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RESEARCH ARTICLE

# Independence, inclusion, and uncertainty: voices of caregivers of youth with CHARGE syndrome on assistive technology and virtual reality

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**ABSTRACT**

**Purpose:** Family caregivers play a critical role in supporting youth with CHARGE syndrome, yet little is known about how they perceive and evaluate emerging assistive technologies such as virtual reality. This study explored caregiver perspectives to better understand how technology is conceptualised, the types of exposure families have experienced, and the perceived benefits and concerns that shape adoption.

**Materials and Methods:** Semi-structured interviews were conducted with thirteen caregivers of young adults with CHARGE syndrome during the 16th International CHARGE Syndrome Conference in July 2025. Using qualitative descriptive methodology, transcripts were analysed to identify themes related to caregiver decision-making, sensory and physical considerations, and the broader context in which assistive technology use is negotiated.

**Findings:** Caregivers described assistive technology in diverse ways, ranging from "fake" or entertainment-based to culturally enriching and potentially educational. Most reported limited exposure, often through arcades or school programs, which shaped cautious attitudes towards adoption. While caregivers anticipated benefits such as increased independence, skill-building, and social participation, they also expressed concerns about sensory overload, headset comfort, cost, and accessibility. Decision-making was influenced by practical constraints, philosophical beliefs, and the perceived balance between caregiver burden and child autonomy.

**Conclusion:** Findings highlight the complexity of caregiver perspectives on assistive technology for youth with CHARGE syndrome. Understanding how caregivers conceptualise, experience, and weigh benefits against concerns can inform the design and dissemination of technologies that are responsive to family needs. These insights provide a foundation for future research and development aimed at enhancing accessibility and supporting caregiver decision-making.

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Visual impairments; accessibility; technological integration; qualitative design; Unified Theory of Acceptance and Use; parental perceptions

**IMPLICATIONS FOR REHABILITATION**

This study provides several rehabilitation-focused insights into how assistive technology, particularly virtual reality, can be more effectively designed, introduced, and implemented for individuals with complex multisensory disabilities such as CHARGE syndrome. Caregivers emphasised that successful AT use depends on aligning technology with the child's sensory profile, physical capabilities, and environmental demands, underscoring the need for individualised assessment and adaptation within rehabilitation planning. Rehabilitation professionals can use VR to create controlled, repeatable, and safe practice environments for navigation, motor planning, daily living skills, and communication, provided that sensory load, balance challenges, and fatigue are carefully monitored.

The findings highlight the importance of gradual exposure, structured scaffolding, and clear routines to support learning and transfer of skills across settings. Interdisciplinary teams, including orientation and mobility specialists, occupational and physical therapists, teachers of the visually impaired, adapted physical educators, and paraeducators can integrate VR as a complementary tool to enhance engagement, build confidence, and promote functional independence. Because caregivers remain central to technology decision-making, rehabilitation providers should offer practical guidance, anticipate concerns about comfort and accessibility, and collaborate with

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families to reinforce strategies at home. Ultimately, these results point to the need for rehabilitation approaches that combine individualised adaptation, caregiver partnership, and thoughtful integration of assistive technologies to support meaningful participation for youth with CHARGE syndrome.

CHARGE Syndrome (CS) refers to a complex autosomal dominant disorder, oftentimes caused by mutations in the chromodomain helicase DNA-binding protein 7, or CHD7 [1]. It is best identified by a set of characteristic clinical features present at birth, as summarised by its acronym "CHARGE": Colobomas of the eye, heart defects, choanal atresia, retardation of growth and/or development, genitourinary malformation, and ear abnormalities [2]. Youth with CHARGE syndrome often have a variety of sensory and motor impairments that significantly impact their independent orientation and mobility.

While all individuals with CHARGE syndrome exhibit varying degrees of CHARGE characteristics, typical CHARGE colobomas are bilateral and chorioretinal, which predispose patients to visual impairment or diminished visual acuity, along with possible associated complications of microphthalmia, cataracts, cortical visual impairment, microcornea, and refractive errors [2]. These ophthalmic complications, then, understandably influence a child's ability to comprehend their surroundings fully, with one study noting that children with CS often have increased difficulty scanning objects and focusing on distant objects or objects located in their upper visual fields [3]. Commonly adding onto these barriers is the presence of sensorineural and conductive hearing loss due to various ear anomalies [4], as well as semicircular canal hypoplasia or complete absence of the semicircular canals, which play an imperative role in the vestibular functioning of the body [5]. As a result, patients are more likely to experience delays in developing fundamental motor skills, including walking, balance, and postural control [4]. This can also be exacerbated by the presence of persistent low muscle tone, or hypotonia, which can cause scoliosis in older children and reduce range of motion [6]. Youth with CS who have colobomas in one or both eyes can experience increased challenges with mobility, given their inability to offset their reduced vestibular stability with visual cues [5].

The features of CS, then, can markedly impact their quality of life, especially as they transition from childhood and adolescence to adulthood. For example, in one study, sensory impairments were noted to most affect relationships with peers in individuals with CS, while their overall health and balance most affected the number of social activities they would be able to participate in Hartshorne et al. [7]. In addition, individuals with dual sensory loss also report significant difficulties in daily activities, basic mobility, and navigating unfamiliar or uncontrolled environments outside of the home. Practicing for such activities meant to promote independence was also hindered by a lack of intervenors or certified orientation and mobility specialists (COMS) to assist when needed [8]. The multifactorial sensory impairments and other features associated with CHARGE can greatly affect the ability to develop towards greater independence and engage in social interactions, emphasising the importance of increased physical support and intervention strategies. For children and youth with CS, however, learning must be modified to fit their individual needs. Due to processing difficulties in addition to low muscle tone and dual sensory loss, children and youth with CS have more difficulty learning and need tasks to be broken down into simple steps within a controlled environment to ensure learning and generalisation [9].

