The consequences of deafblindness rules the family: Parents’ lived experiences of family life when the other parent has deafblindness

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Abstract
Deafblindness is a combined vision and hearing disability that restricts communication, access to information, and mobility, thus limiting a person’s activities and full participation in society. Literature on how this might affect the lives of family members is sparse. The aim of this study is to describe the lived experience of family life from the perspective of one parent when the other has deafblindness. Six partners of deafblind parents, four men and two women, agreed to participate. Three were deaf and communicated in Swedish sign language. Qualitative interviews were conducted and analysed using interpretative phenomenological analysis. Seven themes were identified during the analysis. When one parent has deafblindness, communication within the family and with people outside the family is affected. The non-deafblind partners tried to integrate deafblindness into everyday family life and constantly strove to compensate for the losses caused by deafblindness. They tried to enhance participation and engagement in everyday family life for the parent with deafblindness by facilitating communication and taking a greater part in some areas of their shared responsibilities at home. The results reveal that these partners...
often put themselves in second place. They and their families needed support to manage family life. Deafblindness affects the life of the entire family, and the non-deafblind partner has to take considerable responsibility for everyday life. Everyday life can be facilitated by an adapted environment and appropriate support, which should be offered to the entire family.

**Keywords**
Deafblindness, dual sensory loss, everyday life, family, partner

**Introduction**

The Nordic definition of deafblindness states deafblindness as ‘a distinct disability. Deafblindness is a combined vision and hearing disability. It limits activities of a person and restricts full participation in society to such a degree that society is required to facilitate specific services, environmental alterations and/or technology’ (Nordic Centre for Welfare and Social Issues, 2016). The term deafblindness is sometimes used interchangeably with dual sensory loss (Wittich et al., 2013). About 0.2%–2% of the global population are estimated to have deafblindness (World Federation of the Deafblind, 2018). However, due to the heterogeneity of deafblindness, it is hard to give an exact number of those affected. There are many causes of deafblindness, and the degree of vision and hearing loss varies between individuals (Möller, 2003).

People with deafblindness have in previous qualitative and quantitative studies been identified to experience difficulties with communication (Fletcher & Guthrie, 2013; Hersh, 2013; Möller, 2003), compromised activities of daily life, lack of independence (Dalby et al., 2009; Fletcher & Guthrie, 2013; Hersh, 2013; Rönnåsen et al., 2015), risk of isolation (Fletcher & Guthrie, 2013; Möller, 2003; Rönnåsen et al., 2015), and difficulties with mobility (Dalby et al., 2009; Fletcher & Guthrie, 2013; Hersh, 2013; Rönnåsen et al., 2015) and performing household chores (Fletcher & Guthrie, 2013; Hersh, 2013; Rönnåsen et al., 2015). Their health and well-being have also been found to be affected. Adults of all ages with Usher type II (the most common genetic cause of deafblindness) reported significantly poorer health (e.g., headache, fatigue, depression, suicidal thoughts, and suicide attempts) than a random sample of the Swedish population (Wahlqvist et al., 2013). Pessimistic outlook on the future has also been identified (Fletcher & Guthrie, 2013). However, in another study, 46% of participants with deafblindness reported good or excellent health, and the majority had a positive outlook and found meaning in everyday life (Dalby et al., 2009). Ehn et al. (2019) found that despite their difficulties, people of working age with Usher type II had many strategies for coping and were active agents in control of their lives. Another study found that persons ageing with hearing and vision loss meant that when family members did not understand their losses this could result in misunderstandings, irritations, and increased family tension. Many individuals also felt depressed due to, for example, fear about the future, communication difficulties, problems with participating in activities, and conflicts within the family (LeJeune, 2010). There is also research exploring the lived experience of older adults with dual sensory impairment (Wittich & Lorenzini, 2019).

