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Relationships Among Deaf/Hard-of-Hearing Siblings: Developing a Sense of Self

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Abstract

While sibling relationships are known to be important for children's social and emotional well-being, little is known about sibling relationships when both siblings are deaf or hard-of-hearing (DHH). In-depth interviews were conducted with 10 young DHH adults (20–30 years old) who had studied in mainstream schools to explore their retrospective experiences of growing up with a DHH sibling. Interviews were analyzed using interpretive phenomenological analysis. Findings revealed two superordinate themes: (1) sibling relationship and sense of self and (2) family coping and relationships, with each superordinate theme containing several subthemes. Findings highlighted the various ways sibling relationships contribute to siblings' psychological development, identity formation, and coping with deafness. Potential challenges were identifed, as well as the role of parents' attitudes and coping with hearing loss in promoting supportive sibling relationships. Parents and professionals should be aware of the valuable and unique aspects of DHH siblingship and attend to imporatnt relationship asepcts such as sibling communication, sibling comparisons, and parental differential treatment.

Research has consistently highlighted the immense contribution of sibling relationships to children's socio-emotional development and well-being across the life span (Feinberg, Solmeyer, & McHale, 2012). However, very little is known about the impact of sibling relationships on the development and experiences of deaf or hard-of-hearing (DHH) children. An increasing number of DHH children attend mainstream educational settings (Leigh, Maxwell-McCaw, Bat-Chava, & Christiansen, 2009) and face socio-emotional challenges related to their participation in hearing environments (e.g. Xie, Potměšil, & Peters, 2014). Relationships with DHH peers contribute to DHH children's sense of security (e.g. Schwab, Wimberger & Mamas, 2019), but many children who study in mainstream schools lack access to such relationships (Punch & Hyde, 2011). Hence, identifying and studying potential sources of support in their environment that can promote resiliency, such as sibling relationships, is a priority.

In this qualitative study, we investigated DHH young adults' retrospective and ongoing experiences of growing up with a DHH sibling while studying in mainstream schools and the meanings they gave to these experiences.

Siblings as a Source of Support

A significant body of literature has found associations between sibling relationships and children's development and psychological adjustment (Milevsky & Levitt, 2005; Modry-Mandell, Gamble, & Taylor, 2007). Siblings are a source of social learning (Dunn, 2007). They provide endless opportunities for practicing and learning how to resolve conflicts and interpersonal problems, cope with a wide range of emotions, such as rivalry or jealousy, and develop social understanding and enhanced social skills (for

reviews see Feinberg et al., 2012; McHale, Updegraff, & White-man, 2013). In addition, they offer social and emotional support (Buist, Dekovic, Meeus, & van Aken, 2002). Studies find that warm and supportive sibling relationships can buffer against low self-esteem, depression, and loneliness in the face of low parental or peer support (Milevsky & Levitt, 2005). At the same time, negative, distant, or conflictual sibling relationships may increase the risk of experiencing internalizing (Kim, McHale, Crouter, & Osgood, 2007) and externalizing symptoms (Natsuaki, Ge, Reiss, & Neiderhiser, 2009). Siblings' social and emotional support is associated with socially adaptive functioning (e.g. Milevsky & Levitt, 2005; Modry-Mandell et al., 2007) and the ability to establish intimate relationships during adolescence and adulthood (Feinberg et al., 2012). Finally, as they are often the longest relationships a person has, they are a powerful potential source of support during adulthood and predict mental well-being in old age (Feinberg et al., 2012; Incledon et al., 2015; McHale et al., 2013).

