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experiences of Deaf and hard-of-hearing individuals in Denmark

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Accessibility of medical and psychosocial services following disasters and other traumatic events: experiences of Deaf and hard-of-hearing individuals in Denmark

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ABSTRACT

Purpose: This descriptive study sought to explore barriers faced by Deaf and hard-of-hearing (D/HH) individuals in Denmark when accessing medical and psychosocial services following large-scale disasters and individual traumatic experiences.

Methods: Semi-structured interviews were conducted with nine D/HH individuals who had experienced at least one disaster or other traumatic event.

Results: Difficulties were encountered during interactions with first response and healthcare services, which centered on: (1) lack of Deaf awareness among professionals, (2) problems accessing interpreter services, (3) professionals relying on hearing relatives to disseminate information, and (4) professionals who were unwilling to adjust their speech or try different forms of communication. Barriers reported in relation to accessing psychosocial services included: (1) lack of all-Deaf or hard-of-hearing support groups, and (2) limited availability of crisis psychologists who are trained to service the needs of the hearing impaired. Suggestions for improvements to service provision were provided, including a list of practical recommendations for professionals.

Conclusions: This study has identified significant gaps in post-disaster service provision for D/HH individuals. Results can inform policy makers and other authorities in the position to enhance existing services and/or develop new services for this vulnerable target population.

IMPLICATIONS FOR REHABILITATION

- Being Deaf or hard-of-hearing compromises a person’s ability to obtain and share vital information during times of disaster.
- Medical and psychosocial services are expected to play critical response roles in times of disaster, and should be properly equipped to assist Deaf and hard-of-hearing (D/HH) individuals.
- In a relatively small sample, this study highlights barriers faced by D/HH individuals in Denmark when accessing first response, healthcare, and psychosocial services following large-scale disasters and individual traumatic events, all of which centered on communication problems and resulted in suboptimal care.
- Regarding rehabilitation after disasters, evidence-based information about how to service the heterogeneous communication needs of D/HH populations should be disseminated to professionals, and preferably incorporated into training programs.

Introduction

We are all vulnerable in times of disaster. Deaf and hard-of-hearing (D/HH) individuals are particularly vulnerable because of their inability/limited ability to hear sounds, which affects their capacity to obtain and share information.[1] As with all hearing individuals seeking post-disaster medical and psychosocial services, D/HH individuals also deserve access to these services. An important piece of legislation for D/HH individuals is the Convention on the Rights of Persons with Disabilities (CRPD), adopted by the General Assembly of the United Nations on 13 December 2006.[2] The CRPD provides the full range of rights for persons with disabilities, including during situations of armed conflict, humanitarian emergencies and natural disasters (Article 11). Denmark and many other European countries have signed and ratified the CRPD. In the context of post-disaster service provision, State Parties and public authorities have a responsibility to ensure that medical and psychosocial services are adapted to meet the specific needs of people with disabilities, including people who are D/HH.

Despite the CRPD, the needs of D/HH individuals are still often isolated from services across Europe. This is likely due to the lack of research evidence available informing services about what should be done for D/HH individuals in the event of large-scale, natural, or man-made disasters (e.g., earthquakes, terrorist attacks). Indeed, efforts to arrive at European standards for post-disaster psychosocial care have so far focused exclusively on individuals in the general population; see for example, European Guidelines for
Target Group-Oriented Psychosocial Aftercare [3,4] and European Guidelines for Target Group-Oriented Psychosocial Aftercare – Implementation.[5] D/HH individuals constitute a significant minority group in Denmark. It has been estimated that around 800,000 people have some form of hearing loss.[6] This number corresponds to 14.8% of the Danish population (5,397,640 people).[7] The preferred communication modalities of D/HH individuals vary greatly depending on degree of hearing loss and cultural orientation. Diverse communication modalities include Danish Sign Language (DSL), Sign Supported Communication, Cued Speech, hand alphabet (typically used to spell out names, places or other words that do not have a sign), lip-reading, as well as spoken and written Danish. A proportion of D/HH individuals choose to identify with the Deaf community; a cultural and linguistic minority group centered on the use of DSL. As with all sign languages, DSL differs fundamentally from the spoken language of the country to which it is affiliated. DSL is recognized as an independent language with its own grammar, syntax, and developmental history.[8] There are no precise figures regarding the number of D/HH individuals that constitute the Deaf community; however, the National Danish Deaf Association estimates that there are approximately 4,000 individuals in Denmark whose primary language is DSL.[8]

Consequent to Denmark ratifying the CRPD, the Danish Emergency Management Agency launched a text message warning service to assist D/HH individuals in the event of disasters.[9] Regarding the organization of local emergency responses to disasters and accidents, guidelines laid down by the Danish Emergency Service Act stipulate that local councils are responsible for providing reasonable assistance for personal injuries and property damage. This obligation also covers persons with disabilities.[9] To our knowledge, no research exists addressing whether emergency-related initiatives specific to responding to or promoting preparedness are effectively reaching D/HH populations in Denmark. However, we did find relevant research conducted in the USA.