When one member of the family has a disease, it is necessary to consider the stress and other effects on rest of the family members (McCubbin & McCubbin, 1993). This is likely also true when a person has a disability such as deafblindness. Adult people of all ages with sensory loss and their partners have in a survey study been found to use similar coping strategies and be emotionally interdependent (Lehane et al., 2019). In a quantitative study, couples in middle age living with sensory loss (hearing and/or vision) were reported to be at greater risk of mental health problems (Lehane, Hofsöe, et al., 2017) and the spouses of individuals with sensory loss had poor
well-being, which remained stable over a 6-month period (Lehane et al., 2019). Despite the few studies described above, a literature review of quantitative and qualitative studies (Lehane, Dammeyer, & Elsass, 2017) revealed that research on how deafblindness affects the spouse, family, and parenting a child is sparse. Knowledge from a qualitative perspective could create a valuable base for the healthcare sector and for national resource centres for people with deafblindness around the world when tailoring support interventions for various members of these families.

**Aim**

The aim of the study was to describe the lived experience of family life from the perspective of one parent when the other has deafblindness.

**Method**

**Design**

A qualitative inductive research design was used (Patton, 2015). This article is part of a research project aimed at exploring the health and lived experiences of families with a parent with deafblindness. Qualitative interviews were conducted (Kvale & Brinkmann, 2014) and analysed using interpretative phenomenological analysis (IPA) (Biggerstaff & Thompson, 2008). Members from The Association of the Swedish Deafblind (Förbundet Sveriges Dövblind: FSDB) and the Swedish National Resource Centre for Deafblindness (NKCDB) were linked to the project during its design.

**Procedure**

Inclusion criteria were having a partner with deafblindness regardless of cause, co-habiting with own children for at least 50% of the time, and being able to communicate with the researchers independently or through interpreters. A convenience sampling technique was used. Information about the entire project was shared verbally and over Facebook by board members of the family section of the non-governmental organisation FSDB. Interested people meeting the inclusion criteria contacted the research team when interested in receiving more information or to participate and were given written and verbal information. Partners with deafness (n = 3) were given information in sign language by one of the researchers (M.W.) fluent in Swedish sign language (SSL). After time to ask questions and reflect upon their participation, participants provided informed written consent.

**Participants**

Six partners, four men and two women, aged 38–57 years (mean, 48) agreed to participate. Three were deaf and communicated by SSL. Four were employed to some degree and two had a disability pension. Due to the small sample size and risk of identification, no more demographic data will be provided.

**Data collection**

Individual semi-structured interviews were conducted. Interviews with participants with deafness were conducted in SSL by M.W. The remaining interviews were conducted by A.A.C. An interview guide based on clinical experience in the research team, input from the reference group, and
the literature was used. The opening question was ‘Can you please describe your experiences of what it is to be a parent in a family where the other parent has deafblindness?’ Areas covered in the interview guide included parenting, family situation, family roles, need for support, strength in family members, and the influence of deafblindness on the children. The interviews took place in the participants’ homes or at an event for people with deafblindness and their families. The interviews were digitally recorded or filmed depending on the type of communication. All collected data were transcribed into written text. Interviews performed in oral language were transcribed verbatim. Video recordings of interviews performed in sign language were transcribed by a skilled sign language speaker and researcher within the field (M.W.). The transcriptions were then checked against the video recordings by an experienced authorised interpreter between Swedish oral language and SSL, who is also a PhD. There was a high degree of concordance. When discrepancies were detected, these were discussed until consensus was reached. For the interviews performed in sign language, the analytic process was inspired by the rules described by Arndt (2011).

**Analysis**

IPA (Biggerstaff & Thompson, 2008) was used to analyse the data. In the first step, all the transcribed interviews were read through by two of the authors (M.B. and A.A.C). The second step involved writing down notes in the margins of the transcripts about aspects researchers wanted to pay attention to that arose during the reading. In the third step, M.B. and A.A.C. went back to the notes and reread them and the interview transcripts in order to organise the notes into themes to give the analysis an overall structure. Notes about similar things were clustered together under tentative themes using the researchers’ pre-understandings. In the fourth step, the tentative themes were reviewed and restructured after discussion with the entire research group. Seven themes were finally identified.

**Ethical considerations**

The Regional Research Ethics Board at Uppsala, Sweden, gave formal approval of the study (2016/124).

