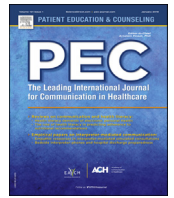




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# Deaf in one ear: Communication and social challenges of patients with single-sided deafness post-diagnosis



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## ABSTRACT

**Objective:** To understand the communication and social challenges that individuals with SSD face post diagnosis.

**Methods:** Fifty-two single-sided deaf patients from all over the world participated in semi-structured interviews. Interviews were digitally recorded, transcribed verbatim, and coded using a thematic analysis approach.

**Results:** Patients with single sided deafness identified challenges including: increased reliance on family members, decreased sense of autonomy, communication quality changes with family members, information discrepancy across family members and various emotional responses, conflicting information from interactions with multiple medical professionals, and lack of knowledge regarding what to anticipate post diagnosis.

**Conclusion:** This study provides insights into patients' perspectives around single-sided deafness and its challenges, and the various health care approaches (e.g., patient- and family-centered care, third party disability, patient navigation) that could be implemented post diagnosis to decrease negative experiences and outcomes associated with SSD.

**Practical Implications:** This study has practical implications for improving our understanding of what single-sided deaf patients need and for health professionals to offer better care to current and future populations impacted by single-sided deafness.

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## 1. Introduction

Single-sided deafness (SSD) refers to severe-to-profound hearing loss ( $\geq 70$  dB HL) in one ear while having nearly normal hearing in the other ( $-10$ – $15$  dB HL) [1]. Although the global incidence figures of SSD is unknown [2], there is an estimated 60,000 individuals diagnosed with SSD in the United States [3] and more than 9000 new cases in the United Kingdom [4] each year.

There are several causes of SSD reported such as sudden sensorineural hearing loss (SSNHL), Meniere's disease, acoustic neuroma, bone fractures, ear infections, and congenital diseases, but there is also a myriad of unknown causes [5]. Individuals with SSD face many unique challenges related to hearing in noisy and complex environments, specifically localizing sound sources, spatial positioning to maximize hearing, and physical outcomes

like vertigo and tinnitus [6]. Because of some of the physiological challenges to having SSD, there are various options for aided hearing to cope with these difficulties. However, many individuals with SSD do not opt-in for aided hearing devices and even those who do opt-in are not completely satisfied [7].

There are also social and psychological implications of SSD [8]. Studies found that individuals with SSD reported increased stress levels in social settings [9,10] and higher levels of social isolation [10]. Patients with SSD have listening fatigue, reduced quality of life, decreased levels of confidence and self-esteem [11], and experience other psychosocial consequences [10,12]. Post diagnosis of SSD, individuals report increased anxiety levels about losing hearing in their other ear, embarrassment related to the social stigma of hearing loss, and decreased social interactions [8].

Post diagnoses of SSD, many individuals are most likely surrounded by a network of family members and health professionals that can influence some of these communication and social interaction outcomes [13]. While the complexities and nuances of SSD have led scholars to identify certain outcomes of being diagnosed with and having SSD, fewer studies have focused

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on the specific challenges that individuals with SSD face post diagnosis, in particular their difficulties communicating and interacting with family members and health professionals. Identifying the challenges of individuals with SSD, especially when it comes to their social and medical interactions, can then help inform us about patient and family-centered approaches to health care as well as illuminate how we can craft interventions, programs, or extensions of theories that can further be tested. Therefore, this qualitative study explores what communication and social challenges individuals face post diagnosis of single sided deafness, regarding their social and medical network. Identifying these challenges and better understanding them through the lens of patient and family-centered care approaches could help us better understand why individuals may experience such detrimental outcomes and explain the contributing contextual barriers. The findings from this study can also shape key recommendations for health providers of SSD.

## 2. Methods

### 2.1. Participants

Study participants included 52 patients with SSD. Inclusion criteria limited the sample to any individual who was 18 years and older and diagnosed with SSD, whether they have an aided hearing device or not. Participants were recruited through multiple social support Facebook groups for individuals with SSD, and through snowball sampling, which is particularly effective for hard-to-reach populations. The participants reside in different states in the United States and various countries around the world including Germany, the United Kingdom, and Australia. Of the participants, 36 identified as female and 16 identified as male. The participants ranged from 18 to 69 years old ( $M = 45$ ,  $SD = 14$ ). Many of the participants were unable to identify the cause for their SSD, but for the participants who were able to identify the cause, the causes include acoustic neuroma, bacterial meningitis, and Ramsay-Hunt Syndrome (see [Table 1](#) for participant information).