Ivey and colleagues assessed whether earlier national recommendations for vulnerable populations (including D/HH individuals) had been incorporated into state- and territorial-level emergency operation plans (EOPs) from 2010.[10] The EOP analysis (n = 55) revealed that while 55% mentioned vulnerable populations, an improvement since 2006, less attention was paid to individuals who are D/HH; only 31% of the EOPs specifically mentioned this group. Critical gaps have also been identified in D/HH emergency preparedness trainings provided by state- and territorial-level emergency management agencies [10,11] as well as deaf-serving community-based organizations (CBOs).[11]

Neuhauer and colleagues assessed the availability and readability of printed emergency preparedness materials (EPM) provided by CBOs to D/HH populations.[12] Results showed that less than half of the CBOs (n = 7) had EPM for their clients. All of the EPM (n = 5) tested above the recommended 4th-grade reading level for D/HH populations, even though CBOs are expected to be aware of the unique literacy and functional needs of their clients.[12] One study evaluated a cultural competency workshop for law enforcement personnel working with D/HH individuals during domestic violence emergencies.[13] Results showed improved post-training scores for knowledge of communicating with D/HH individuals and perceived self-efficacy about working with them, but not for knowledge about policy and the law. In sum, research from the USA highlights critical areas for improvement in relation to planning for and responding to the specific needs of D/HH populations in disasters and emergencies.

Disaster preparedness and response research should include the involvement of D/HH individuals who have experience with accessing affiliated services, as they can provide a unique perspective on what they need and want before, during, and after disasters that others cannot. A limited number of studies have examined the perspectives of D/HH individuals regarding the accessibility of services expected to play critical response roles in times of disaster; that is emergency response, healthcare, and psychosocial services.[14–19] All report a lack of Deaf awareness among professionals. “Deaf awareness” means having an understanding of: (a) the barriers faced by D/HH individuals when attempting to communicate with hearing individuals, and (b) the means by which these communication barriers can be overcome.[17]

Of investigations concerning general healthcare experiences of D/HH individuals, two were conducted in the USA [15,18] and one in Brazil.[16] One English study explored the barriers experienced by Deaf individuals when accessing primary healthcare and accident and emergency services.[17] The majority of these studies found that D/HH individuals faced communication barriers when attempting to retrieve information from healthcare staff either directly and/or through relatives/sign language interpreters.[16–18] The lack of availability of sign language interpreters to assist with communication is a severely limiting factor.[17,18] Furthermore, two studies [15,16] reported that inadequate communication can lead to dangerous misunderstandings about treatment.

Two American studies investigated the experiences of D/HH individuals with accessing psychosocial services.[14,19] Both report a lack of services targeted D/HH individuals resulting in difficulty finding clinicians/therapists who can meet their specific communication needs. It is often necessary for Deaf individuals to have a sign language interpreter to assist with communication with mental health professionals, yet they are rarely available.[14] In rural areas where there are even fewer interpreters, Deaf individuals often have to use the same interpreter for more than one venue (e.g., the mental health clinic and the classroom). This is problematic as Deaf individuals reported feeling uncomfortable sharing intimate trauma experiences with dual role interpreters.[19] Regarding peer-support groups, which are often used in mental health settings, all-Deaf support groups are difficult to find.[14]

To summarize, the above-mentioned studies bring attention to communication barriers faced by D/HH individuals when accessing medical and psychosocial services. In addition, most of the studies provide suggestions/recommendations for how services can be improved, but they are country specific. Therefore, findings from these studies are difficult to generalize to fit the experiences of D/HH individuals living in Denmark. In order to determine whether post-disaster medical and psychosocial services in Denmark are properly equipped to meet the needs of D/HH individuals, there is an urgent need for studies investigating the experiences of D/HH individuals with accessing these services.

This descriptive study is the first of its kind to be conducted in Denmark. It was part of a larger, 2-year project funded by the European Commission. The project entitled The European Network for Psychosocial Crisis Management – Assisting Disabled in Case of Disaster (EUNAD) focused on developing and implementing standardized EU human rights-related assistance programs for people with disabilities, among which D/HH individuals were included. The project represents a collaborative research effort between partners from Germany, the Czech Republic, Norway, and Denmark.