Assistive technologies (AT) offer compelling possibilities to enhance skill development and acquisition for children and youth with CS [10,11]. AT addresses the physical, accessibility, and social barriers influencing the quality of life for individuals with visual impairments through an abundance of technologies and medical interventions meant for rehabilitation and addressing mobility, orientation, object identification, education, and information access [12,13]. Currently, AT devices can be characterised as low-tech, which include items such as communication books, tactile maps, tactile schedules, canes, and auditory balls and high-tech, where there are augmentative/alternative communication apps on mobile devices or other helpful communication devices [14]. In recent years, apps, or programs readily accessible for use on mobile devices, have also become more widespread among those with visual impairments due to their convenience, availability, and user-friendliness [15]. Within mobile devices, such as phones or tablets, specific functions like screen or text magnifiers have been identified as beneficial solutions for reducing visual accessibility barriers for low vision individuals [14]. One survey on the usage of mobile applications for the visually impaired found that frequently utilised apps included those for visual identification, such as Be My Eyes, ColorID, and Camfind, seconded by reading and writing aid apps like TalkBack and BrailleTouch [15]. Likewise, various popular forms of AT are available for deaf and hard-of-hearing children and include devices like hearing aids, soundfield amplification, and speech recognition programs that allow for automatic captioning and increased engagement with peers or educators [16]. Some mobile device apps include amplification or frequency adjustment apps, such as Ear Trumpet, and speech-to-text apps like Dragon Dictation or IP-Relay, which is available for anyone with Internet access [17]. These assistive technologies, when used as supplements, can profoundly assist individuals with visual and/or hearing impairments to access information necessary for more independent activities of daily life, whether it be for navigation and orientation or for inclusion with peers and education.

An extension of AT, virtual reality (VR), refers to the creation of interactive simulated environments that oftentimes seem or feel similar to real-world objects or events [18]. For the purposes of this paper, we considered augmented reality under the umbrella of VR. For individuals with visual impairments, deafness, or deafblindness, VR could allow them to practice navigation and mobility without the assistance of professionals. Through this is the potential for VR to be utilised clinically for motor skill training and repetition, where users can benefit from the stability of a controlled, safe environment tailored to their practice needs while also simulating real-world experiences. Additionally, research done on the application of VR in vestibular rehabilitation suggests that VR can promote increased vestibular function due to its encouragement of eye and head movements when focusing on various targets while balancing, as well as provide an engaging mode of rehabilitation *via* increased customisation as opposed to standard vestibular rehabilitation [19]. Similarly to this, in individuals with CS, who also have vestibular anomalies, may benefit from VR as a medium where they can practice different orientation and mobility skills systematically in safe, controlled environments. Additionally, there may be the potential to gamify VR and play with peers in a virtual space from their home which could give the parent some potential respite and be a meaningful activity, which could appease parental guilt.

As parents and caregivers play direct roles in the care and support surrounding children with CHARGE, their perspectives are salient in understanding the various accessibility and feasibility challenges faced by children with CS when using AT or VR. By conducting interviews with the caregivers of children with CHARGE, the purpose of this study was to document the lived experiences of CHARGE families and the current technological interventions utilised by these families, noting their barriers and identifying recommendations for enhancement of such technology and their possible implementation. The research questions for this study included; 1) How do caregivers of youth with CHARGE syndrome conceptualise and make sense of assistive technology and virtual reality in everyday life?; 2) What experiences, perceived benefits, and concerns shape caregiver attitudes towards the adoption of assistive technology for their children?; and 3) How do sensory, physical, and contextual factors influence caregiver decision-making about whether and how assistive technology is used?

## Materials and methods

### *Study participants and recruitment*

Family caregivers were recruited through purposive sampling at the 16th International CHARGE Syndrome Conference, held in Phoenix, Arizona in the summer of 2025. This venue was selected because it brought together a concentrated group of caregivers with extensive experience supporting children diagnosed with CHARGE syndrome. To be eligible, participants needed to be the primary caregiver of a child with a confirmed CHARGE syndrome diagnosis. Study information was circulated both before and during the conference. Individuals who expressed interest contacted the research team, completed a brief screening process, and were enrolled if they met inclusion criteria.

Participation was voluntary and uncompensated. Ethical approval was granted by the Author's Institutional Review Board, approval number MOD00003517. Informed consent procedures were completed in two stages: participants first provided consent electronically *via* Qualtrics, and written consent was obtained prior to data collection. Consent materials emphasised confidentiality, voluntary involvement, and the right to withdraw at any point. Before interviews began, caregivers also completed a demographic questionnaire about their child with CHARGE syndrome. Screening questions were administered using iPads supplied by the research team.

Thirteen caregivers of children with CHARGE syndrome ultimately took part in the study. The mean age of the caregiver's children was 16.85 years (SD = 7.70) and 51.23 years (SD = 13.24) for the caregivers. All caregivers were parents of the children with the exception of one grandparent. Six (46.2%) of the children with CHARGE syndrome were male and 7 (53.8%) were female. Two out of the thirteen caregivers (15.4%) were male. Reported age of independent walking was a mean of 4.62 years (SD 4.41 years). Most of the children had siblings ($n = 10$, 76.9%). Six out of the thirteen caregivers indicated that they work full-time, three indicated part-time, three did not work, and one did not indicate if they worked. The children with CHARGE syndrome varied in their school attendance with four attending a deaf school, two attending a regular school, two attended an inclusive/transition school, and four were no longer in school. Each interview was conducted with at least two members of the research team present. Interviews were qualitative in nature and ranged from 23 to 56 min in length.