### 2.2. Data collection

After obtaining Institutional Review Board approval from the authors' associated institution, the first author reached out to SSD social support groups on Facebook that could help with participant recruitment. Some social support group moderators required the completion of confidentiality forms and applications for recruitment purposes, which the author completed. Following moderator approval, the first author posted a recruitment letter on the main Facebook page of the social support groups. Individuals interested in participating in the study contacted the first author directly to schedule an interview. All the interviews were conducted over the phone or Skype.

The author obtained verbal informed consent from the participants by reading a written informed consent form that was also sent to the participant through email so each participant would have a copy. The semi-structured interviews took place from April 2018 to October 2018 and the interviews lasted between 43 to 100 min. Semi-structured interviews were used to explore and probe for key elements, as well as to ask follow-up questions [14]. Semi-structured interviews also allow for flexibility to avoid limiting the field of inquiry and for the interview to naturally take form [15].

### 2.3. Data analysis

The interviews were audiotaped, transcribed verbatim, and edited to remove any identifiers. Additionally, confidentiality of all participants was maintained by omitting all personal references

that may have identified the individuals with the interview transcripts. Each participant was given a number that corresponded to the interview transcripts (Pn). To further protect participants' privacy, we used pseudonyms following each quotation in the findings section used to illustrate the study's findings. After all the authors read through the interview scripts multiple times to become acquainted with the data, the authors imported the transcripts into Dedoose, a qualitative data analysis software for categorization. We conducted data analysis by using iterative and thematic coding [15]. The authors identified key themes around factors that patients identified as communication and social challenges regarding their medical teams and their family members following SSD diagnosis. We then grouped excerpts with similar codes and wrote a series of memos analyzing those responses during all phases of analyses to highlight key themes and relationships in the data, refine categories, and ensure a close association between participants' responses and emerging analyses. The research team met regularly to debrief, code interviews together, and reconcile all discrepant cases until agreement was reached. After distinct concepts and categories were identified, extracted, and agreed upon, focused coding was employed where thematic codes were systematically applied to all of the data.

## 3. Findings

The findings are organized to highlight themes that emerged from the data, illuminating the communication and social challenges that patients with SSD identified, regarding their social and medical network.

### 3.1. Family members are a critical component to the quality of health care during and after SSD diagnosis

#### 3.1.1. Patients increase their reliance on family members, which decreases their sense of autonomy

Participants emphasized that SSD affects all members of the family especially because patients with single sided deafness become more reliant on them. Samantha, who has been SSD for 5 years, P15, stated that she went from being able to do everything to being able to do nothing herself, which decreased her sense of autonomy ([Table 2](#), quotation 1). Many participants also expressed feelings of helplessness because they increased reliance on their partners or adult children to do everyday tasks for them like answering the phone or asking them to repeat what others have said. Florine, who has been SSD for 3 years, P10, said that she feels like a completely different person because she went from being someone who was so independent and proactive about doing everything herself to asking her husband and children to do things for her like ordering for her at restaurants ([Table 2](#), quotation 2).

#### 3.1.2. Communication quality changes with family members

A common challenge that patients with SSD identified was how much family dynamics change post diagnosis, consequently resulting in a myriad of emotions and negative experiences, such as denial, anger, isolation, and impatience. Participants emphasized how much their relationships changed with their significant other because of their SSD. Annette, who has been SSD for 10 years, P14, said that her SSD affects her partner equally because of the social isolation that they both experience. Because Annette's partner does not want to leave her alone, he also stays isolated ([Table 2](#), quotation 3). Participants also emphasized the increase in marital turbulence post diagnosis of SSD. Lily, who has been SSD for 7 years, P37, said SSD increases emotional and relational turbulence in marriages so much so that couples contemplate separation and divorce ([Table 2](#), quotation 4). In addition to challenges between significant others, many participants highlighted the issues they face with their children post diagnosis.