**Results**

The lived experiences of partners of co-parents with deafblindness were comprehensively interpreted as *The consequences of deafblindness rule the family*. The partners’ experiences of family life with a partner with deafblindness are described through the themes *Communication barriers in almost every situation*, *Integrating deafblindness as a part of everyday life*, *Compensating for the deafblindness*, *Enhancing participation in family activities*, *Having mutual and shared responsibilities*, *Putting oneself in second place*, and *Needing a great deal of support*. The results are illustrated with quotations from the participants. The number in parentheses after each quotation is the individual study number of the participants.

**Communication barriers in almost every situation**

The participants (‘partners’) described the different ways deafblindness affected communication (verbal, visual, or tactile sign language) within the family. If family members were not sensitive to what the parent with deafblindness could comprehend in conversation or if they were not fluent in visual or tactile sign language, the partner felt there were misunderstandings. Partners also
experienced that communication was easier when it was daylight or the lights were on than when it was dark during evenings and nights. Therefore, children often turned to the parent without deafblindness during darker conditions when misunderstanding with the parent with deafblindness was more likely. This made the partner feel they needed to take greater responsibility. When communication was not optimal or went wrong, the partner thought that the parent with deafblindness sometimes felt excluded or misunderstood.

Well, [. . .] it is the hearing that is the cause of misunderstandings. So, we [family members] urge her [parent with deafblindness] to repeat what she has apprehended, so that we can correct her at once. (Man, #56)

Partners experienced that when emotions were involved, communication became especially challenging and could cause conflict and irritation within the family. Sometimes the parent with deafblindness felt depressed, exhausted, frustrated, or worthless because of their disability. These emotions could then spill over and cause discord within the family and further affect communication. It was also hard to express emotions quickly and explicitly through sign language (visual and/or tactile). Therefore, partners felt that it was difficult for the parent with deafblindness to solve conflicts, for example, with the children. At those times, the partner tried to act as a mediator.

As I have full vision and hearing, I can pick up cues from the children, which NN (person with deafblindness) can’t, as she has impaired vision and hearing, and then I have to support them. In addition, there is always a risk for misunderstandings between children and adults, but even more so when you have to communicate in a language that is not your first, and furthermore if you must use tactile sign language. So, there are some obvious obstacles, so to say, and one might have to engage in those conversations and offer support in order for the communication to work out as intended, which might not have been necessary in the case of full vision and hearing. (Man, #34)

**Integrating deafblindness as a part of everyday life**

The partner felt it was important to accept their partner’s disability. They tried to view the disability as something normal that was integrated in their everyday life. Some parents had hesitated to have children because of the hereditary risk. However, once the couples became parents, they felt their children had benefits other children did not, for example, their children usually had one parent at home because of the parent’s deafblindness. They also felt that the children had a different upbringing than many others. One parent related,

Well, she [daughter] has had the opportunity to see and learn different things than children who have one or two parents with full hearing and vision. She has met people [with deafblindness], as we have participated in activities for these people, so she has learned some sign language. But of course, she has had to learn to pay more considerations to her mum as compared to other children, and then they have had time together, as her mum is at home. Thus, she [daughter] has not been to day care; instead, they have had time together until she started school. (Man, #53)

The partner felt it was easier to integrate deafblindness as part of everyday family life when the parent with deafblindness accepted the disability. In some families, the parent with deafblindness received help from the Law of Special Support, which was regarded as positive. However, sometimes the parent with deafblindness did not want that help as it was hard to have someone that close and to be dependent on assistance all the time. This service could therefore be put on hold by the parent with deafblindness. In those cases, the deafblindness became a huge part of every family member’s life, and partners felt that all were then forced to help with guiding and interpretation.
However, they did it for the sake of the parent with deafblindness. In such circumstances, the partner felt that they themselves were at risk of becoming more isolated as they mostly stayed at home and did not have many friends. This could also affect the children, who also tended not to have or bring home many friends. Some, however, said that their children did invite other children to their home. ‘Sometimes, they invite their friends to our home, yes they do’ (Woman, #36).