### *Interview procedures*

Interviews followed a semi-structured format and were held in a private room at the conference venue. Refer to Appendix for the interview questions. A pilot-tested guide was employed to promote consistency across interviews while still encouraging open-ended discussion. With participant permission, all sessions were audio recorded and later transcribed word-for-word. Transcripts were checked against the recordings to confirm accuracy before analysis began.

### *Data analyses*

Interview transcripts from thirteen family caregivers of youth with CHARGE syndrome were examined by two members of the research team. A qualitative descriptive approach guided the analysis, chosen for its ability to provide a clear and faithful account of caregiver experiences [20]. This methodology emphasises inductive reasoning, allowing researchers to generate categories and themes directly from participant narratives, and prioritises the use of participants' own words to capture and summarise observed phenomena [20].

Each analyst reviewed the transcripts independently, organising key segments of text into preliminary categories that reflected shared meanings in relation to the study's three guiding research questions. Following these individual reviews, the analysts met to compare interpretations. A third team member participated in these meetings to assist with reconciliation of differences and ensure consistency across analyses. Although specialised software was not employed, an audit trail was maintained to document analytic decisions throughout the process. Discrepancies were discussed collectively until consensus was achieved, resulting in a set of themes that addressed the study's research aims.

### *Trustworthiness/study rigor*

Several strategies were implemented to strengthen the rigour of the study. At the outset of each interview, the research team acknowledged their positionality by introducing their professional background, qualifications, and prior experience with CHARGE syndrome and family caregiving. This practice provided transparency and helped situate the researchers in relation to the participants. During analysis, the team engaged in ongoing reflexivity, documenting and discussing potential biases to minimise the influence of their own perspectives on the interpretation of data [21–23]. The researchers involved in the interviews included three professors with backgrounds in motor behaviour, adapted physical education, and health administration, each with extensive experience conducting qualitative research. Two of the three have over 20 years of experience with individuals with visual impairments and CHARGE syndrome. Additionally, two college students participated in the interviews. One student was an undergraduate in a clinical healthcare field and the other in a graduate health-related field. Both students had experience with individuals with visual impairments and qualitative research. During the interviews there were always at least two researchers and one student present.

Data analysis was primarily conducted by two authors, with a third researcher independently reviewing transcripts and the themes that emerged. This additional layer of evaluation ensured that the findings remained closely aligned with the participants' accounts. Credibility was further supported through triangulation, which involved the use of multiple analysts, methods and data sources to corroborate interpretations and enhance trustworthiness. For example, the involvement of multiple investigators and analysts in the study enhanced the credibility of the findings. Further, in addition to the qualitative data collected during the interviews, data were also collected using online Qualtrics survey. The variation and triangulation of the two methods allowed for different perspectives that may otherwise be missed. Finally, the use of these multiple data sources helped ensure the capturing of rich information about personal experiences and perspectives [24,25].

## Results

Five themes from the caregivers of children with CHARGE syndrome emerged: 1) Caregiver Conceptualisation of AT/VR; 2) Exposure and Familiarity with AT/VR; 3) Potential Benefits and Concerns with their Child using AT/VR; 4) Child-specific Sensory and Physical Considerations; and 5) Decision-Making Influences. Each theme included several subthemes. The subthemes of theme 1, caregiver conceptualisation of AT/VR were confusion and basic associations, multisensory learning potential, and cultural enrichment. This theme revealed a wide range of caregiver experiences and perceptions of AT/VR. Theme 2, exposure and familiarity with AT/VR revealed that most exposure was entertainment-based and direct use of AT/VR was limited, however some positive experiences were revealed to be typically tied to family outings. Subthemes included entertainment-based, limited/no direct experience and situational positive experience. The subthemes of theme 3, potential benefits and concerns of AT/VR use included skill-building and independence, socialisation and communication, and concerns: sensory overload and overuse. Caregivers specifically discussed the potential of VR as a tool for learning new motor, navigation, social, or communication skills. However, they were concerned about headset comfort or sensory overload. Subthemes for theme 4, child-specific sensory and physical considerations included vision preferences, balance and headset fit, and auditory sensitivities. These are all features that are important considerations for adopting a new technology. Subthemes of theme 5, decision-making influences, included independence and reduced caregiver burden, affordability and accessibility, and philosophical/religious beliefs. Refer to Table 1 for a sample of quotes and a description of each subtheme.

## Discussion

AT/VR can reduce the caregiving burden for caregivers of children with disabilities by improving their child's independence [26,27]. Caregiver burden is a multidimensional concept. It can be defined as the extent to which caregivers perceive that the role has had a negative impact on their overall well-being [28,29, p. 261). While there are many benefits of AT/VR for children with disabilities, their caregivers are often the adopters of AT/VR for their child. Caregivers must feel confident in the benefits of the AT/VR and competent themselves in using the device to use it with their child [26]. Children with CHARGE syndrome experience a range of severe sensory and motor impairments [4,5] and could greatly benefit from assistive devices with customisation. Where there are many AT/VR devices available [15,16], the caregiver perceptions of these devices were unknown for caregivers of children with CHARGE syndrome. Understanding caregivers' perceptions of AT/VR is critical to developing technologies that will more effectively assist their child and increase the likelihood of caregiver acceptance to the technologies [30]. Reducing burden, enhancing physical health, and improving communications may be important goals for family caregivers, considering the high level of unfavourable health outcomes in this population [31–33].