**Table 1**  
Sociodemographic information about participants.

Participant (n)	Sex of Participant	Cause for SSNHL/SSD	Age/Number of years with SSD	Aided Hearing Device	Residence Location
1	M	Vestibulocochlear nerve infarction	64/2	Cochlear Implant	Oregon, USA
2	F	Unknown	58/1	None	Massachusetts, USA
3	M	Acoustic Neuroma	56/12	None	Oregon, USA
4	F	Unknown	21/10	None	Oregon, USA
5	M	Unknown	53/13	BAHA and then Cochlear Implant	New York, USA
6	F	Unknown	58/17	BAHA	Wisconsin, USA
7	M	Acoustic Neuroma	54/3	CROS hearing aid	Washington, USA
8	F	Acoustic Neuroma	43/22	BAHA	Wisconsin, USA
9	M	Unknown	55/20	CROS hearing aid	UK
10	F	Acoustic Neuroma	51/3	BAHA	New Jersey, USA
11	M	Unknown	65/59	None	Oregon, USA
12	F	Unknown	58/38	CROS hearing aid	Oklahoma, USA
13	F	Bacterial Meningitis	47/7	CROS hearing aid	Pennsylvania, USA
14	F	Unknown	38/10	CROS hearing aid	Illinois, USA
15	F	Unknown	59/5	BAHA	Michigan, USA
16	M	Acoustic Neuroma	59/23	Ponto bone anchored hearing system	Pennsylvania, USA
17	F	Unknown	56/2	Cochlear Implant	Berlin, Germany
18	F	Unknown	55/5	BAHA	Florida, USA
19	M	Acoustic Neuroma	36/7	Phonak CROS hearing aid	Arkansas, USA
20	F	Unknown	49/1	BAHA	Illinois, USA
21	F	Acoustic Neuroma	69/11	BAHA	Washington, USA
22	F	Unknown	34/1	CROS hearing aid	Australia
23	F	Unknown	42/3	CROS hearing aid	Kentucky, USA
24	F	Ramsay-Hunt Syndrome	66/5	BAHA	Washington, USA
25	M	Unknown	46/1	BAHA	New York, USA
26	F	Unknown	22/5	BAHA	Florida, USA
27	M	Unknown	64/30	CROS hearing aid	New York, USA
28	F	Unknown	33/7	None	Colorado, USA
29	M	Unknown	30/8	None	Kentucky, USA
30	F	Unknown	54/30	None	Maryland, USA
31	M	Unknown	55/15	None	New York, USA
32	F	Unknown	56/3	Cochlear Implant	Basel, Switzerland
33	F	Mumps (assumption)	36/27	None	Birmingham, United Kingdom
34	M	Unknown	42/21	None	Akureyri, Iceland
35	F	Unknown	28/2	None	London, United Kingdom
36	M	Unknown	35/1	None	Cowdon, United Kingdom
37	F	Unknown	29/7	CROS hearing aid	London, United Kingdom
38	F	Flu (assumption and self diagnosed)	22/4	None	Nuevo Leon, Mexico
39	F	Acoustic neuroma tumor	18/11	CROS hearing aid	Michigan, USA
40	F	Unknown	50/15	None	Wuppertal, Germany
41	M	Unknown	35/20	None	Arizona, USA
42	F	Mumps	40/29	None	Arizona, USA
43	F	Unknown	38/7	CROS hearing aid	Oregon, USA
44	F	Head injury	20/6	None	California, USA
45	F	Unknown	62/8	None	Texas, USA
46	F	Unknown	33/6	CROS hearing aid	Alabama, USA
47	F	Unknown	30/3	None	California, USA
48	F	Unknown	42/15	Cochlear implant	Stuttgart, Germany
49	F	Unknown	36/1	None	Sainsbury, United Kingdom
50	M	Head trauma	44/22	CROS hearing aid	Gyomro, Hungary
51	F	Acoustic Neuroma	50/15	None	California, USA
52	F	Unknown	28/7	Cochlear implant	North Carolina, USA

Participants reported that their children oftentimes felt anger and annoyance because they felt like they were not being heard or because they would have to repeat themselves multiple times. Paula, who has been SSD for 15 years, P51, said that her daughter was quicker to anger because of the change in communication quality. Her daughter would oftentimes yell at her and would get frustrated because Paula could not hear her the first time (Table 2, quotation 5).