Sibling Relationships of DHH Children

Research on the sibling relationships of children with disabilities, including DHH children, has increased. Yet most studies examine the influence of having a sibling with a disability on the sibling without the disability (Aronson, 2009; Incledon et al., 2015; Meadan et al., 2010; Wennick & Huus, 2012). Similarly, most studies on DHH sibling relationships focus on DHH-hearing sibling dyads, with an emphasis on the impact of the DHH child on the hearing sibling (Antonopoulou, Hadjikakou, Stampoltzis, & Nicolaou, 2012; Bat-Chava & Martin, 2002; Dardeen, 2008; Raghuraman, 2008; Tattersall & Young, 2003; Verté, Hebbrecht, & Roeyers, 2006). The few studies that have examined the influence of siblings or sibling relationships on DHH children indicate that in families who use sign language, positive relationships with hearing siblings contribute to the DHH child's cognitive and socio-emotional development (Marschark, 1997; Woolfe, Want, & Siegal, 2003). However, when the family does not use sign language, and when hearing siblings are older, DHH children may suffer from communicational and emotional isolation within the family (Berkowitz & Jonas, 2014; Macaulay & Ford, 2013). In contrast, when more than one child is deaf (this happens in up to 20% of families with a deaf child), there is more use of sign language, communication is more fluent and natural, and the deaf children are treated like any other siblings (Marschark, 1997).

The presence of a DHH sibling may provide a significant source of familial support for a DHH child. To the best of our knowledge, only one study has investigated the psychological experience of having a DHH sibling from the perspective of the DHH child. In that study, Wolfe and Smith (2001) examined the impact of parents' and siblings' different hearing status on DHH children's self-esteem and sense of family cohesion. Forty-five DHH children (10–14 years old) represented four groups classified by their parents' and siblings' hearing status. Their self-esteem was measured using a self-report questionnaire, and their sense of family cohesion was assessed using the Family Systems Test (FAST; Gehring & Wyler, 1986). In the FAST task, children were asked to locate figures of family members on a board and explain their choices. Findings indicated that their siblings' hearing status was not associated with the participants' own self-esteem. Yet DHH children with DHH siblings reported closer sibling relationships than DHH children with hearing siblings. In addition, some DHH children described their DHH

siblings as role models and a source of support (Woolfe & Smith, 2001). These findings point to a special closeness between DHH siblings and suggest the potential of this relationship to provide emotional and communicational support.

DHH Children in Mainstream Educational Settings

With recent cultural, legislative, medical, and technological developments, increasing numbers of DHH children are attending mainstream schools (Leigh et al., 2009; Wauters & Knoors, 2008). Given this and because more than 90% of parents of DHH children are hearing (Mitchell & Karchmer, 2004), the majority of DHH children have limited opportunities for daily interactions with other DHH children or adults in their familial and social-educational environments. Studies show that DHH children in mainstream schools are at risk of loneliness and social difficulties (Nunes, Pretzlik, & Olsson, 2001; Rieffe et al., 2018; Xie et al., 2014; Zaidman Zait & Dotan, 2017). Social and communicational barriers may challenge the development of their self-identity and sense of belonging, in both Deaf and hearing cultures (Israelite, Ower, & Goldstein, 2002; Punch & Hyde, 2011; Zaidman-Zait & Dotan, 2017). Although having social contact with other DHH peers has been found to increase DHH children's sense of closeness and security in social relationships (Bat-Chava & Deignan, 2001; Israelite et al., 2002; Schwab et al., 2019), most DHH students in mainstream schools lack such contact (Kent & Smith, 2006; Punch & Hyde, 2011). Hence, having a DHH sibling might provide significant socio-emotional support (Wolfe & Smith, 2001).

To the best of our knowledge, no research has focused on DHH sibling relationships among DHH siblings who use spoken communication and who are the only DHH children in their classes. Such research is needed considering the increased participation of DHH children in mainstream schools, the social and emotional challenges they face, and the potential protective influence of having a sibling who is also DHH. Of particular interest is the extent to which and the mechanism by which the sibling relationship provides emotional resources.

The purpose of this qualitative study was to explore main-streamed DHH young adults' idiographic, retrospective experiences of growing up with a DHH sibling and the meaning they ascribed to their sibling relationships. In this respect, an interpretive phenomenological analysis (IPA) suited our purpose, as it features an in-depth exploration of individuals' lived experience and how they make sense of it (Smith & Shinebourne, 2012). IPA is suitable for relatively small samples (Smith & Shinebourne, 2012). It emphasizes individual phenomenology, trying to stay as close as possible to the individual's idiosyncratic experience. At the same time, it acknowledges that experience is always mediated by interpretation (Smith, 2011). In what is called a double hermeneutic process, IPA seeks to integrate a participant's attempt to make sense of his or her world with the researcher's attempt to understand the participant's meaning-making process. The process is facilitated by the researcher's own understanding and knowledge of psychological theories (Pietkiewicz & Smith, 2014; Smith, 2011).