One of the aims of this study was to understand how caregivers of youth with CHARGE syndrome conceptualise and make sense of assistive technology and virtual reality in everyday life. Theme 1 revealed a wide range of caregivers understanding of AT/VR. Some caregivers viewed them as "fake" or simply entertainment, while others imagined multisensory or cultural enrichment benefits. Participant 3 asserted, "When I first heard about virtual reality, I thought it was just fake—like a video game where you put on goggles and pretend, you're somewhere else. I didn't really see how that could help my daughter, because she needs things that are real and concrete. So, at first, I didn't take it seriously." Whereas Participant 11 described a positive experience "We went to a virtual reality exhibit in Jerusalem, and it was amazing. It felt like being

**Table 1.** Themes and subthemes from caregiver perspectives on AT/ VR.

| Theme | Subtheme | Description of Subtheme | Quotes |
|---|---|---|---|
| 1. Caregiver Conceptualization of VR/AT | Confusion & Basic Associations | Caregivers often equate VR with games or “fake” environments, showing limited understanding. | 1. I’ve never thought about this stuff at all… at all, literally, we just got a MetaQuest at home, so that’s about as far as it’s gotten. So the whole VR thing for… figuring out life skills, that’s… y’all have now brought that to my attention. That’s a whole new realm.” (P1)<br>2. ‘I never really thought about it until, like, you mentioned it, and I was thinking about it, and I don’t know how… I don’t know enough about it to know how you would use it to help him.” (P 10)<br>3. “Like fake. I think of not reality.” (P3)<br>4. “What do you mean virtual reality?” (P12) |
| | Multisensory Learning Potential | Some caregivers see VR as involving multiple senses and offering new ways to learn. | 1. “It could be used as a learning tool… visual, hearing, smell, sensation.” (P13)<br>2. “It gives… social stories, because she really struggles with social.” (P6)<br>3. “VR… improving visual performance… allow them to learn strategies.” (P8) |
| | Cultural Enrichment | VR is seen as valuable for situational, cultural, or historical experiences. | 1. “We went to a beautiful virtual reality thing in Jerusalem… it was amazing.” (P11)<br>2. “It was like going to the movies.” (P11)<br>3. “You could certainly travel to places or experience something like that.” (P4) |
| 2. Exposure & Familiarity | Entertainment-Based Exposure | Most caregiver/child exposure to VR is through arcades, simulators, or phone-based headsets. | 1. “Whenever we go to an arcade… he had that thing around his head and played one of the virtual reality games.” (P3)<br>2. “Just games… my son loves those games where you put the headset.” (P3)<br>3. “Arcade ride… simulator type things.” (P13) |
| | Limited/No Direct Experience | Several caregivers report no VR use, only familiarity through media or second-hand accounts. | 1. “No, neither of us had, other than just a tabloid.” (P6)<br>2. “No one in my family has ever experienced that.” (P10)<br>3. “I don’t understand the question.” (P12) |
| | Situational Positive Experience | Some report positive but rare experiences, often tied to cultural or family outings. | 1. “We went to a beautiful virtual reality thing in Jerusalem… it was amazing.” (P11)<br>2. “He enjoyed it… thought it was fun.” (P13)<br>3. “He probably would enjoy things like that… he’s a tech guy.” (P9) |
| 3. Potential Benefits & Concerns | Skill-Building & Independence | Caregivers imagine VR as a tool to teach navigation, daily living skills, and independence. | 1. “If it could be a teaching tool… practice a skill like cooking or cleaning.” (P13)<br>2. “Orientation and mobility… navigating to find a bus stop.” (P10)<br>3. “He might be able to… have job skills enhanced with this.” (P9) |
| | Socialization & Communication | VR is seen as a way to practice social skills, advocacy, and communication in safe environments. | 1. “It gives… social stories, because she really struggles with social.” (P6)<br>2. “Communicating with an avatar is less stressful.” (P4)<br>3. “Would help him interact socially… he’d rather interact with adults than peers.” (P7) |
| | Concerns: Sensory Overload & Overuse | Caregivers worry about headset comfort, auditory overload, eye strain, and excessive screen time. | 1. “That’s all he wants to do… play with his phone 24-7.” (P7)<br>2. “If the radio’s on, he turns it off right away… background music bothers him.” (P9)<br>3. “Couple hours of computer, and her eyes are really suffering.” (P11) |
| 4. Child-Specific Sensory & Physical Considerations | Vision Preferences | Children with CHARGE often have unique visual profiles, preferring high contrast, specific colors, or larger print. | 1. “She tends to focus more on things with the black background.” (P3)<br>2. “Her favorite colors might be red and yellow.” (P3)<br>3. “She needs larger print… captioning an inch big.” (P6) |
| | Balance & Headset Fit | Poor balance, small head size, or headset weight can make VR use difficult; lightweight, snug-fitting devices are preferred. | 1. “He doesn’t have good balance… seated position would be better.” (P13)<br>2. “If it was heavy, it could pull him over.” (P13)<br>3. “Sometimes he doesn’t like stuff on him.” (P7) |
| | Auditory Sensitivities | Background noise, Bluetooth connections, or unexpected sounds can cause overload, discomfort, or even physical reactions. | 1. “If the radio’s on, he turns it off right away… background music bothers him.” (P9)<br>2. “Bluetooth directly into her ears… throws her off balance.” (P11)<br>3. “Unexpected sounds like clapping overstimulate her.” (P6) |
| 5. Decision-Making Influences | Independence & Reduced Caregiver Burden | Caregivers prioritize technologies that foster independence and reduce reliance on them. They want tools that work reliably without adding caregiver workload. | 1. “It has to be something he can use independently… if it’s more work for me, I won’t do it.” (P13)<br>2. “I want him to be as independent as possible… worried if I’m not here.” (P5)<br>3. “Anything that helps him to be more independent, we’re all for.” (P10) |