### 3.1.3. Information discrepancy and family members' emotional reactions

Several participants discussed how family members, including spouses, parents, adult children, and teenage children made the

copying process more or less difficult after SSD diagnosis, depending on the level of knowledge that the family members had about SSD. The discrepancy in levels of knowledge caused partners of patients with SSD to experience frustration and impatience, and children of patients with SSD to feel uncertainty and anger. Tabetha, who has been SSD for 17 years, P6, expressed that her family members do not understand SSD and they never had experience with anyone who had hearing loss so it is difficult for them to have empathy and understand what it is like being SSD (Table 2, quotation 6). Many participants emphasized the strong emotional reactions that their family members had and patients assumed a lot of it came from their lack of knowledge about SSD. Max, who has been SSD for 22 years, P50, elaborated on all the emotional backlash he got from his

**Table 2**

Communication and social challenges that individuals with SSD face regarding their social and medical network post diagnosis: Categories, sub-themes, and demonstrative quotes.

Category / subtheme For overall sample; N = 52	Demonstrative Quotes
<p><b>Family members are a critical component to the quality of health care during and after SSD diagnosis</b>  <i>Patients increase their reliance on family members, which decreases their sense of autonomy</i>  <i>Communication quality changes with family members</i>  <i>Information discrepancy and family members emotional reactions</i></p>	<ol style="list-style-type: none"> <li>1. "So, I think they don't understand. It impacts the whole family and I think the family needs some education. Especially with a sudden loss because you go from being perfectly capable of doing everything to hardly being able to do anything. So, just to involve the whole family in the treatment and not just the patient . . . I also think these programs would be better if they used layman's terms so they really understand what I'm going through and how bad it is. It's not the same when doctors talk to family members themselves and just explain things about my SSD with fancy medical words. It would be helpful for everyone involved if families were educated formally because it really does affect family structure and dynamics when you have sudden hearing loss and that kind of stuff. (P15)</li> <li>2. "I feel like a totally different person since I have been diagnosed with SSD. My whole life I was so independent and I never asked for help. I was really depressed after I lost my hearing in my left ear because I had to rely on and ask my family to do everything for me. It's gotten better but I still have to ask them to repeat things that other people have said or order for me at restaurants. Even basic house things like picking up the phone? I have to ask them to do that. I feel helpless and not helpful around the house. I'm still getting used to it. I've gone almost 45+ years without asking for much help with anything and now I'm always calling on my husband and children." (P10)</li> <li>3. "Family counseling to help reduce the amount of frustration that happens in the family would have been so helpful. Hearing loss impacts family dynamics drastically and sometimes affects the partner just as equally as the person who has it because of the social isolation. The partner doesn't want to abandon their spouse so they stay isolated too. And it impacts both of their lives." (P14)</li> <li>4. "I am so grateful that my marriage is a blessing to me because I hear stories about marriages that are in turmoil after someone experiences sudden hearing loss. They're always threatening divorce and there's all this and it's like they need help. Options should be given to families for counseling and have other people, not the patient, as "ok do you need to speak to someone too?" or because it's going to be emotional, you may also go through some emotional turbulence so we are offering counseling to you, to you and your partner, etc. This would be a big help for married couples where one person is diagnosed with single sided deafness." (P37)</li> <li>5. "It goes beyond the person who is actually going through losing hearing. It would have been helpful if there was family counseling, especially for my kids. I have teenagers and I feel like they sometimes, well actually my daughter especially she feels . . . angry, I suppose . . . when she's talking to me she has a tendency to look at me and yell do you have your hearing aids in? I can't tell if it's just her being a teenager or if she is actually