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Research Article

# “Out of the Woods”: Perspectives of Caregivers of Adult Children with CHARGE Syndrome

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## Abstract

CHARGE syndrome is complex genetic condition that affects approximately 1 in 8,500 to 10,000 newborns worldwide. Individuals living with CHARGE syndrome frequently face significant physical challenges from birth, requiring managed medical and developmental assistance. Many of these individuals are cared for by family caregivers who often report elevated levels of stress. However, as children with CHARGE Syndrome get older, their medical complications often subside. With the resolution of many of their medical complications, it is possible the experiences of these caregivers may be different than the experiences of caregivers for younger children with this condition. The purpose of this study was to determine the quality of life of caregivers of older (18 years and older) individuals with CHARGE Syndrome. A total of seven family caregivers of adult children living with CHARGE syndrome participated in this study. Transcripts from these semi-structured interviews were analyzed using qualitative description methodology. The following four themes emerged from the qualitative interviews: (1) Reshaping Identity and Autonomy, focusing on how caregiving transforms parents' sense of self and freedom; 2: Emotional Resilience and Coping, highlighting the strategies parents use to manage stress and maintain wellbeing; 3: Systemic Barriers and Support, addressing the challenges with formal systems and reliance on informal networks, and 4: Child's Health Profile and Responsibilities, detailing the specific medical complexities and daily caregiving demands. The coping strategies and unique approaches to managing difficult times that caregivers in this study described can be helpful to specialists and parent groups as they navigate CHARGE syndrome.

**Keywords**: CHARGE syndrome; Family caregiving; Quality of life; Coping strategies; Qualitative methodology

**Abbreviations:** CHARGE: Coloboma of the eye, Heart defects, Atresia of the choanae (blockage of the nasal passage), Retardation of growth and development, Genital and/or urinary abnormalities, and Ear abnormalities and deafness

## INTRODUCTION

CHARGE Syndrome is a rare and complex genetic condition that affects approximately 1 in 8,500 to 10,000 newborns worldwide [1]. The word ‘CHARGE’ is an acronym for the most prevalent clinical features of the condition, involving coloboma, heart defects, choanal atresia, delayed growth and development, genitourinary irregularity and ear abnormalities [2,3]. Colobomas lead to various vision issues from low vision to blindness depending on the severity of the colobomas. Heart defects are common yet can be resolved with surgery (or surgeries) at a young age to alleviate the defects. Choanal atresia is when a child's nasal passages do not open up at birth. They will require surgeries in their mouths to open up these airways. These surgeries can affect eating, swallowing, speaking and breathing, depending upon the severity. Delayed growth and development are often exacerbated by some of the issues with eating with many children often needing to eat liquid food or being tube fed. Genitourinary irregularities are also characteristic of this condition [1]. Lastly, eating abnormalities often lead to the child being left with little hearing or no hearing at all. Many children do benefit from a cochlear implant or a BAHA device to amplify sound.

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CHARGE Syndrome diagnosis is based on major and minor clinical criteria. For example, molecular testing in clinically diagnosed individuals identifies variants in CHD7 (OMIM 608892) in 70–90% of cases [4]. The syndrome is a result of mutations in the CHD7 gene that plays a fundamental role in initial embryonic development. Because multiple organ systems are affected by CHARGE Syndrome, babies frequently face significant physical challenges from birth, requiring managed medical and developmental assistance. These medical issues are described below.

Children with CHARGE Syndrome most often necessitate care from a wide variety of specialists, often more than 17 by the age of 10 and undergo numerous surgical procedures [5]. Common medical complications include feeding and swallowing difficulties due to cranial nerve abnormalities, which can lead to aspiration and require specialized feeding strategies. Airway and breathing issues are prevalent such as choanal atresia and floppy tracheal cartilage, complicating anesthesia and respiratory care. Hearing and vision impairments are very common, including conductive hearing loss from malformed ear structures and vision loss from colobomas or detached retinas. Many children also have gastrointestinal problems, like gastroesophageal reflux, which may persist for years and require surgical or pharmacological intervention. It is also common for children to have frequent infections, such as sinusitis and otitis media, which can disrupt development and schooling. These complications require vigilant monitoring and practical proactive medical management, often coordinated by caregivers who serve as de facto case managers [5].