(*Continued*)

**Table 1.** Continued.

| Theme | Subtheme | Description of Subtheme | Quotes |
|---|---|---|---|
| | Affordability & Accessibility | Cost, availability, and ease of access are major factors influencing adoption. Caregivers are more likely to try VR/AT if it is affordable or provided through schools/ programs. | 1. "VR seems to be expensive… that's probably the biggest barrier." (P6)<br>2. "If it was offered to him, yeah." (P9)<br>3. "Cost, of course… but I thought it would be something they lend you." (P10) |
| | Philosophical/Religious Beliefs | Some caregivers reject immersive technology entirely due to ideological or religious concerns, framing it as deceptive or harmful to family values. | 1. "We will never do anything that will introduce deception in our brain." (P11)<br>2. "I don't rely on technology for anything… I still use maps." (P11)<br>3. "Children should be outside… never with computers." (P11) |

at the movies, but more immersive. For me, it was cultural enrichment, but I could see how it might be used for learning too. If it could be adapted, maybe it could help her practice skills in a safe way." Importantly, this sentiment is consistent with studies that have shown improvements in development and participation among children with disability because of technological intervention [34,35].

Using the Unified Theory of Acceptance and Use (UTAUT; 36] as a primary lens explains the cognitive determinants of the caregiver acceptance. UTAUT's four key constructs (performance expectancy, effort expectancy, social influence, and facilitating conditions) map directly onto this theme. Regarding performance expectancy, the degree to which an individual believes that using the device will help them achieve gains in performance or daily tasks, caregivers who see VR as "fake" perceive low usefulness, while those who recognise cultural enrichment or multisensory learning perceive higher potential benefits. Effort expectancy, the degree of ease associated with the use of the device, is demonstrated through the confusion of VR as "games" or "glasses" reflects uncertainty about its ease of use. Caregivers imagining VR as a learning tool anticipate more accessible, structured applications [37]. The social influence was demonstrated through the external exposure through cultural enrichment experiences that can shape caregivers' attitudes. Observing VR in meaningful contexts increases perceived legitimacy [38]. Caregivers' ability to envision VR adapted for their child depends on environmental support and resources. Without clear pathways for integration, VR remains abstract or "not real."

The main idea of theme 2, AT/VR exposure and familiarity revealed that for most of the caregivers, direct VR exposure was rare. Most of the caregivers and children encountered AT/VR through entertainment, such as arcades or simulators, while others had little to no experience. Participant 3 stated that "Whenever we go to an arcade, he'll try the simulator with the headset. He thinks it's fun, but it's not really teaching him anything. It's just a game. That's the only exposure we've had, so I don't know how it would work for something more practical." Participants 4 and 6 discussed school exposures that were more structured, 'At school, they use apps like MapQuest and crosswalk training programs. Those are more structured, and she engages better in that environment. It's different from the arcade, because the teacher's guide her and connect it to real routines." Exposure and familiarity with AT/VR directly shape UTAUT constructs. Without meaningful experiences, caregivers perceive AT/VR as entertainment and thus irrelevant. With situational positive exposures, some caregivers have seen the potential benefits of AT/VR. Caregivers who have only had entertainment-based exposure have low performance expectancies, shaped by social influence of a gaming culture. With limited or no experience, there is a weak effort expectancy and facility conditions further reinforcing their scepticism.

This study also sought to examine the experiences, perceived benefits, and concerns that shape caregiver attitudes towards the adoption of assistive technology for their children. Caregivers' acceptance of AT/VR hinges on balancing high perceived usefulness [39], such as skill building or improving independence and mobility, with low ease of use and weak facilitating conditions (e.g. sensory concerns and headset discomfort). The potential benefits and concerns of using AT/VR emerged as theme 3. Some of the benefits expressed were skill-building, independence, socialisation, and communication. Participant 13 stated ""If it could be a teaching tool, I"d want her to practice cooking or cleaning in a safe environment. That way, she could learn step by step without me worrying about her burning herself or breaking something. It could help her be more independent." VR was valued by some for teaching practical skills and mobility in safe environments. Others also discussed VR as a tool for practicing social interactions without the stress and anxiety of real-world situations. These benefits demonstrate strong performance expectancy with moderate social influence when tied to meaningful contexts. A variety of concerns were also expressed such as sensory overload and fatigue, "After a couple hours on the computer, her eyes are really suffering. She gets headaches, and then she doesn't want to move around the house. I worry that VR would make that worse, because it's so visually demanding," or headset comfort by participants 7 and 13, "'Sometimes he doesn't like stuff on him. If it's tight around his head or face, he'll fidget and push it off. If the headset is heavy, it could even pull him over. That makes me nervous about trying it," which creates barriers to adoption.