Method

Participants

Our participants consisted of 10 young adults (four men and six women; age range: 20–30 years) with hearing loss (HL) since

birth or early childhood. All participants had bilateral HL, with hearing levels ranging from mild to profound (HL of 40–120 db). Seven used hearing aids, and one had a cochlear implant. The remaining two did not use hearing devices. All participants had a DHH sibling, and except for one, all had hearing siblings as well. Four had an older DHH sibling (age gaps 6–14 years), four had a younger DHH sibling (age gaps 2–5 years), and two had a DHH twin. The participants and their siblings used spoken communication and came from families who used oral communication. All the participants and their siblings had been individually integrated into mainstream classes throughout their school years. Seven participants had hearing parents, and three had one hard-of-hearing parent and one hearing parent. The participants did not report having any other disabilities.

The sample size was adequate for an IPA approach, which does not aim at generalization but at understanding the personal meanings given to a specific experience. IPA is concerned with detailed case-to-case analysis and interpretative accounts; this is time consuming and only realistically achievable with small samples. In addition, sufficient homogeneity is required for an in-depth exploration of the participants' personal experiences (Pietkiewicz & Smith, 2014). Therefore, we aimed at a sample of DHH young adults who differed in familial backgrounds and levels of HL, but at the same time, shared a common experience of using oral modality and studying in mainstream educational settings. We chose to focus on the diverse perspectives that could exist in this specific socio-cultural and communicational context, as this had not been studied.

Interview Schedule

An interview schedule was developed to assess participants' relationships with their DHH siblings. Consistent with IPA, the interview was semi-structured, inviting the participants to talk at length about their experience of having a sibling who was also DHH and allowing an iterative exploration of the emerging topics. The first part of the interview focused on relationships in the present. Interviewees were asked to describe their current relationships with their DHH siblings, including joint activities, involvement in each other's lives, communication, and/or conflicts. Questions were open, and throughout the interview, participants were prompted to share their personal memories, reflections, thoughts, and emotional experiences. The next set of questions focused on the sibling's HL as an aspect of the relationship (sample questions included: In what way does the HL influence your relationship?; How do you think the relationship would have looked like without the HL?; Do you talk between yourselves about the HL?; How does your relationship with your deaf sibling compare to your relationships with the other (hearing) siblings?). The second part of the interview focused on the sibling relationship throughout childhood and adolescence. The questions were similar to those in the first section of the interview, but focused on retrospective accounts and memories (sample questions included: Compared to your relationship today, how was your relationship during childhood?; Do you remember how you felt when you first noticed that your sibling had HL?). In addition, participants were asked to reflect on childhood advantages or disadvantages of having a sibling who was also DHH (e.g. Were there moments when you felt that your sibling's HL was a (dis)advantage for you?). The last section of the interview set the sibling relationship within the familial context (e.g. How did your parents experience your and your sibling's HL?; Was there a difference in the way they treated you and your sibling in this aspect? How did you feel about that?; In what way, if at all, did the HL influence the way your parents treated you and your sibling compared to the rest of the siblings?). Each interview lasted about an hour and was audio-recorded.

Procedure

Ethical approval was obtained from the university ethics committee. Participants were recruited from a larger cohort of 88 DHH young adults participating in a research project conducted by the first author (Eichengreen, Hoofien, & Bachar, 2016; Eichengreen & Hoofien, 2017). Inclusion criteria for participation in the current study included: (1) having a DHH sibling, (2) identification of an HL by age three, (3) fully attending mainstream educational settings throughout the school years, and (4) age range of 20–30 years at the time of the study. Invitations to take part were sent to 21 individuals who met the inclusion criteria. Of these, 13 responded: 3 declined the invitation indicating they were busy and 10 gave their consent and took part. Semi-structured, in-depth interviews were conducted by the first author. For this paper, some attributes of the participants have been altered to protect their anonymity. Interviews were conducted face-to-face (N = 6) or through on-line Skype video conferencing (N = 2) or via written correspondence (N = 2). There is growing empirical evidence that interviews using online tools such as Skype are ideal for sensitive topics and can provide rich accounts of experiences (Sipes, Roberts, & Mullan, 2019; Trier-Bieniek, 2012).