angry and annoyed with my single sided deafness. Perhaps it's both, but either way I think especially for my daughter it would have been helpful to get family therapy after I was diagnosed." (P51)</li> <li>6. "I think the thing I would have liked most after I found out I was single-sided deaf is if there had been some class or program for the whole family. The family still doesn't really understand. I'm getting better at trying to explain it now, but they haven't had experience with anybody with hearing loss, so they don't really get it. It would have been less taxing on me if they learned about my single-sided deafness from a professional or if there was some type of family therapist that could have walked them through ways to help me or help themselves" (P6)</li> <li>7. "First I thought it would just be my wife, but then it was my children too. My wife was so angry and sad at the same time because our conversations would last a long time when I had a hard time hearing her. Sometimes she would just give up and we would end conversations early. It helped when I learned how to position myself better. My children would be embarrassed of me. The older they get I think they get less embarrassed but in public they would get frustrated. They all never knew anyone who could not hear well before me so they don't have that empathy for me. When sometimes I think it is getting better, but I still feel all their intense feelings towards me. It is all sad to me." (P50)</li> <li>8. "The first person I went to was just an audiologist where they did a hearing test on me. They determined that I had sensorineural hearing loss. So the next person I went to go see was an ENT who had studied with my brother. I knew him, I trusted him. He had his audiologist in the office also take a look at me. Anyway long story short I saw different ENTs and different audiologists just to see if anyone could pinpoint why this was happening to me. I even saw a neurologist, one that specifically studies the ear and the nerves of the ear and has a little bit more experience with it. I went all over the place and I was hearing all different things. I wish that there was just one team where everyone had a different role and function. I wish there was a team where the ENT, the audiologist, the neurologist, the therapist even, all knew each other and talked with one another so there was no conflict. I think seeing so many different people caused even more anxiety for me." (P43)</li> <li>9. "Specialists that have to do with the ear should all work together. For example, therapists, psychologists, people who would help you more socially and emotionally with people who help you physically like your ENT and neurosurgeon. I made an appointment at the tinnitus center in Berlin today to get some psychological help and I had to call 10 to 15 different phone numbers to also get help with my actual hearing and emotional help. It would have been time efficient if they just knew who I should or could contact." (P17)</li> <li>10. "I was really lucky that I was already part of a support group online. Towards the beginning, right after I knew I had single-sided deafness, I was having a lot of issues with it and the healing process and all that. So I was messaging with, I guess the creator of one of the groups. And she was really, really very helpful and she gave me a lot of advice on what she did with her daughter and just kind of guided me through the first few days after the procedure. If they had an official guider or some sorts to help me during and after the procedure where I experienced SSD that would have been great. Almost like I was the blind sheep and someone would have the job of a shepherd leading me until I could get the hang of surviving on my own. The shepherd or whatever that role would be called would not just help with functional things like teaching me to sit on one side of the room or how to get by but also with the emotional rollercoaster I might go through." (P18)</li> <li>11. "And if there could be a way to somehow give people the guidance initially when this happened to them, "okay, there's these things that are gonna happen to you, this is what you need to do, you know, these are the steps to take. There's these options if you're faced with this, with your spouse or if you're emotionally this way, this is options for you." There needs to be some way to..like lead someone to where they need to get to be okay with this whole thing." (P20)</li> </ol>
<p><b>Disparate, disconnected, and hard to reach medical professionals</b>  <i>Patients with SSD interact with multiple medical professionals</i>  <i>Patient's lack of knowledge in what to anticipate post diagnosis</i></p>	