Painful experiences such as intensive medical procedures, acute complications, medications, and various therapies (e.g., physical therapy) are common. These individuals may encounter considerable occurrences of intense pain, mostly due to complications related to CHARGE Syndrome which includes constipation, migraines, surgery-related pain, chronic otitis media, sinusitis, dental issues, gastroesophageal reflux, and breathing-related pain [6]. Individuals with CHARGE also have chronic pain concomitant to their intense acute pain experiences [7]. When the parents rated their child's occurrence of pain for a variety of identified painful experiences, difficulty swallowing, gastroesophageal reflux, breathing difficulty, abdominal migraines, hip/back pain, and muscle pain occurred 95 or more days annually, frequently happening along with one or more other uncomfortable and painful experiences [7]. Pain from surgery is frequent along with persistent conditions that result in chronic pain. Between the ages of 1 and 18, the average number of surgeries reported was 12 (range of 1–47) [7].

During the early years of caregiving for a child with CHARGE Syndrome, there is often extreme emotional, physical, and logistical demands [8,9]. Parents, most often mothers, must navigate a labyrinth of medical appointments, therapies, and educational planning while managing their child's daily needs [10]. Many children with CHARGE experience motor delays, limited communication abilities, and sensory processing challenges, which compound the caregiving burden [11,12]. Caregivers often report significant impacts on their own quality of life, including stress, isolation, and financial strain [8]. Despite these challenges, many families develop resilient coping strategies, such as building strong support networks and advocating fiercely for their child's needs.

Family caregivers of children with CHARGE have been found to have the following common concerns, anxiety, anxiety disorders, and anxious behaviors. A study of 87 families with a child with CHARGE determined that anxiety disorders were the most common mental health characteristic [13,14], conducted a study and concluded that 43% of family caregivers of children with CHARGE expressed that their child was labeled with obsessive–compulsive disorder and 37% shared that anxiety disorder was also a diagnosis [15]. Similarly, Hartshorne et al. (2016) determined that 50% of the children with CHARGE Syndrome in their study reported difficulties attributed to anxiety and/or obsessive-compulsive behaviors. The findings documented here have determined that anxiety is a common experience in children with CHARGE Syndrome. Similar findings were also shared by other family caregiver populations, including family members with dementia and visual impairments [16].

Certainly, the plethora of research linked to medical complications, anxiety, as well as issues with functional communication suggest that for family caregivers of children with CHARGE Syndrome there is a lot of stress on a day-to-day basis. These parents have been known to develop exceptional and unique coping mechanisms in order to manage the complications of having a child with CHARGE Syndrome. These coping strategies include looking for social support, keeping an optimistic attitude, and finding meaning in their experiences [17].

Resilience is commonly influenced by the dynamics in a family, such as the availability of resources, emotional support from schools and family members, and successful communication within the family [17]. Although caregivers of these children experience elevated levels of stress, several demonstrated significant adaptability. These coping mechanisms include redefining their roles and expectations and also finding joy and strength in small achievements [18]. Encouragement from healthcare professionals and availability of resources play a critical role in promoting resilience. Parents value helpful information, emotional support, and acknowledgement of their efforts [17].

1. As children with CHARGE Syndrome get older, their medical complications often subside [14]. For example, children will have the tracheotomy closed, their feeding tube out, heart surgeries to correct malformations, and have surgeries to correct ear malformations. With the resolution of many of their medical complications, the experiences of caregivers of older children with CHARGE Syndrome may be different than the experiences of younger children with CHARGE. The purpose of this study was to determine the quality of life of caregivers of older (18 years and older) individuals with CHARGE Syndrome. The research questions asked wWhat is the current quality of life among caregivers of young adult children aged 18 years and older with CHARGE syndrome?