The goal of the present study was to gain insight (via semi-structured interviews) into barriers faced by D/HH individuals when accessing medical and psychosocial services (e.g., support...
groups, psychological crisis treatment) following large-scale, natural, or man-made disasters, and their suggestions for improving these services. Disasters are relatively uncommon in Denmark, hence recruiting D/HH individuals with disaster experience proved difficult. We therefore expanded our recruitment strategy to include D/HH individuals who had experienced other potentially traumatic events (e.g., serious accidents, interpersonal violence). The rationale behind this was that D/HH individuals’ experiences with accessing services in connection with other traumatic events can help highlight potential areas for improvements in service provision that are likely also to be relevant in times of disaster.

Our specific research questions were as follows:

1. What difficulties were encountered during interactions with first responders (e.g., paramedics, firefighters, and police) and healthcare professionals (e.g., hospital staff, general practitioners)?
2. Were barriers experienced when accessing psychosocial services (e.g., crisis psychologist, support groups)?
3. What future directions should be taken to better assist D/HH individuals in the event of disasters and other traumatic situations?

### Method

#### Participants

A total of nine D/HH individuals who had experienced at least one disaster or other traumatic event were selected to participate in this study. All were of Danish Nationality. The majority \( n = 7 \) were females. Participants’ ages ranged from 27 to 81 years. Six identified themselves as Deaf, and three as hard-of-hearing. Of the deaf participants, three were born deaf and reported DSL as being their primary language (referred to as Deaf DSL participants for the remainder of the article). The remaining deaf participants referred to themselves as “late-deafened” and used speech (Danish language) as their principle method of communication (Deaf Speech participants). The hard-of-hearing participants experienced hearing loss either in childhood or later in life, and used speech as their principle form of communication (Hearing Speech participants). An overview of the study participants is presented in Table 1.

Authors L.S. and T.J. recruited participants with the help of organizations that serve D/HH individuals. Collaboration with the National Danish Deaf Association was initiated at the start of the project. Both sign language and written announcements for participation in the project were posted on the Association’s website. In addition, an email asking for help with recruitment was sent to the local Deaf Union in Odense. The authors also participated in an interview with a journalist working for the National Danish Hearing Association. A subsequent article about the project was published in the December 2013 issue of the Association’s magazine.[20] Six of the participants responded to either the announcements or the article about the project. The remaining participants were recruited via the help of the local Deaf Union or through word-of-mouth.

#### Materials

A semi-structured interview guide was developed by authors L.S., T.J., and A.E. The first page featured a list of potentially traumatic events (Table 2). Participants were asked to select the event(s) they had experienced during their lives. Events could be selected according to direct (experiencing the event oneself) or indirect (witnessing or having a person close to oneself experience the event) exposure. The events list was compiled from relevant scientific research and clinical experience, variations of which have been used in previous studies investigating rates of trauma exposure in diverse samples of adolescents.[21–25]

This inquiry was followed by a series of open-ended interview questions. The questions were designed to:

- Reveal any difficulties encountered during interactions with first response and healthcare services, e.g., “what functioned well or poorly with regards to the communication between you and the professional(s)?”
- Ascertain whether barriers were experienced when accessing psychosocial services, e.g., “what functioned well or poorly in relation to you seeking psychological crisis treatment.”

### Table 1. Summary of characteristics of study participants \( n = 9 \).

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Sex</th>
<th>Age</th>
<th>Participants’ subjective descriptions of hearing impairment</th>
<th>Hearing apparatus</th>
<th>Principle method of communication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ana</td>
<td>F</td>
<td>20+</td>
<td>Born deaf, affiliated with the Deaf community</td>
<td>No</td>
<td>DSL</td>
</tr>
<tr>
<td>Jens</td>
<td>M</td>
<td>40+</td>
<td>Born deaf, affiliated with the Deaf community</td>
<td>Cochlear implant</td>
<td>DSL</td>
</tr>
<tr>
<td>Stine</td>
<td>F</td>
<td>60+</td>
<td>Hard-of-hearing due to aging; affiliated with the hearing community</td>
<td>Hearing aid</td>
<td>Danish language</td>
</tr>
<tr>
<td>Mathilde</td>
<td>F</td>
<td>80+</td>
<td>Hard-of-hearing due to aging; affiliated with hearing community</td>
<td>Hearing aid</td>
<td>Danish language</td>
</tr>
<tr>
<td>Kirsten</td>
<td>F</td>
<td>60+</td>
<td>Late deafened; affiliated with both the hearing community and deaf community</td>
<td>Cochlear implant</td>
<td>Danish language</td>
</tr>
<tr>
<td>Jakob</td>
<td>M</td>
<td>60+</td>
<td>Late deafened; affiliated with both the hearing community and Deaf community</td>
<td>Cochlear implant</td>
<td>Danish language</td>
</tr>
<tr>
<td>Pernille</td>
<td>F</td>
<td>40+</td>
<td>Late deafened; affiliated with both the hearing community and Deaf community</td>
<td>No</td>
<td>Danish language</td>
</tr>
<tr>
<td>Brit</td>
<td>F</td>
<td>50+</td>
<td>Hard-of-hearing since childhood; affiliated with hearing community</td>
<td>Hearing aid</td>
<td>Danish language</td>
</tr>
</tbody>
</table>