Data Analysis

All transcripts were entered in ATLASti.8 program for qualitative analysis. Data were analyzed according to the IPA five-stage process (Smith & Shinebourne, 2012). The first author completed all aspects of the analysis, but as emergent themes were identified, these were discussed in length with the second author. In the first stage, each transcript was thoroughly read and re-read; observations of and reflections on content and language use were made in relation to the research questions, and distinctive phrases were highlighted. In the next stage, the initial notes were transformed into emergent themes reflecting both the participants' words and the analyst's interpretation (Smith & Shinebourne, 2012). Throughout all stages of analysis, the researchers engaged in ongoing discussions of the observations and themes. When relevant, each successive transcript was coded into already existing themes, while at the same time, being searched for new themes. The process was iterative; transcripts of all the interviews were reviewed when new themes emerged. After all themes were listed, connections across the themes within each case and across cases were explored, further abstracted, and grouped into superordinate themes. The final step included an iterative cross-case analysis, where each transcript was reviewed in light of the new higher-order themes. This stage resulted in final themes that were written in a narrative account with verbatim extracts to support them.

We adhered to Yardley's (2000) guidelines for conducting good qualitative research. More specifically, we displayed sensitivity to the context by exploring links between the data and diverse empirical and theoretical literature, and sensitivity to the data by relying heavily on participants' descriptions. The requirements of commitment and rigor were met by our use of lengthy in-depth interviews and our thorough theme analysis following defined guidelines. Detailed descriptions of the data collection and analysis and the presentation of representative excerpts

Table 1 Summary of themes extracted from the interviews

Superordinate themes	Subthemes
Sibling relationship and sense of self	Unique twinship, belonging, and normalization of the self
	Sibling's provision of emotional and communicational support
	Facilitating integration of the deafness into self-identity
Family coping and relationships	Impact of parents' attitudes to deafness on the sibling relationships
	Impact of the older DHH sibling on parents' coping with the younger sibling's deafness
	Parental differential treatment

expressing the participants' own voices ensured transparency. The study also has impact: it enriches the understanding of this population and has practical implications for families and professionals. We strove for reflexivity by remaining alert to our own perspectives and preconceptions that we brought with us to the interviews and analyses. For the sake of transparency, we should mention that the first author is a hard-of-hearing researcher and clinical psychologist working with DHH children and has one hard-of-hearing sibling. The second author is a hearing researcher with hearing siblings who has a rich background in research and work with DHH children and their families.

Results

The findings were classified according to two superordinate themes, each divided into several subthemes, as noted above and summarized in Table 1. Throughout the Results and Discussion sections, we use the terms deafness and HL to reflect the variety in the participants' perceptions and terminologies. Unless otherwise stated, we have tried to convey as directly as we could the meanings given to these words by the participants. For the sake of transparency, whenever we add our interpretation to the participants' meaning-making process, we explicitly comment on it.

Superordinate Theme I: Sibling Relationship and the Sense of Self

This superordinate theme encapsulated the various ways the relationship with a sibling or even the sibling's existence supported the development of a positive sense of self among our interviewees and helped to embed the HL within a personal sense of identity. This superordinate theme included three subthemes: (1) provision of a sense of alikeness, belonging, and normalization of the self; (2) provision of emotional and communicational support; and (3) integration of HL into self-identity.

Alikeness, belonging, and normalization of the self. This subtheme reflected participants' sense of "alikeness" (i.e. basic similarity) to their siblings as a result of the common HL/deafness, which, in their experience, unified them and reduced their feelings of isolation. This alikeness was also experienced as a common characteristic that distinguished the sibling dyad from the rest of the "hearing" world. As one of the participants said: "I remember how after he was born, I saw that my parents were extremely worried about him [. . .] and then I realized that there is one more person in the world that is like me, and that we are different from the rest of the world." This alikeness feeling was so meaningful that it existed even when there was a wide age

gap between the siblings, or when the siblings did not discuss the HL. For example, one participant said that after he tried hearing aids for the first time in young adulthood, he assumed his brother was having a similar experience, even though they did not communicate at all about this subject. We interpreted this assumption of alikeness as stemming from the need to mitigate loneliness.