wife but also his children. He attributed the anger, sadness, embarrassment, confusion, and frustration to how much they do not know about SSD and the lack of empathy they had for him because of their lack of knowledge (Table 2, quotation 7).

### 3.2. *Disparate, disconnected, and hard to reach medical professionals*

#### 3.2.1. *Patients with SSD interact with multiple medical professionals*

Many participants expressed their anxiety and frustration from having to consult different kinds of specialists at various medical practices. Patients reported that their dissatisfaction with their health care providers oftentimes stemmed from conflicting diagnoses, treatments, and constant referrals. Carla, who has been SSD for 7 years, P43, expressed her frustration with seeing several specialists and how the process caused her anxiety because of their conflicting views (Table 2, quotation 8).

Participants also expressed the overemphasis on the physiological aspects of being diagnosed with SSD over the emotional components of coping with the diagnosis. Patients with SSD expressed a need for social, emotional, and psychological help. For example, Sasha, who has been SSD for 2 years, P17, expressed her frustration about having to reach out to so many health professionals before having access to psychological help, specifically related to her hearing loss. She expressed the myriad of emotions she experienced post diagnosis and the need for a therapist but the difficulty of getting access to one (Table 2, quotation 9).

#### 3.2.2. *Patient's lack of knowledge in what to anticipate post diagnosis*

Participants discussed how they felt a lack of guidance and advice post diagnosis of SSD. They did not know what to anticipate after certain procedures related to their SSD or how to cope emotionally after being diagnosed with SSD. Karen, who has been SSD for 5 years, P18, expressed that she needed functional advice on things like where to sit in a room to maximize hearing but also emotional guidance on how to cope with new experiences post diagnosis. She emphasized the different kinds of hardships post diagnosis that she was unable to anticipate (Table 2, quotation 10). Other participants stated that the challenge they faced post diagnosis was not knowing what to anticipate might happen after every step in the coping process. For example, Rita, who has been SSD for 1 year, said she did not know what steps to take after certain procedures or what options she may or may not have related to her SSD diagnosis or what kinds of emotions she may experience (Table 2, quotation 11).

## 4. Discussion and conclusion

### 4.1. Discussion

This study provides new insights into the communication and social challenges that patients with SSD face post diagnosis, especially regarding their network of family members and health professionals. Patients with SSD emphasized how family members are a critical component to the quality of their care, during and after diagnosis. A challenge that patients with SSD point to is the increased reliance on family members. Another challenge that participants also identified is adjusting to changes in communication quality that occur post diagnosis, which consequently alters the dynamics of the family unit. This type of impact on family members of someone with a newly diagnosed health condition is consistent with what is referred to as third party disability [16]. Third party disability research has found that patient- and family-centered care (PFCC) approaches can be effective as part of the treatment process post diagnosis [17–19]. While PFCC has been shown to help address the multidimensional components

associated with a diagnosis of full hearing loss; this study finds that the framework can also be applicable to SSD. This is important because some might assume that individuals with SSD do not need support because they still retain some hearing function, but this study found that individuals with SSD face many of the challenges (e.g., emotional, cognitive, interpersonal, behavioral, and physical) that do necessitate PFCC.

Individuals who have SSD experience negative emotions such as denial, anger, depression, isolation, resentment, and even feelings of jealousy that their hearing partners have a more favorable relationship with other hearing family members [12,20], to the extent that some patients with SSD describe their post diagnosis a mourning process [21]. Existing research shows that family therapy can help all members of the family with making sense of the impact of a health condition. In many chronic health contexts, families that participated in family focused treatment implemented effective communication and problem-solving skills as part of a collective coping process [22]. Tools like goal sharing for partners strategy (GPS) also provides a framework for families to set communication goals and to achieve them together [23]. The key question for family therapy is what types of customized behavioral and cognitive intervention strategies are given to family members based on the illness. Whereas existing research into functional family therapy has been mainly applied to contexts of mental health concerns, drug abuse, and other related family problems, these have to do with questions of addiction and how families may enable or accentuate the problem [24–26]. The SSD context is more about a sudden change in physiology, which results in family communication challenges that are unique to SSD. By identifying key barriers as part of third party disability dynamics combined with the negative emotions and experiences of the patient with SSD (i.e., when patients with SSD ask family members to repeat phrases repeatedly or when there is marital tension because of communication breakdowns, relationship tensions, and frustration [27]), this study sheds light on specific challenges that could inform a more systematic coping process like family therapy.

Participants discussed how the varying levels of knowledge about SSD across family members made the post-diagnosis transition stressful and frustrating. This discrepancy in knowledge may stem from different causes, one of which may be explained by the patient serving as the main message transmitter about their SSD. Oftentimes, patients who are diagnosed with a health condition are the ones that relay information to their family members, and because patients are emotionally charged when receiving such information, or because patients are hesitant and reluctant to talk to others about certain things they hear from their physicians, and patients skew or change information to be accommodating for their partner [20], information discrepancy occurs. Having family members involved in information acquisition at the time of diagnosis have been proven to be effective in increasing the quality of health care for patients in multiple chronic health condition contexts [28–31]. This study advances the need to apply family information acquisition at the time of diagnosis of SSD to alleviate negative emotions caused by knowledge discrepancy post diagnosis.

This study also found that participants experienced stress from seeking multiple health professionals, anxiety from different specialists with conflicting views, and frustration from information uncertainty. Participants also emphasized the importance of their socioemotional health after being diagnosed with SSD and discussed how therapists' roles on these medical teams could help familiarize them with the social and psychological impacts of SSD. Existing studies found that interdisciplinary health care teams, consisting of family caregivers and multiple health care specialists collaborating to develop holistic plans for a patient's needs, leads to increased health literacy, better patient-provider relationships,

increased psychosocial counseling, and increased communication frequency between family members, patients, and health care providers [32]. When multiple doctors collaborate on one case together, there is an improvement of the reliability of diagnosis, reduced numbers of mistakes, and increased education enrichment for the health professionals involved [33]. The findings regarding the negative emotions experienced by disconnected and disparate medical teams offer evidence that multifaceted and interconnected medical teams may advance the quality of health care for individuals with SSD.