### Table 2. Potentially traumatic events and number of D/HH participants who experienced them.

<table>
<thead>
<tr>
<th>Type of event</th>
<th>Direct exposure</th>
<th>Indirect exposure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Traffic accident</td>
<td>4 (3)</td>
<td>1 (1)</td>
</tr>
<tr>
<td>Other serious accidents</td>
<td>2 (2)</td>
<td>1 (1)</td>
</tr>
<tr>
<td>Rape</td>
<td>1 (1)</td>
<td>–</td>
</tr>
<tr>
<td>Witnessed others being injured or killed</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Came close to being injured or killed</td>
<td>1 (1)</td>
<td>–</td>
</tr>
<tr>
<td>Threatened to be beaten</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Near drowning</td>
<td>2 (2)</td>
<td>–</td>
</tr>
<tr>
<td>Attempted suicide</td>
<td>1 (1)</td>
<td>–</td>
</tr>
<tr>
<td>Robbery/theft</td>
<td>1 (1)</td>
<td>–</td>
</tr>
<tr>
<td>Serious illness</td>
<td>2 (2)</td>
<td>1 (1)</td>
</tr>
<tr>
<td>Shooting, fighting</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Death of a family member</td>
<td>3 (2)</td>
<td>–</td>
</tr>
<tr>
<td>Divorce</td>
<td>1 (1)</td>
<td>–</td>
</tr>
<tr>
<td>Sexual abuse</td>
<td>1 (1)</td>
<td>–</td>
</tr>
<tr>
<td>Physical abuse</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Sexual abuse</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Neglect</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Humiliation and persecution by others (bullying)</td>
<td>3 (3)</td>
<td>–</td>
</tr>
<tr>
<td>Other (please state)</td>
<td>2 (hurricane)</td>
<td>1 (explosion)</td>
</tr>
</tbody>
</table>
• Ask for participants’ recommendations as to what future directions should be taken to assist D/HH individuals in the event of disasters and other traumatic events e.g., “if you were to recommend anything in relation to how the professional(s) could have assisted you better, what would it be?”

Due to the low number of participants who reported having experienced a disaster, hypothetical questions regarding recommendations for professionals in the event of a disaster were also asked, e.g., “imagine that you were to experience a disaster where your life was in danger and you needed the assistance of first response services, what type of technical assistance would be useful?”

**Procedures**

Data collection took place between May 2013 and July 2014. The authors followed the Nordic ethical guidelines for psychologists. Prior to the interviews, participants were informed about the study objectives as well as issues of anonymity and confidentiality. They were also informed about their right to drop-out of the study at any time. All participants provided written consent to participate in the study.

The interviews were conducted by authors L.S. and T.J. Two of the participants were interviewed at the same time. The rest were interviewed on a one-to-one basis. Interviews lasted approximately 1–2 h. Sign language interpreters were hired to assist with communication during interviews that were conducted with Deaf DSL participants. The majority of the interviews took place at the University where this study is affiliated or in participants’ homes. One interview took place at the National Danish Deaf Association, Copenhagen. Participants were reimbursed for travel expenses. All interviews were recorded on tape. The interviews were subsequently transcribed by author L.S. Authors L.S., T.J., and A.E. formed the data analysis team. They each reviewed the transcripts several times and identified key reoccurring themes associated with each category of research question. The authors discussed the themes during face-to-face meetings. Disagreements about themes were deliberated until consensus was reached.

**Results**

The main themes emerging from the analysis are presented in this section.

**Category 1: difficulties encountered during interactions with first response and healthcare services**

Difficulties centered on four major themes:
1. Lack of Deaf awareness among first responders and/or healthcare professionals.
2. Problems gaining access to interpreter services at the hospital.
3. Healthcare professionals who relied on family members to disseminate information to D/HH patients.
4. Healthcare professionals who were unwilling to adjust their speech or try different forms of communication.

One of the major complaints that all participants had about first response and/or healthcare professionals was a lack of Deaf awareness (Theme 1). Professionals lacked experience in dealing with D/HH individuals and were consequently unprepared to meet their heterogeneous communication needs.

They [the paramedics] didn’t have much experience in dealing with deaf people. They were very unsure. It has to do with ignorance of course. (Jens, Deaf DSL participant)

One participant (Jakob) expressed concerns regarding the unpreparedness of the whole healthcare system.