Additionally, this study aimed to examine how sensory, physical, and contextual factors influence caregiver decision-making about whether and how assistive technology is used. Theme 4, child-specific and physical considerations, directly shape all four UTAUT constructs, making accessibility adaptations central to caregiver acceptance of AT/VR. Performance expectancy rises when AT/VR is tailored to sensory/physical needs, showing clear benefits for independence and learning. Vision preferences included high contrast, specific colours (red/yellow), and large captioning text to improve accessibility. Participant 7 stated, "Her vision is 20/400, and it's spotty where the vision is. Sometimes she can see tiny print if the contrast is perfect, but bigger signs get cut off. That makes it hard to know how she'd respond to VR, because it depends so much on the visual setup." While there are currently many AT/VR devices, people who are low vision or blind have not widely accepted or adopted AT/VR [40]. Effort expectancy drops when devises are heavy, visually demanding or auditorily overwhelming, but rises with adaptive designs. Participant 11 expressed balance and auditory sensitives or their child, "Social influence plays a role when caregivers see professionals or peers validating VR adaptations." Facilitating conditions are critical as without accessibility features, ergonomic hardware and sensory-friendly environments, caregivers are very unlikely to adopt the device.

Decision-making influences emerged as theme 5. Caregivers will likely adopt AT/VR if they believe it will empower their child and reduce their own workload [39]. Participant 13 asserted, "If VR or other technology could give him prompts without me having to step in, that would reduce my burden and help him feel more independent." However, for some families perceived usefulness is overridden by ideological values. Even if VR could be beneficial, these individuals would reject it outright. Like previous research, a critical deciding factor was the cost and accessibility [12,37]. If AT/VR is seen as expensive or difficult to set up, caregivers anticipate high effort and low ease of use [39]. Participant 6 expressed "Accessibility is always the first barrier—if it's not affordable or easy to use, it won't be realistic for us." Ease of use is critical as well. If AT/VR can deliver prompts seamlessly, caregivers see it as reducing effort for both the child and parent [34,35,41].

## *Strengths and limitations*

This study offers several notable strengths. Recruiting at the CHARGE Syndrome International Conference enabled access to a relatively large, heterogeneous, and concentrated group of family caregivers, resulting in a sample of 13 participants. While qualitative studies in rare conditions often rely on very small case series, this diverse sample size provided broader perspectives and enhanced thematic saturation. The use of semi-structured interviews generated rich, detailed accounts of caregiver experiences, and methodological rigour was supported through independent coding, reflexivity, consensus meetings, and maintenance of an audit trail. Additionally, the dual analytic framing—both the original thematic lens and the motor behaviour lens—strengthened interpretation by situating caregiver perspectives within practical and theoretical contexts. Finally, the credibility of the findings was enhanced by the use of method triangulation, investigator triangulation, and data source triangulation.

At the same time, several limitations must be acknowledged. Recruitment from a single conference may have introduced bias, as participants were likely families with the resources and interest to attend such an event. Although the sample of 13 caregivers is larger than many qualitative studies in rare conditions, it remains modest and somewhat limits generalisability. Furthermore, caregiver exposure to assistive technology and virtual reality was often limited or entertainment-based, constraining the depth of responses about practical applications. Finally, while manual coding was rigorous and documented, the absence of qualitative software may have limited systematic data management.

### *Practical implications*

The perspectives of family caregivers in this study underscored the importance of tailoring assistive technology and virtual reality interventions to the unique sensory, physical, and contextual needs of youth with CHARGE syndrome. By working in partnership, practitioners and families can maximise the potential of assistive technologies to promote independence, safety, and meaningful participation for youth with CHARGE syndrome. Orientation and mobility instructors can use AT/VR and related tools to provide safe opportunities for practicing navigation skills, gradually introducing technology while accounting for balance and auditory sensitivities [12]. Teachers of the visually impaired may find AT/VR useful for enhancing literacy and communication, particularly when high-contrast visuals and individualised instructional strategies are incorporated. Therapists across disciplines can employ simulations to scaffold daily living skills, motor planning, and communication, emphasising structured environments and reinforcement to promote transfer of skills. Classroom aides and paraeducators play a vital role in supporting engagement, monitoring fatigue, and reinforcing instructions to sustain motivation. Adapted physical education teachers can integrate AT/VR into motor skill practice, using gamified environments to encourage safe participation and build confidence. Finally, family members remain central to decision-making, weighing independence gains against concerns about cost, accessibility, and sensory strain. Practitioners can support families by providing clear, practical information and by reinforcing routines at home. Taken together, these implications highlight the need for family education, individualised adaptation, collaborative planning, and consistent reinforcement across settings.

## Conclusions

Caregivers' perceptions of AT/VR adoption can be understood through the Unified Theory of Acceptance and Use of Technology (UTAUT), which highlights how performance expectancy, effort expectancy, social influence, and facilitating conditions shape decision-making. Across themes, caregivers often begin with limited or entertainment-based exposure, which constrains performance expectancy, but situational positive experiences reveal potential for skill-building, independence, and socialisation. At the same time, concerns about sensory overload, headset discomfort, and accessibility challenges lower effort expectancy and emphasise the need for strong facilitating conditions such as ergonomic design and affordability. Social influence emerges through cultural enrichment experiences, professional validation, and community norms, while philosophical or religious beliefs can override perceived usefulness altogether. Ultimately, caregivers' acceptance of AT/VR depends on balancing high expectations for independence and reduced burden with practical barriers of cost, accessibility, and child-specific sensory and physical considerations.