Many participants expressed a common challenge post diagnosis of SSD to be uncertain of what to anticipate physically, emotionally, and socially. In certain health contexts, there have been efforts to implement patient navigation, which is the process of helping patients effectively and efficiently use the health care system (i.e., choosing, understanding, and using health coverage, health providers and services, treatment decisions, and managing multiple provider care) [34] to address and overcome barriers. The primary context in which patient navigator training programs have been evaluated is in cancer care [35,36], where the implementation of patient navigators has been proven to increase patient self-efficacy for engaging in recommended health behaviors and increasing perceived levels of social support [37,38]. The findings of this study demonstrate the need for patients' with SSD to have access to patient guides to give them advice during decision-making processes related to aided hearing interventions, emotional complexities patients may go through, and coping processes. Future studies could implement patient navigation programs to other chronic and long-lasting health conditions [39,40] to evaluate the effectiveness for health conditions like SSD; consequently, it could highlight how existing patient navigation programs could extend beyond preventative measures and overcoming functional barriers and extending it to other phases of a patient's health process.

Taken together, the findings from this study provide an important contribution to SSD literature by highlighting the rationale for a patient- and family-centered approach to health care in the SSD context, family information acquisition, and patient navigation systems. However, this study had a few limitations that need to be considered. Although many of the findings focused on family dynamics, this study only evaluated one family member's perspective. Future studies should focus on multiple family members and their perspectives with coping with SSD to provide a more holistic perspective. Additionally, this study primarily recruited from social support groups online, meaning that participants of this study were already actively seeking support. It is recommended that future studies should recruit participants from various sources to have a more diverse range of participants, including those who may not have much of a support network.

#### 4.2. Conclusion

A diagnosis of SSD is a life-changing event for individuals and families. Many studies have found that a SSD diagnosis leads to negative outcomes for patients, which makes it imperative to understand why that is and how we can prevent them. Beyond a strictly medical based explanation for these outcomes, this study finds that many of the key factors that contribute to these are communicative and social, whether it is family dynamic changes, anxiety about future medical issues, or uncertainty due to conflicting medical recommendations. By illuminating communicative and sociological factors that contribute to negative outcomes and building existing approaches to health care to identify what may help individuals with SSD in the post diagnosis phase of their health care, this study can benefit health providers by identifying gaps and implementing protocols to improve care

during and after a SSD diagnosis. By advancing our understanding of the patient's perspectives around SSD, we can facilitate improved education of SSD family members, help scholars, medical professionals, and policy makers working on SSD, and consequently help SSD impacted communities and future patients.

#### 4.3. Practical implications

This study has real-world practical implications for multiple industries and fields such as medicine, education, and communication. While medical diagnoses and counseling are often centered on the individual, this study found that a broader focus is necessary, based on first-hand SSD experiences. Because individuals with SSD diagnoses are likely to need support from multiple stakeholders including family members, it is recommended that diagnoses and counseling be directed toward family units, as opposed to just the patient. This could help prevent negative outcomes of SSD such as social isolation, stigma, and interpersonal conflict. Regarding medical teams, patients with SSD report being confused, anxious, and stressed by the wide range of specialists and medical professionals they encounter. Because SSD requires expertise from several areas (e.g., audiologists, ENTs, therapists, etc.), patients could work with integrated teams of experts that work collectively, as opposed to receiving individual expert knowledge that can be fragmented and potentially contradictory. Because the period of diagnosis is stressful, minimizing confusion in this period is especially important. As patients continue to live with SSD over time, they may experience negative health and emotional outcomes, which could be mitigated by patient navigators. Although some of these recommendations may require a broad reorganization of certain medical practices and processes, others are as simple as broadening the members who hear the initial diagnosis and offering counseling services. These recommendations have practical implications for improving our understanding of what patients with SSD want and for health professionals to offer better care to current and future populations impacted by SSD.

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#### Disclaimer

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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