The whole healthcare system is not prepared to meet the needs of the hearing impaired. Children who are born deaf today are offered a CI operation, and the system thinks that there are no more hearing impaired people left. The fewer deaf and hard-of-hearing people there are, the less attractive it becomes to develop a system that can be used. (Jakob, Deaf Speech participant)

In Denmark, hospitals are required to provide interpreter services for D/HH patients. Furthermore, the hospital has to pay. Despite this, all of the Deaf DSL participants reported experiencing problems gaining access to a sign language interpreter at the hospital (Theme 2).

One participant (Ana) reported being refused a sign language interpreter on several different occasions at the emergency room due to disputes about who should pay. She had to insist on getting one. Despite sending a letter of complaint to senior management and helping them compile a list of qualified sign language interpreters, she still experienced delays in getting an interpreter on subsequent occasions. This resulted in conversations with the doctor being postponed. There were times when hospital personnel didn’t book her an interpreter altogether, thinking they could make do with writing short messages.

Having to insist on getting a sign language interpreter creates extra stress for D/HH individuals who are already in a crisis situation.

It was an added stress for me. The situation was serious enough already. I had absolutely no resources left. It ought to be easy to get a sign language interpreter. (Stine, Deaf DSL participant)

Gaining access to interpreter services at the hospital becomes even more challenging when D/HH individuals are relatives of a patient and not the patient themselves. In this case, the hospital is not required to pay for an interpreter. It is up to the D/HH individual to find funding. One Deaf DSL participant (Ana) spoke of a family member who was admitted to hospital following a serious accident. She could no longer sign with her family member because he had become brain damaged and blind. The following excerpt illustrates the many difficulties she went through trying to obtain funding for an interpreter.

I complained to the National Interpreter’s Authority, the Appeals Board, and the Ministry of Social Affairs, but was rejected. It was very frustrating. I applied for an extra expense allowance through the municipality, but was rejected. I even complained to the Parliamentary Ombudsman and got rejected. I ended up borrowing an iPad from the municipality. It has a program that translates text to speech and vice versa. There are times when my family member gets very confused and asks “why are you silent all of a sudden?” I try to explain to him that I am not being quiet but trying to write things down. He has difficulty understanding that. (Ana, Deaf DSL participant)

The issue of healthcare professionals relying on hearing relatives to disseminate information to D/HH patients was brought up by the majority of D/HH participants whose principle method of communication was speech (Theme 3). One Deaf Speech participant (Jakob) described an incident involving a family member who had been in an accident and needed an operation to get her CI re-attached. After the operation, the family member returned to the ward with the sound switched off on her CI.

The only way we could communicate together was if I looked directly at her so she could lip read. A nurse came in and stood behind her, rusting her pillow and talking. If I hadn’t been there, then she [the family member] wouldn’t have gotten any of the information. I said to the nurse “you need to face her so she can see your mouth.” The nurse wasn’t particularly understanding about it, and this was in the department where they perform CI operations?!? (Jakob, Deaf Speech participant)
Having to rely on relatives to receive information can exacerbate feelings of dependency among D/HH individuals.

I got really angry because I want us hearing impaired to be able to fend for ourselves. I take pride in being able to fend for myself without having to ask for help. (Kirsten, Deaf Speech participant)

It is inappropriate for health professionals to rely on relatives to disseminate information to D/HH patients as there is a chance they may leave out important details without realizing. Furthermore, it is unreasonable to burden relatives with this extra responsibility, especially in emotionally laden situations.

When hospital personnel depend on hearing relatives to disseminate information to D/HH patients, additional problems arise when these relatives are not available to assist with communication. Hospital personnel do not have a back-up plan to deal with such situations, and due to busy work schedules, they are often unwilling to adjust their speech or try different forms of communication (Theme 4). Again, the majority of D/HH participants whose principle method of communication was speech reported experiencing this problem themselves or knowing someone else who had.

I couldn’t hear what he [specialist doctor] was saying at all. I told him but he maintained his original tone. I was pushed out of the door very quickly. He could have spoken louder. He could have looked at me. He could have spoken more slowly. (Sophie, HH Speech participant)

A nurse came into my room and started saying a whole lot even though she knew I had no sound on my CI. I said to her “it doesn’t help you saying a whole lot of things to me. Write it down!” She continued [talking] anyway. Finally she went to get some paper. I wonder why they [hospital personnel] can’t figure out how to communicate in other ways. I’m thinking that they could make use of technical aids. (Kirsten, Deaf Speech participant)

Thus, D/HH individuals risk not receiving the information they need when hearing relatives are unavailable to assist with communication. This can have serious consequences, as illustrated by the following citation.

