description of resilience, *“Life keeps going. So, no matter what, we just have to keep on going. And look at how we can advocate for ourselves. Stand up and stand for what we believe in.”*

The final step in Moustakas's (1994) phenomenological analysis requires the reduction of the phenomenon into its essence. The essence reduced from the interviews discussing resilience was **Sources of Strength**. While the parents feel they have had challenges in raising a child who is deaf or hard of hearing they also recognize they have several strengths. The ones identified by the parents in this study include: connecting with parents in similar situations, maintaining their perspective, understanding their journey, and pushing through.

Table 1. Parent's Personal Definitions of Resilience

Family	Definition of Resilience
Family 1	Getting beat down and then getting up again, and you just have to keep on getting up
Family 2- Father	Synonymous or so with perseverance. Resilience is having strength but also flexibility.
Family 2- Mother	The will to thrive
Family 3	Being able to keep going even when things are hard. Just being able to not let like the little things get you down or keep you from doing what you need to do
Family 4	Life keeps going, so don't no matter what, we just have to keep on going

Conclusions

Findings of this study suggest that families with children who are deaf or hard of hearing with access to a group such as The Care Project are likely to have high levels or perceived family resilience. This is shown as the parents in this study reported high levels of family resilience as measured by the FRAS. The parents who participated in the semi-structured interviews all expressed the importance of the concept of resilience in their journey with raising a child who is deaf or hard of hearing. More research is needed in this area to investigate if these perceptions of resilience carry through to other populations of parents with children who are deaf or hard of hearing. The implications of these findings will assist those who work with families to understand how families adapt to the life changing event of the diagnosis of hearing loss in their children.

This study investigated a small number of participants so inferential statistics were unable to be performed. Therefore, it is tenuous to make any statements generalizing these findings to the larger population of parents with children who are deaf or hard of hearing.

Future research in this area should include studies with larger samples and an investigation of the experiences and perceptions of parents of other age groups of children. A survey of extended family members should also be conducted to compare the perceptions of stress and resilience as expressed between the parents with children who are deaf or hard of hearing and other family members.

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