Compensating for the deafblindness

To help the parent with deafblindness and the entire family, the partner strove to compensate for things the parent with deafblindness could not do or that did not function well for them. The partner often took greater responsibility for some chores at home that were difficult for the parent with deafblindness to do independently. For example, it could be difficult to take the children outside for play, to shop, or to participate in school and leisure activities. The partner tried to facilitate family life by being there for the children, problem solving, teaching the children to remain within sight of the parent with deafblindness, telling the parent with deafblindness where the children were, and teaching the children how it is to live with vision and hearing impairments. To succeed in parenting, partners thought it was important to try to be responsive to each other and understand the other parent’s perspective. One parent said, ‘Well, you have to be open-minded, and listen to each other; she must listen to me and I must listen to her’ (Man, #6). However, this was not always easy. Another said, ‘It must be a common interest [for both partners in a relationship], both trying to convey a message and trying to understand what is conveyed, and that’s what’s terribly difficult’. (Man, #34)

Different aids facilitated everyday life and compensated for the sensory loss of the parent with deafblindness. The partners found that the white cane improved independence for parents with low vision, and a microphone and hearing aids could facilitate communication, for example, when driving and when it was impossible to see each other’s faces. The deafblindness could also be compensated for by installing web cameras in the home as the partner then could see what was happening when away from home, for example, at work. In this way, the parent with deafblindness could sleep on their own with a minor child. Some of the aids needed to facilitate everyday life were difficult for the parent with deafblindness to get used to, but the partner tried to normalise them.

The partners found that assistance and guidance from social services also helped to compensate for the disability and facilitated everyday life for the parent with deafblindness and the whole family:

Well, when we go on an outdoor activity. When NN [wife with deafblindness] has a personal guide, that’s good, because then she can keep track of the children, and we are together. Then it’s fine, but without a guide, then it’s not so much fun . . . (Man, #6)

Enhancing participation in family activities

The partners strove to improve participation in family life for the parent with deafblindness by actively trying to counteract exclusion, such as encouraging the parent with deafblindness to engage with the children on their own in activities they both enjoyed. They also sometimes stepped aside in favour of the deafblind parent and the child so they could create a special bond. Other times, the entire family engaged in joint activities.
If we’re picking mushrooms, then the rest of the family do the picking and we place her [wife with deafblindness] on a stump: ‘Here, you have [the mushrooms] to brush clean’. And she’s happy with that, so when we leave the forest, it has all been sorted. (Man, #56)

Partners tried to facilitate communication with the parent with deafblindness by, for example, encouraging the children to talk slower or to use visual or tactile sign language. Other strategies were to repeat what was said in a conversation or encourage the parent with deafblindness to repeat what had been said, so the partner could correct any misunderstanding. Texting on the phone was experienced as more equal and inclusive of the parent with deafblindness. ‘Well, I tried to share her [wife with deafblindness] e-mail address, when we share our addresses at school, so that the other parents could keep in contact with her, but it hasn’t worked out that well’ (Man, #34).

**Having mutual and shared responsibility**

According to the partners, the parents tried to share mutual responsibilities based on their abilities and interests. If the parent with deafblindness, for example, was good at listening and had a great amount of patience, they might spend more time with the children, while the other parent took responsibility for things that were not so easy for the parent with deafblindness. ‘He [husband with deafblindness] has always been a good listener and discussion partner. [. . .] If they [the children] have done something they shouldn’t, he’s good at discussing such things through’ (Women, #50).

In some families, cooking was a shared responsibility, as the deafblind parent could do several tasks related to preparing meals. Other activities (e.g., vacuum cleaning, driving the car, or reviewing written homework with the children) were more difficult, so the parent without deafblindness took more responsibility for them. Partners said that they tried to share societal responsibilities, such as contacts with authorities, daycare, school, and children’s leisure activities.

The partners felt that the progression of deafblindness made the couple search for new solutions for problems in everyday family life. Partners experienced that it was more difficult to take mutual responsibility at home when the parent with deafblindness did not accept the deafblindness, or when it progressed, and it could lead to conflicts.

**Putting oneself in second place**

Partners wanted to show respect and consideration to the parent with deafblindness. Sometimes they prioritised this so much that they put themselves in second place and sacrificed their own interests. This was mentioned in relation to more trivial aspects, such as accepting the need for extra lightening at home, even if they felt dazzled and uncomfortable with such levels. In another example, the partner had to adapt to avoiding uneven ground, which meant walking on paths in the woods and not in the real wood, which the partner preferred.