2. What factors (e.g., severity of symptoms, age, urban/suburban/rural location, siblings, coping strategies, etc.) influence the quality of life of caregivers of young adult children with CHARGE syndrome?

3. What type of coping strategies are used among caregivers of young adult children with CHARGE syndrome?

## MATERIALS AND METHODS

### Study Context and Design

The current study focused on family caregivers of young adult children aged 18 years or older living with CHARGE Syndrome and related disabilities. Specifically, the study sought to understand the current quality of life among these caregivers, factors influencing their quality of life, as well as any coping strategies that these caregivers use in managing the day-to-day stresses associated with caring for a young adult child with CHARGE syndrome.

### Study Participants and Recruitment

Participants were recruited using purposive sampling during the CHARGE Syndrome 16th International Conference that took place in Phoenix (AZ) during summer 2025. This conference was chosen for its access to a concentrated population of experienced family caregivers of children with CHARGE syndrome. Eligibility criteria included being the primary caregiver of a child aged 18 or older diagnosed with CHARGE syndrome. The study was advertised before and during the conference. Once potential participants contacted the research team, they were screened and then enrolled in the study if eligible.

Participants did not receive compensation for participating in the study. The study received ethics approval from the SUNY Brockport Institutional Review Board (IRB). Participants gave informed consent on a Qualtrics survey prior to participating in the study. Written informed consent was obtained from all participants prior to data collection, including information about confidentiality, voluntary participation, and the right to withdraw at any time. A demographic survey with questions about their child with CHARGE syndrome was also completed prior to the interview. Participants were provided with iPads to complete the screening questions ahead of their interviews.

A total of seven family caregivers of adult children living with CHARGE syndrome participated in this study. At least two members of the research team were present at each interview. Each qualitative interview lasted between 23-56 minutes.

### Interview Procedures

Semi-structured interviews were conducted in a private meeting room during the conference. A piloted interview guide was used to ensure consistency across sessions while allowing for open-ended responses. Interviews were audio-recorded with participant consent and transcribed verbatim. Transcripts were reviewed for accuracy prior to analyses.

### Data Analysis

Transcripts from the interviews with the seven family caregivers of young adult children aged 18 years and over with CHARGE syndrome were analyzed by two authors. The authors used qualitative description methodology to identify the main themes from the interview transcripts [22]. Qualitative description methodology was chosen for this study because it facilitates the provision of a comprehensive and accurate description of the experiences of family caregivers of young adult children aged 18 years and over with CHARGE syndrome. It allows for the use of an inductive approach to develop overarching theories, hypothesis, or explanations regarding an observation or phenomenon [22]. Importantly, it uses the participants' own words to summarize or describe the observation or phenomenon.

To conduct the analysis, each author read the transcripts independently and then grouped the key information into categories. These categories represented similar meanings in relation to the three research questions that the study sought to address. After the authors' independent analysis of the seven interview transcripts, the authors met to compare their analysis results. A third author was present at the meetings to help compare and reconcile the independent results obtained by the other two authors. Although no software was used, an audit trail was maintained to document analytic decisions. Any areas of disagreement were discussed by the three authors until final consensus was reached on the results. This analytics approach facilitated the generation of themes addressing the research questions.

## Study Rigor

Deliberate steps were taken to ensure the study's rigor. For example, since the researchers are experienced in the field of CHARGE syndrome and family caregiving, positionality was established at the start of each interview. All members of the research team present at the interview describe their position, qualifications, as well as their experience in relation to CHARGE syndrome and family caregiving. As part of the analytic process, the researchers engaged in a process of critical reflection that included noting and discussing their biases. This helped to ensure that the researcher's background and experience in these fields do not influence the research process and findings [23-25].

Also, while two authors primarily conducted the data analyses, a third author reviewed the interview transcripts and the emergent themes. The independent assessment and evaluation by these authors helped to ensure the findings were close to how the study participants described them. Finally, the validity and credibility of the findings were enhanced through triangulation. Specifically, multiple researchers and data sources were used while conducting the study. The study data came from qualitative interviews and online Qualtrics survey.