## Author contributions

CRediT: **Pamela Beach**: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Resources, Supervision, Validation, Writing – original draft, Writing – review & editing; **Samantha Leung**: Data curation, Formal analysis, Investigation, Writing – original draft; **Afeez Hazzan**: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Validation, Writing – original draft, Writing – review & editing; **Lauren Lieberman**: Conceptualization, Formal analysis, Methodology, Writing – review & editing; **Nicole Ness**: Data curation.

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## References

[1] Vissers LE, van Ravenswaaij CM, Admiraal R, et al. Mutations in a new member of the chromodomain gene family cause CHARGE syndrome. Nat Genet. 2004;36(9):955–957. doi:10.1038/ng1407.

[2] Hsu P, Ma A, Wilson M, et al. CHARGE syndrome: a review. J Paediatr Child Health. 2014;50(7):504–511. doi:10.1111/jpc.12497.

[3] McMain K, Blake K, Smith I, et al. Ocular features of CHARGE syndrome. J Aapos. 2008;12(5):460–465. doi:10.1016/j.jaapos.2008.02.009.

[4] Choo DI, Tawfik KO, Martin DM, et al. Inner ear manifestations in CHARGE: abnormalities, treatments, animal models, and progress toward treatments in auditory and vestibular structures. Am J Med Genet C Semin Med Genet. 2017;175(4):439–449. doi:10.1002/ajmg.c.31587.

[5] Wineland A, Menezes MD, Shimony JS, et al. Prevalence of semicircular canal hypoplasia in patients with CHARGE syndrome: 3C syndrome. JAMA Otolaryngol Head Neck Surg. 2017;143(2):168–177. doi:10.1001/jamaoto.2016.3175.

[6] Sanlaville D, Verloes A. CHARGE syndrome: an update. Eur J Hum Genet. 2007;15(4):389–399. doi:10.1038/sj.ejhg.5201778.

[7] Hartshorne N, Hudson A, MacCuspie J, et al. Quality of life in adolescents and adults with CHARGE syndrome. Am J Med Genet A. 2016;170(8):2012–2021. doi:10.1002/ajmg.a.37769.

[8] Fletcher PC, Guthrie DM. The lived experiences of individuals with acquired deafblindness: challenges and the future; 2013.

[9] Blake KD, Salem-Hartshorne N, Daoud MA, et al. Adolescent and adult issues in CHARGE syndrome. Clin Pediatr (Phila). 2005;44(2):151–159. doi:10.1177/000992280504400207.

[10] Schloss I, Dillon A, Bailey J. Why use Virtual Reality as a treatment for children and youth's mental health and wellbeing: a review. Digit Soc. 2025;4(2):38. doi:10.1007/s44206-025-00193-8.

[11] Stasolla F. Virtual Reality and wearable technologies to support adaptive responding of children and adolescents with neurodevelopmental disorders: a critical comment and new perspectives. Front Psychol. 2021;12:720626. doi:10.3389/fpsyg.2021.720626.

[12] Beach P, Lytle B, Ness N, et al. Navigating innovation: the lived experiences of orientation & mobility specialists using assistive technology and virtual reality. J Disabil Rehabil Assist Technol. 2026:1-13. doi:10.1080/17483107.2026.2626466.

[13] Bhowmick A, Hazarika SM. An insight into assistive technology for the visually impaired and blind people: state-of-the-art and future trends. J Multimodal User Interfaces. 2017;11(2):149–172. doi:10.1007/s12193-016-0235-6.

[14] Zdravkova K, Krasniqi V, Dalipi F, et al. Cutting-edge communication and learning assistive technologies for disabled children: an artificial intelligence perspective. Front Artif Intell. 2022;5:970430. doi:10.3389/frai.2022.970430.

[15] Griffin-Shirley N, Banda DR, Ajuwon PM, et al. A survey on the use of mobile applications for people who are visually impaired. J Vis Impair Blind. 2017;111(4):307–323. doi:10.1177/0145482X1711100402.

[16] Levesque E, Duncan J, Snoddon K. Empowering deaf youth: cutting-edge technology for independence. Deafness & Education International. 2025;27(1):1–3. doi:10.1080/14643154.2025.2452104.

[17] Lesner SA, Klingler M. Apps with amps: mobile devices, hearing assistive technology, and older adults. Leader. 2011;16(12):14–17. doi:10.1044/leader.FTR2.16122011.14.

[18] Ghali NI, Soluiman O, El-Bendary N, et al. Virtual reality technology for blind and visual impaired people: reviews and recent advances. Intell Syst Ref Libr. 2012;363–385. doi:10.1007/978-3-642-23363-0_15.

[19] Hong SK. Clinical application of virtual reality for vestibular rehabilitation. Res Vestib Sci. 2024;23(4):124–131. doi:10.21790/rvs.2024.019.

[20] Ghabrial MA, Andersen JP. Identity affirmation is associated with adaptive cardiovascular flexibility in response to stress among sexual and gender minority people of color. Soc Sci Med. 2023;320:115703. doi:10.1016/j.socscimed.2023.115703. [36716696]

[21] Lietz CA, Zayas LE. Evaluating qualitative research for social work practitioners. ASW. 2010;11(2):188–202. doi:10.18060/589.

[22] Lincoln Y, Guba E. Naturalistic inquiry. Sage: Newcastle upon Tyne, UK; 1985.

[23] Sandelowski M. What's in a name? Qualitative description revisited. Res Nurs Health. 2010;33(1):77–84. doi:10.1002/nur.20362.[20014004]

[24] Carter N, Bryant-Lukosius D, DiCenso A, et al. The use of triangulation in qualitative research. Oncol Nurs Forum. 2014;41(5):545–547. doi:10.1188/14.ONF.545-547.