Partners also put themselves in second place in more significant areas, for example, by acquiescing when the parent with deafblindness did not want help from social services. This was sometimes exhausting for the partner.

Well, I think we are getting on well with each other, but I have to act as a guide for him [husband with deafblindness]. I think that is an extra burden. I used to say, ‘You can use the services’, but he doesn’t want to . . . Then I feel a bit forced to assist, almost as if I’m working as a guide, although I’m not! But at times, I have to pull myself together and take on the responsibility . . . (Women, #36)
From time to time, partners felt they needed more leisure time to rest from their responsibilities and planning and steering the family.

Well, I need some leisure time, and so NN [wife with deafblindness] needs a guide meanwhile . . . Now, when the children are young, it’s difficult, but maybe I’ll find some spare time when they grow older. I’ll have to wait and see how things will turn out . . . But in the evenings, sometimes I might want to do something, yes. (Man, #6)

In some families, where the parent with deafblindness was more independent, the other parent had some time to rest or do things they were interested in themselves.

**Needing a great deal of support**

Partners felt that both they and the family needed support. Support from their own family, such as babysitting, helping the children with homework, or driving them to activities, was experienced as helpful. Although the family could benefit from such support, partners felt it was difficult when relatives wanted to take a greater responsibility for the children and their upbringing than the parents wanted them to. They wanted to stress that they were still the parents even though one of them had a disability.

For one family who struggled with their everyday life, social services offered a contact family for the children, which brought the entire family some relief and rest. Partners felt the primary healthcare nurse was supportive in offering tips on bringing up the children but not in managing with deafblindness, which was handled by a special team. The deafblindness team, however, did not always have competence around children and the practicalities of having children. The partners felt it was important that some support was centralised since deafblindness is a rare and complex disability, and thus the local support teams might lack specific experience. Some, however, managed to find solutions on their own.

It doesn’t have to be complicated . . . There are technical devices that you can use if you’re interested and knowledgeable, so that hasn’t been a problem. I’ve solved them one by one. I have not been very troubled, no . . . I’ve found good help on Google and followed the advice given there. (Man, #53)

When the deafblindness progressed, the partners’ need for assistance and professional guides increased. These supports could, however, be experienced as both beneficial and somewhat harmful. If the parent with deafblindness was entitled to and received assistance, the partner felt their family life was facilitated. They felt more like a family, life felt freer, and the family members had increased independence. One parent said, ‘It means that she [wife with deafblindness] can live her life more independently, and I can live my life. She doesn’t have to spend all her time with me . . .’ (Man, #6). The partner felt that stress related to the children decreased when they had assistance. The assistance enabled the parent with deafblindness to do more outside activities with the children, whose ability to act like children increased. Without assistance, parents had to find other solutions.

If your vision is poor, you need to adapt accordingly. Maybe you can use a harness when out on your own with your children [if you have deafblindness], a harness and a lead. You can’t just let go and trust the children to cope, that’s a too big risk, they will run away. (Woman, #50)

However, some partners found it hard to get assistance even when the parent with deafblindness had the right to it. The partners found that assistance differed by living area and that authorities passed the responsibility for assistance among different services.
Having an understanding employer made life easier for the partner. One partner was even allowed to leave the workplace for a short period of time when there was an acute need at home, and the family could plan parental leave in accordance with the family needs without paying much attention to the other employees.

The partners appreciated when the county council’s professional deafblind team planned events where they could meet other people in the same situation. These led to emotional and practical support and increased knowledge about deafblindness, which in turn made it easier to support the parent with deafblindness. Others in a similar situation could also be met through family groups on the Internet or non-governmental organisations such as the FSDB, which arranges an annual family week. The entire family can meet other families in the same situation at these gatherings, and it can feel like a vacation.

A guide dog was also felt to be very supportive of the parent with deafblindness and to increase the partner’s independence.

Discussion

The purpose with this study was to explore the lived experience of family life from the perspective of one parent when the other has deafblindness.