## RESULTS AND DISCUSSION

Four themes emerged from the interviews of caregivers of young adult children with CHARGE syndrome: 1: *Reshaping Identity and Autonomy*, focusing on how caregiving transforms parents' sense of self and freedom; 2: *Emotional Resilience and Coping*, highlighting the strategies parents use to manage stress and maintain wellbeing; 3: *Systemic Barriers and Support*, addressing the challenges with formal systems and reliance on informal networks, and 4: *Child's Health Profile and Responsibilities*, detailing the specific medical complexities and daily caregiving demands. Each theme included four subthemes. See Table 1 for the themes, subthemes and illustrative quotes.

The Adaptive Identity Trajectory Model can be used to understand the perspectives of family caregivers who participated in this study [20,21]. The main idea in this model as it applies to the current research is that family caregivers experience identity transformation through caregiving, moving from role absorption to role integration. As the duration of caregiving progresses, caregivers are likely to modify their lifestyle in order to compensate for the stresses associated with caring for an older child living with CHARGE syndrome [8-20]. By framing caregiving as a dynamic identity transformation, from role absorption to role integration, how caregivers adapt, cope, and redefine themselves over time is illuminated. Early caregiving often demands full immersion [8], where caregivers' personal identities are eclipsed by the caregiving role. Statements like "the only thing I do in my life is...', or "I am alive because she still needs me' reflect a deep role absorption. Related to theme 1, Reshaping Identity and Autonomy, parents expressed a reclaiming of personal time and relationships which coincided with the decreased stress and anxiety from far fewer life-threatening medical issues than when their child was very young [14-19]. As caregivers move toward role integration, they began to reassert personal autonomy, as seen by 'we go on dates... walks with my friends' signaling a rebalancing of self and caregiving identity. Their child turned a corner and often became more independent and did not need constant medical care and supervision. The number of medical appointments subsided, and their time then became more of their own. Many even said their child could do more with them and they had family outings and time spent together. They supported their child's autonomy as a strategy to reclaim their own freedom, 'the more independent he becomes, the more free I become.' Quality of life fluctuates with caregiving demands, but over time, caregivers develop strategies to stabilize it reflecting the model's emphasis on adaptive transformation and lifestyle modification.

Theme 2, Emotional Resilience and Coping, focused on the strategies the caregivers used to manage stress and maintain wellbeing, similar to the model's identity integration through coping mechanisms. These coping mechanisms ranged from physical activity, nature, faith, and integrating the child into their daily routines. These are similar findings to the study by [8], where it was found that many families turned to physical activity and faith to get through difficult times. These strategies evolved over time as when their children were younger, they did not always have time for active involvement in their faith communities or taking walks or hikes [14]. It was clear that as their child became healthier and stronger they had more time to spend on their hobbies and recreational activities. Additionally, some indicated that they were able to incorporate their child into meaningful activities 'talk about the flowers... good for him and for me', reflecting a blending of identities, where caregiving becomes part of a fulfilling lifestyle. This is similar to the findings of [18], where they found that caregivers found strength in small achievements and celebrated successes as they occurred.

In the theme Systemic Barriers and Support, caregivers shared their focus and reliance on their network of other families with children with similar disabilities, which identified external constraints upon identity integration. They did not always seek support from the system of doctors, therapists, and specialists as most did not understand CHARGE Syndrome as many expressed distrust and fatigue with the medical system. This aligns with the findings of [26], where the teachers did not know anything about children with CHARGE Syndrome. Caregivers talked about the frustration with navigating a system that is not made for their unique circumstances [19]. Navigating an inaccessible system required constant advocacy, reinforcing the caregiving identity and complicating efforts to reclaim autonomy. Instead of taking the exorbitant time to educate professionals many turned to relatives and friends to help with childcare and support. This led to an inability to delegate care 'very few people we could leave him with' forcing a continued role absorption, delaying personal reintegration. Additionally, some caregivers expressed a reliance on aging informal networks causing them to face renewed pressures, often reverting to earlier stages of role absorption.