Someone I know got hit by a car. His hearing aid was destroyed. They [hospital personnel] didn’t communicate with him at all. They did some things, such as putting a catheter in without letting him know. They neglected to inform him about what they were going to do before they did it. It was deeply traumatic for him. (Sophie, HH Speech participant)

Barriers to accessing psychosocial services

Two major themes arose from D/HH participants’ accounts of barriers experienced when accessing psychosocial services.

1. Lack of all-Deaf or hard-of-hearing support groups for trauma victims and their relatives.
2. Limited availability of crisis psychologists who are trained to service the needs of D/HH populations.

In Denmark, there are no all-Deaf or hard-of-hearing support groups for trauma victims and their relatives (Theme 1). D/HH individuals have to settle for trying to find a hearing support group. One participant reported being rejected by a hearing support group.

I wanted to join a support group for relatives of people with brain damage. But they [the group] rejected me because of difficulties related to sign language interpretation. (Ana, Deaf DSL participant)

Concerns were expressed regarding the limited availability of crisis psychologists who are trained to service the specific needs of D/HH populations (Theme 2). Deaf DSL participants reported preferring to work with a crisis psychologist who is proficient in DSL. However, when seeking a crisis psychologist, the reality for D/HH individuals who rely on DSL to communicate is that they often end up having to choose a hearing crisis psychologist who understands trauma but cannot sign. As illustrated by the following citation:

At first, I wanted to choose one [a psychologist] who had experience working with deaf people, so I wouldn’t have to explain that I was deaf and all the things connected with that. But I couldn’t find one who was trained in sign language and who had the right [trauma] specialty. I had to prioritize and ended up choosing the one who had the right specialty because this was the primary reason of me going to see a psychologist. (Ana, Deaf DSL participant)

Interestingly, D/HH individuals do not necessarily want to work with a deaf psychologist due to issues of trust and confidentiality.

In principle everybody [in the Deaf community] knows everybody. There would be a chance of meeting one’s psychologist at a party. I know that they [psychologists] have a duty of confidentiality, but it is wrong. It is better to go to a hearing psychologist who is more neutral. (Stine, Deaf DSL participant)

For some D/HH individuals, the use of interpreter services is often a necessity during sessions with a hearing crisis psychologist. Fortunately, the National Interpreter’s Authority has a budget for psychological crisis treatment, and there is no limit to the number of interpreting hours a D/HH person can get. The responsibility of booking the interpreter lies with the D/HH individual, not the psychologist.

Using an interpreter for psychological crisis treatment can, however, cause some challenges. One Deaf DSL participant (Jens) described working with an interpreter as a strange experience because it disrupted the flow in conversation and his ability to communicate directly with the psychologist. Other problems reported by participants included “lack of chemistry” with the interpreter and “fear of being misinterpreted.”

The chemistry between us was poor. It is important for me to work with an interpreter whom I have good chemistry with so I can feel comfortable. I don’t want to have to repeat myself and I don’t want to feel misunderstood. But this interpreter interrupted me all the time because she didn’t understand me. (Stine, Deaf DSL participant)

In Denmark, the likelihood of a D/HH person having to use the same interpreter for more than one venue is high. This can be problematic.

I didn’t want to use an interpreter from the center where I usually book one from because I use that center in connection with my work. I wanted to keep things separate. I know that interpreters have a duty of confidentiality, but it would always be in the back of my mind – that they [the interpreters] would know something about me. (Ana, Deaf DSL participant)

For psychological sessions to function properly with an interpreter, certain practicalities need to be in place.

The psychologist was really talented. The sign language interpreter ensured that the conversation flowed throughout. It meant a lot to me that I had the same interpreter with me for all my sessions [with the psychologist]. It made me feel secure. The interpreter knew my background and language code. We could read and understand each other and we didn’t need to start from scratch each time. (Stine, Deaf DSL participant)

D/HH participants whose principle method of communication was speech reported preferring to work with a hearing crisis psychologist who has knowledge of deafness/hearing loss. Of those who reported having been to see a crisis psychologist, one HH Speech participant (Berit) described not having experienced any communication problems since the psychologist had made sure to sit directly opposite her when talking. Another HH Speech participant (Sophie) expressed dissatisfaction with her psychologist because he had sat away from the light resulting in her having to use all her energy on trying to hear what he was saying.
Future directions

Participants provided extensive suggestions for improvements to service provision for D/HH individuals who are victims of disasters and other traumatic events. They would like to see more sign language interpreters be made available, so that D/HH individuals will have a better chance of getting one at the scene of an emergency as well as in crisis situations at the hospital. Some participants felt it was important that funding be made available to finance sign language interpreters for D/HH individuals who are relatives of hospital patients. Regarding psychosocial services, participants would like to see them expanded to include all Deaf/ hard-of-hearing support groups for trauma victims and their relatives as well as more crisis psychologists who are trained to service the specific needs of D/HH populations.