[25] Naderi R, Oberndorfer TA, Jordan SR, et al. Resident perspectives on the value of interdisciplinary conference calls for geriatric patients. BMC Med Educ. 2021;21(1):314. doi:10.1186/s12909-021-02750-4.

[26] Alabbas NA, Miller DE. Challenges and assistive technology during typical routines: perspectives of caregivers of children with Autism Spectrum Disorders and other disabilities. Int J Disabil Dev Educ. 2019;66(3):273–283. doi:10.1080/1034912X.2019.1578864.

[27] Nicolson A, Moir L, Millsteed J. Impact of assistive technology on family caregivers of children with physical disabilities: a systematic review. Disabil Rehabil Assist Technol. 2012;7(5):345–349. doi:10.3109/17483107.2012.667194.

[28] Secinti E, Fischer IC, Brennan EA, et al. The efficacy of psychosocial interventions for cancer caregiver burden: a systematic review and meta-analysis of randomized controlled trials. Clin Psychol Rev. 2023;99:102237. doi:10.1016/j.cpr.2022.102237.

[29] Zarit SH, Todd PA, Zarit JM. Subjective burden of husbands and wives as caregivers: a longitudinal study. Gerontologist. 1986;26(3):260–266. doi:10.1093/geront/26.3.260.

[30] Kim AJ, An K-O, Yang J, et al. Predicting adoption of the assistive technology open platform: extended unified theory of acceptance and use of technology. Disabil Rehabil Assist Technol. 2024;19(7):2506–2518. doi:10.1080/17483107.2023.2300050.

[31] Hazzan AA, Dauenhauer J, Follansbee P, et al. Family caregiver quality of life and the care provided to older people living with dementia: qualitative analyses of caregiver interviews. BMC Geriatr. 2022;22(1):86. doi:10.1186/s12877-022-02787-0.

[32] Ku B, Moon H, Lee H, et al. Differences in physical health between caregivers of children with and without disabilities: a systematic review and meta analysis. Disabil Health J. 2026;19(2):101977. doi:10.1016/j.dhjo.2025.101977.

[33] O'Neill M, Bourke-Taylor H, Bhopti A, et al. The experiences of families of children with cerebral palsy and complex disability after three years accessing the National Disability Insurance Scheme. Aust Occup Ther J. 2024;71(6):910–924. doi:10.1111/1440-1630.12973.

[34] Feldner HA, Logan SW, Otieno S, et al. Short-term powered mobility intervention is associated with improvements in development and participation for young children with cerebral palsy: a randomized clinical trial. Phys Ther. 2025;105(1) pzae152. doi:10.1093/ptj/pzae152.

[35] Kenyon LK, Sloane BM, Beers LN, et al. Tiny drivers, big decisions: parental perceptions and experiences of power mobility device trials for young children with cerebral palsy. Disabil Rehabil Assist Technol. 2025;20(5):1566–1573. doi:10.1080/17483107.2025.2459884.

[36] Venkatesh V, Morris MG, Davis GB, et al. User acceptance of information technology: toward a unified view. MIS Q. 2003;27(3):425–478. doi:10.2307/30036540.

[37] Okonji PE, Ogwezzy DC. Awareness and barriers to adoption of assistive technologies among visually impaired people in Nigeria. Assist Technol. 2019;31(4):209–219. doi:10.1080/10400435.2017.1421594.

[38] Hameed A, Perkis A. Authenticity and presence: defining perceived quality in VR experiences. Front Psychol. 2024;15:1291650. 1291650. doi:10.3389/fpsyg.2024.1291650.[38708019]

[39] Yee A. Family caregivers' acceptance of using artificial intelligence-enabled technology in the care of older adults. Canada: McGill University; 2023.

[40] Theodorou P, Tsiligkos K, Meliones A. Challenges in acceptance of smartphone-based assistive technologies: extending UTAUT for people with visual impairments. J Vis Impair Blind. 2024;118(1):18–30. doi:10.1177/0145482X241231990.

[41] Gefen N, Mazer B, Krasovsky T, et al. Novel rehabilitation technologies in pediatric rehabilitation: knowledge towards translation. Disabil Rehabil Assist Technol. 2025;20(5):1209–1218. doi:10.1080/17483107.2024.2445017.

## Appendix

1. Please describe what virtual reality (VR) and augmented virtual reality (AVR) means to you.
2. Have you or your child had any previous exposure to virtual reality or similar immersive technologies?
    a. If yes, please describe your (and/or your child's) experiences. What did you (or your child) do and how often did you (or your child) participate in VR.
    b. If your child has used it, what was their reaction? How comfortable is your child with using technology independently or with assistance?
3. What do you think are the potential benefits of using VR for your child? Do you have any concerns about your child using VR? (e.g., safety, sensory overload, usability)
4. How interested are you in using technology—specifically VR—to support your child's learning or mobility?
5. Is there anything that would make you more likely to try or adopt a VR tool for your child?
6. What physical or sensory limitations does your child have that might affect their ability to engage with VR? For example, what types of colour schemes, contrast levels, or viewing ranges (e.g., distance, angle) are more comfortable for them when interacting with visual content?
7. Would your child need specialised adaptations to use VR effectively?
8. What factors would make VR easier or more difficult for your child to use?
9. Does your child use any other assistive technologies such as apps? Please describe what they use.
10. If you could develop an assistive device for your child, what would you develop?
11. What influences your decision to use an assistive device/technology for your child?
12. Is there anything else you would like to add?