Theme 4, Child's Health Profile and Responsibilities illuminated the very complex and unique medical complications that come with the diagnosis of CHARGE Syndrome revealing a complexity of caregiving that shaped identity trajectory. The intensity of medical needs anchors caregivers in role absorption early on. Over time, familiarity with these demands may facilitate integration. These various medical complications are exacerbated by anxiety [13], and obsessive-compulsive disorder [14],

**Table 1**: Themes, subthemes, and illustrative quotes for each subtheme

| Theme | Subtheme | Illustrative Quotes | Participants |
|---|---|---|---|
| **1. Reshaping Identity and Autonomy Through Caregiving** | Sacrificed autonomy and spontaneity | "You may have to give up what you want to do." / "For me to go mountain biking for 4 hours, I have to figure out someone to watch Adam." / "The only thing I do in my life is… I am alive because she still needs me." | P7, P13, P10 |
|  | Reclaiming personal time and relationships | "Now that I can have time to myself… we can go on dates… go on walks with my friends." / "Stress is minimal now… very different from 15 years ago." / "I think it was much more stressful when he was younger… we've figured out coping mechanisms." | P10, P7 |
|  | Encouraging child independence to regain freedom | "The more independent he becomes, the more free I become." / "I try to encourage him to be as independent as possible… it's important for him and for me." / "When he could stay at home alone, things improved significantly." | P13, P11, P10 |
|  | Changes in quality of life | "Much better once he was more independent in college." / "There's days when it's great, and days when it's really hard." / "Quality of life better when she's healthy." | P10, P13, P4 |
| **2. Emotional Resilience and Coping Strategies** | Physical activity and nature as therapy | "Walking helps a lot." / "I try to exercise as often as possible… I really like to be outside." / "Running helped me manage stress." | P4, P11, P10 |
|  | Faith and social connection | "Prayer, going to church… having a faith has made a big difference." / "Faith keeps me grounded." / "I'll call a friend and we can go do something… that helps a lot." | P10, P4 |
|  | Creative integration of child into routines | "I've learned I have to incorporate Adam into a lot of those things." / "We're going to talk about the flowers… that's kind of good for him and for me." / "We stay busy with arts, crafts, cooking… being grateful." | P11, P9, P12 |
|  | Managing ongoing stress and burden | "Hard not knowing what future holds." / "Pretty high… especially since he's out of school and we're filling his days." / "Stress is constant, but faith helps." | P7, P13, P10 |
| **3. Systemic Barriers and Support Limitations** | Distrust and fatigue with systems | "The system is stressing. The system that they force upon her." / "I just don't know if a paid provider is actually going to do that." / "The system wants my daughter to stay disabled… IRIS program has no respect." | P11, P4 |
|  | Limited access to trained support | "You can't hire the 13-year-old down the street like you can with a lot of kids." / "With the trach… very few people we could leave him with." / "To go mountain biking, I need someone to watch Adam… lack of support." | P7, P10, P13 |
|  | Reliance on aging informal networks | "It's up to one grandmother or the other." / "My parents… are getting definitely older." / "One parent had to quit working… difficult choices." | P9, P7, P12 |