In considering the different types of professionals (first responders, healthcare professionals in hospital settings, crisis psychologists) who are likely to encounter victims of disasters and other traumatic events, participants felt it was important that they acquire knowledge about the varying communication needs of D/HH individuals. They would like for guidelines about how to service the needs of D/HH individuals to be incorporated into the training of first responders and for brochures on deafness and hearing loss to be distributed to different workplaces (e.g., hospitals, doctor’s surgeries, psychology clinics). Finally, participants offered a number of practical recommendations for first responders, healthcare professionals (hospital settings), and crisis psychologists (Table 3).

Discussion

This is the first study to investigate barriers faced by D/HH individuals in Denmark when accessing medical and psychosocial services following disasters and individual traumatic experiences. The use of semi-structured interviews enabled us to gain an in-depth understanding of participants’ experiences. Regarding difficulties encountered during interactions with first response and healthcare services, all of our participants expressed concerns about the problem of first responders and/or healthcare professionals lacking Deaf awareness. This finding is consistent with those of previous international studies investigating D/HH individuals’ experiences with accessing accident and emergency and/or healthcare services.[15–18] The consensus among our participants was that professional(s) had limited or no contact with D/HH individuals in connection with their work, and, therefore, lacked the necessary knowledge about how to communicate with them. This finding implies that local-level professionals in Denmark are not receiving adequate response training specific to D/HH populations, which is in accordance with the findings of Engelman and colleagues who reported gaps in training within local-level deaf-serving CBOS.[11]

An issue brought up by our Deaf DSL participants was problems gaining access to interpreter services at the hospital. They would prefer to have unlimited access to professional sign language interpreters in healthcare contexts. However, interpreters were frequently not provided to them at the hospital. Similar findings have been reported in several international studies.[17,18,26] Our participants explained that reasons for why hospitals failed to provide them with an interpreter most often centered on disputes over who should pay. Funding issues are also frequently cited in the international literature as being the reason why healthcare professionals neglect to provide interpreter services.[15,17,18]

Our finding suggests a possible lack of knowledge among healthcare professionals regarding the Danish Health Act, which states that public hospitals are required by law to pay for interpreter services for D/HH patients. Similarly, Engelman and Deardorff found that most law enforcement personnel who completed a cultural training workshop were unable to answer a question regarding their departmental policy on communicating with deaf people.[13] This may indicate that general legal requirements for D/HH clients should be targeted more thoroughly in training programs. The Danish Health Act does not, however, stipulate
that D/HH individuals who are relatives of hospital patients are entitled to interpreter funding. In such instances, D/HH individuals have to find funding themselves. This can be an extremely difficult, time-consuming and frustrating process, which often leads to no results. We found no other studies that have examined this issue.

An issue brought up by a number of our D/HH participants who relied on speech to communicate was the problem of health professionals relying on hearing relatives to disseminate information to D/HH patients. This problem is reported in the international literature.[15-18] There are a number of negative consequences associated with healthcare professionals relying on hearing relatives to disseminate information. Our participants conveyed that it exacerbates their feelings of dependency, and that it is unreasonable for health professionals to expect relatives to take on this responsibility. Moreover, they felt that their relatives sometimes unintentionally failed to tell them all the necessary healthcare information. Similarly, Reeves and colleagues found that when asked how much of the communication at a GP consultation had been passed on, only 42% of deaf participants who had gone to see the GP with a hearing companion answered that everything or most of what was said had been passed on.[17]

The problem of D/HH individuals receiving less complete and accurate healthcare information is reported in other international studies.[15,18,27,28] Other negative consequences include “feeling excluded from the healthcare conversation”[18] and “compromised privacy”[18,27,28]

Healthcare professionals should make use of other modes of communication to maximize communication with D/HH patients. However, the majority of our D/HH participants whose principle method of communication was speech reported encountering healthcare professionals who were “unwilling to adjust their speech or try other forms of communication” when hearing relatives were unavailable. This problem was also reported by lezzoni and colleagues who found that physicians were unwilling to speak more slowly even to facilitate communication with hard-of-hearing patients.[15] Technological progress has the potential to significantly improve communication between healthcare professionals and all types of D/HH patients. Such are Apps for mobile phones or iPads/tablets that translate speech to text (and vice versa) and Video Communication Apps that allow for remote video sign language interpretation, as reported by our participants.