The consequences of the deafblindness affected the entire family. Communication barriers arose in almost every situation both within and outside the family and were especially troublesome when emotions were involved. It is known that people with deafblindness have problems with communication (Fletcher & Guthrie, 2013; Hersh, 2013; LeJeune, 2010; Möller, 2003; Rönnåsen et al., 2015). Communication is crucial in family life. Therefore, it is important that every family member and those close to the family get professional education in visual or tactile sign language. When the entire family is skilled at using the same language, it might decrease misinterpretations.

In this study, the partners tried to integrate deafblindness in everyday family life, and they also compensated for the other parents’ losses. The partners experienced the environment around their family as sometimes facilitating and sometimes hindering. To feel healthy, it is important to have an environment that facilitates participation in everyday life situations (Imms et al., 2017). The partners tried to involve and engage the parent with deafblindness in family life, as in the example of cleaning the mushrooms that the other family members picked. According to the partner, this promoted well-being in the parent with deafblindness. Other studies have found that individuals with hearing and vision loss can experience depression due to restrictions in activities, mobility difficulties, and increased isolation (LeJeune, 2010). Challenges to participation are often attributed to the individual rather than to environmental factors, an attitude that needs to be changed. Understanding the experiences of people with deafblindness and their families may enable the design of interventions to increase their participation in everyday life (Jaiswal et al., 2018).

Sometimes the parents with deafblindness wanted and received assistance from outside the family, but sometimes they did not want or were not allowed a personal assistant, and this put an extra burden on the partner. Partners occasionally put themselves in second place and wanted some respite to ‘charge their batteries’. When social services did not offer assistance, the partners sometimes felt their needs were not understood. The social services are, according to the International Classification of Functioning, disability and health (ICF), a part of the environment, which comprises not only support but also attitudes (World Health Organization [WHO], 2007). Even though the same law regulates social services throughout Sweden (Social Service Act), the partners felt that the ease of getting assistance varied and they requested more equal needs assessments. Gilmore et al. (2019) reported that when professionals learned more about disabilities such as deafness, they changed their attitudes towards the disability. So, the question arises: Do social services
professionals, those who decide whether and to whom to provide assistance, need to learn more about deafblindness and to reflect upon their attitudes? The partners of parents with deafblindness and their families are clearly in great need of support, and they stress the need for more knowledge among, and more equal support from, the professionals in Sweden.

One limitation of the study is the small number of participants. Deafblindness is a rare condition (Möller, 2003), but even though partners of parents with deafblindness constitute a small group with specific needs, they have the right to be included in research and more knowledge about their situation is warranted. Of those people asked to participate, many declined due to poor mental health reasons, which is in line with results from other studies (Lehane et al., 2019; Lehane, Hofsöe, et al., 2017). However, they thought it was an important study.

The four researchers who performed the analysis had different backgrounds. M.B., K.H., and A.A.C. are paediatric nurses with extensive knowledge and experience of qualitative research and interviewing family members. M.B. and K.H. had no previous research experience in the field of deafblindness, but A.A.C had. M.W. is a social worker with extensive knowledge on working with people with deafblindness, sign language usage, and research on deafblindness. The preconceptions of the researchers were compared, contrasted, and modified in the process of making sense of the interview data, in accordance with the underpinnings of the IPA method (Biggerstaff & Thompson, 2008).

Conclusion and clinical implications

From the perspective of the partner, deafblindness affects the entire family and family life. The partner has to take a considerable responsibility for everyday life. If the environment is adapted and support offered, everyday life is facilitated. Lehane et al. (2018) claim that interventions need to focus on the family, not just the person with deafblindness (Lehane et al., 2019), which is also highlighted in the results from this study. When meeting a partner to a parent with deafblindness, social services staff need to consider the needs of the entire family when applying laws, whether and to whom to provide assistance (e.g., guidance, interpreters), and also to extend their own knowledge about this disability and what it implies. It is also of importance that policymakers have an awareness of the deafblindness’ impact of the entire family when enacting laws. Identified strengths and strategies of people in family with at least one parent with deafblindness could also be shared with others in a similar situation to help them cope with their everyday situation in order to enhance their quality of life.

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