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|---|---|---|---|
| | Education and healthcare barriers | "School system didn't understand CHARGE." / "College accessibility inconsistent." / "Public school not working… forced us to homeschool." / "Cane training delayed by system." | P7, P10, P12, P11 |
| **4. Child's Health Profile and Caregiver Responsibilities** | CHARGE-related medical complexity | "She has heart defects… CHARGE features." / "He was born with choanal atresia and deafness." / "He's Deafblind… moderate hearing loss… no vision in left eye, 2400 in right." / "Colobomas of optic nerve… trach till he was 5… one kidney." | P4, P7, P13, P10 |
| | Mobility and navigation challenges | "She tires easily, struggles with balance." / "Didn't walk until 5… balance issues outdoors, needs someone's arm." / "Uses a cane… poor balance… uses apps to navigate." | P4, P10, P13 |
| | Vision and hearing accommodations | "She uses FM system… needs extra lighting." / "Patchy/ narrow visual field… relies on hearing aids + cane." / "Depth perception really bad… hits car mirrors… enlarged print needed." | P4, P13, P11 |
| | Daily coordination and advocacy demands | "Driving him everywhere… advocating in school." / "We pulled her out of school… one of us quit our job to homeschool." / "It's daily… a lot of mental energy every single day to coordinate." | P7, P12, P13 |
| | Future hopes and concerns | "I just want her to live on her own someday." / "We'd like him to be more independent… still concerns for his future." / "As he achieves more independence, the more free I become." | P4, P10, P13 |

and can be extremely difficult to manage were seen by these caregivers. These caregivers provided specific examples of the specific medical complexities and daily caregiving demands very similar to the findings of [8], that illuminated similar experiences. Specifically, mobility and navigation challenges were prominent with physical support needs which prolonged hands-on-caregiving, and adaptive tools (e.g. walkers, canes, apps) which enabled gradual shifts toward independence not only the child with CHARGE syndrome but the caregiver as well. Vision and hearing accommodations were also prominent requirement the caregivers to advocate for and manage accommodations reflecting a high level of caregiver involvement, and also a growing expertise that can empower identity integration. What was clear in this study was that each child went through these complications early in life, but the extreme nature of the medical issues subsided over time. The 'mental energy every single day' required for coordination showing how caregiving becomes a central identity, yet the mastery of these routines can lead to a more balanced self-concept. Aspirations for the child's independence "I just want to live on her own someday" mirror the caregiver's desire for identity expansion beyond caregiving.

These findings directly relate to the Adaptive Identity Trajectory Model [20,21], as these participants started their child's life caregiving 100% of the time and worrying about the medical complications and life expectancy of their child. Then they changed their role into more of a supporter and manager. Caregivers often found others they trusted to care for their child, and they did not worry as much about the life expectancy once the child overcame the acute medical complications they experienced.

While this study offers valuable insights into the lived experiences of family caregivers, it was not without limitations. A sample size of seven participants is an adequate sample size for a qualitative study particularly for a population with such a small incidence, however, it should be noted that the findings may not be representative of the broader population of caregivers of young adults with CHARGE syndrome. The limited sample restricts generalizability and may not capture the full spectrum of caregiving experiences. The recruitment context may also be considered a limitation as participants were recruited exclusively from the CHARGE syndrome 16th International Conference. Again, due to the very low incidence of the population, it is difficult to complete research on this population outside of an opportunity such as this conference, however, it should be considered that this setting may have attracted caregivers who are more engaged, resourceful, or connected to support networks, potentially introducing selection bias. It is also possible that by conducting interviews during a conference may have affected the depth and openness of responses due to time constraints, environmental distractions, or lack of privacy. Finally, researcher bias should always be considered in a qualitative study. Although multiple researchers analyzed the data and reached consensus, the inherent subjectivity of qualitative analyses may influence theme development. Finally, member checking was not conducted because the participants were recruited at a research conference.

## CONCLUSION

The results of this study may give caregivers of younger children with CHARGE Syndrome some hope. These coping strategies and unique approaches to managing difficult times can be helpful to specialists and parent groups. This light at the end of the tunnel may show caregivers of young children ways to navigate their lives to minimize the stress and anxiety associated with children with CHARGE Syndrome.

The Adaptive Identity Trajectory Model helps decode the nuanced evolution of caregiver identity in these caregivers of young adults with CHARGE syndrome. How caregivers navigated the tension between self-sacrifice and self-reclamation, and how their journey was shaped by both internal coping strategies and external systemic forces. This model not only validates their lived experiences but also offers a framework for designing interventions that support identity integration over time.

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