Our Deaf DSL participants expressed a desire to receive support from other D/HH individuals who have been through similar events. However, there are no all-Deaf or hard-of-hearing support groups for either victims of traumatic events or their relatives, and D/HH individuals have to settle for hearing support groups. Cabral et al. reported mixed opinions from D/HH mental health consumers regarding all-Deaf peer support groups.[14] Whereas some preferred to receive peer support in a group of people with the same cultural background, others were concerned about speaking about their mental health condition for fear of sensitive information being shared with others in the small D/HH community. In any case, the study revealed that there are a limited number of all-Deaf peer support groups targeted mental health consumers.

Regarding psychological crisis treatment, the preference of our D/HH participants who relied on speech to communicate, is to work with a hearing crisis psychologist who has knowledge about deafness/hearing loss. Our Deaf DSL participants reported preferring to work with a hearing crisis psychologist who is trained in DSL. They did not want to work with a Deaf psychologist because of issues of trust and confidentiality within the Deaf community. Cabral et al. have reported similar findings.[14] However, the problem remains that there are not enough hearing crisis psychologists who are trained to service the needs of the hearing impaired. This problem is not specific to Denmark. Indeed, Cabral et al. and Tate report on the lack of qualified mental health service providers who are proficient in American Sign Language.[14,19]

In the study by Tate, Deaf sign language users reported that, even when they did manage to find a service provider who could sign the quality of the service provided did not always match their therapeutic needs.[19] In such instances, they often settled for suboptimal care because they considered themselves lucky simply to find a service provider who could sign. One of our Deaf DSL participants reported experiencing a similar dilemma; that is, choosing between seeing a (hearing) psychologist who understands trauma but cannot sign and one who has experience working with D/HH individuals but does not specialize in trauma. She ended up choosing a hearing crisis psychologist and using an interpreter to assist with communication.

In the study by Cabral et al., D/HH participants reported being told that there was no funding available for an interpreter or being refused an interpreter.[14] D/HH individuals in Denmark are a little more fortunate in this regard given that the National Interpreter’s Authority has a special budget for psychological crisis treatment. However, even with an interpreter, communicating about trauma experiences can sometimes be challenging. Some of our Deaf DSL participants felt that the interpreter disrupted the flow in conversation and misinterpreted what was being said. Similar findings are reported by Cabral et al. [14] and Tate.[19] Given that Denmark is small and has a limited number of sign language interpreters, it is often the case that D/HH individuals have to use the same interpreter for more than one venue (e.g., sessions with the crisis psychologist and meetings at the municipality). This can be problematic due to issues of confidentiality. The study by Tate also reports on this issue.[19]

Overall, the present study illustrates significant gaps in the provision of medical and psychosocial services for D/HH individuals following disasters and individual traumatic experiences. The difficulties reported by participants when accessing services are all centered on communication barriers. When communication barriers are present it is highly likely that D/HH individuals won’t receive all the information they require. Recent research suggests that information deprivation has the potential to detrimentally impact D/HH individuals with trauma experiences. Schild and Dalenberg found that, in addition to experiencing the full range of trauma symptoms that hearing individuals do, some D/HH individuals may experience a unique type of trauma altogether – Information Deprivation Trauma; defined as an event that is experienced as traumatic or more traumatic because information or knowledge about the event is limited or unavailable.[29]

There are certain things that can be done to limit information deprivation and other problematic outcomes for D/HH individuals. Our participants provided us with extensive suggestions for improvements to service provision, including a list of practical recommendations for first responders, healthcare professionals (hospital settings), and crisis psychologists (Table 3). Ensuring equal access to medical and psychosocial services for D/HH individuals following disasters and other traumatic events is an issue that urgently needs to be addressed in Denmark. Our findings can inform policy makers and others authorities in the position to enhance existing services and/or develop new services.

The limitations of the present study are acknowledged. The reliance of this study on convenience sampling and its small sample size restrict the generalizability of the findings. In addition, our study sample consisted of D/HH individuals whose principle method of communication was either DSL or speech, and they all
had good Danish literacy skills. However, only a limited number of D/HH individuals know DSL and many have lower than average Danish language skills. There are also D/HH individuals who have the added burden of being part of an ethnic minority. It is possible that the experiences reported by our participants present a more positive depiction of service provision following disasters and other traumatic events than those of the target population at large. While some of our recommendations may also apply to the provision of services for other D/HH sub-populations, communication needs are diverse, and future research is needed to yield additional recommendations. Furthermore, since the scope of this study was limited to investigating the perspectives of D/HH individuals on the accessibility of services typically responsible for responding to disasters, future research should inquire into their perspectives on emergency preparedness initiatives implemented in Denmark as well as in other countries.

Notes
1. A capital "D" is used to distinguish the cultural, linguistic Deaf community and its members, from the audiological condition of being deaf.
2. “Late deafened” means deafness that happened post-lingually.

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