Sibling identification could construct identity as "normal", in terms of not being an outsider because of one's deafness. For example, one participant mentioned that the presence of her sibling made deafness "less strange and more natural" in their hearing family. Another participant described how her sibling helped her to normalize her identity:

> I personally had a great difficulty with that [going to afternoon social gathering with other DHH children] "Why am I going to the school of the stupid?" I am not a moron, a stupid, I am normal. I felt that I am better. We [referring to her sister] did not accept them [other DHH children]. We thought that we are not like them; that we belonged to the hearing, with the normal people. We also have hearing aids, but we are not like them.
>
> [Interviewer: Is it the way she helped you to feel normal?]
>
> I know how I perceived it at that time – you are helping me, you are with me, we are the normal against . . . the deaf.

This type of identification also generated a sense of a mutual fate, which, at times, caused negative feelings and raised concerns. One participant remembered that his older sister was socially rejected and stigmatized. This "imprinted memory" generated a fear that in the future, he too might become a "victim of injustice".

Emotional and communicational support. This second subtheme focused on the support provided by the DHH sibling. Some participants experienced a strong emotional closeness to their DHH sibling, which they attributed to the shared HL. This closeness was sometimes fostered by shared communication needs. For example, one participant indicated that because she and her sister had to read lips, it made them focus exclusively on each other while conversing. In her experience, this connected them, but it isolated them from other people. Some siblings had explicit conversations about coping with HL; they listened, shared, and consulted with each other.

During childhood, such conversations focused on social and interpersonal contexts, for example, coping with difficulties they had with their hearing peers and/or teachers:

> We were laughing, crying, talking about what is difficult for us and turning everything into black humor, soul-conversation into the night [...] laughing about things and sometimes talking about our difficulties; how we don't always understand what is going on, and how to ask the teacher to put on an FM transmitter.

With increasing independence and separation from parents in adulthood, conversations turned to coping with practical issues, such as fitting hearing aids, adjusting to university, or handling administrative issues related to state-assistance rights. For example, one participant used to advise her brother on how to manage at university:

> I have just finished a degree, so I advised him on how to deal with the studies when you have a hearing problem, that one should go and collect material etc., He [DHH sibling] is currently just before starting his studies. On the one hand, I give him all this advice in order to help him, and on the other hand, it is a kind of release I think [...] there is someone who identifies with me, it is not just me alone here.

In some instances, DHH siblings helped to prevent isolation when participants faced communication barriers, particularly in the context of family conversations. The presence of two DHH siblings provided a "stronger weight", which reminded family members to attend to their needs. Sometimes one sibling was indirectly assisted by the support given to the other sibling, for example, when family members repeated what was said as per the other sibling's request. In the absence of familial support, siblings helped each other to understand what was said during family meals. A sibling provided safe companionship when the other could not follow family conversations, which prevented feelings of loneliness within their own family:

> I come from a British family, and when my uncles or grandparents arrived, and everyone in a second would start talking English, I and my sister were looking at each other, not understanding anything; we were just playing together in all the times when it was difficult for us. We always had our own haven.

In the social sphere, the sibling sometimes fulfilled social needs; during school hours or afterwards, they could play together when they did not have hearing friends.

Integration of HL into self-identity. The third subtheme focused on processes of identity formation. The sibling provided a focal point for identification or differentiation, thus uniquely constructing HL as part of self-identity. One way siblings facilitated this process was by serving as a *role model* on coping with HL. One participant said her brother's and father's coping with HL encouraged her to be confident: "My big brother and father have both hearing loss. I saw that they are okay and that they don't have problems in different areas in life. So, it gave me more

confidence in my life; having hearing loss is different, but one can cope with it."

Comparison was another process by which the sibling's presence helped participants to integrate HL into self-identity. Having a DHH sibling facilitated self-reflection, even in the absence of explicit conversations about coping. For example, one participant indicated that he never shared his feelings about HL, yet he remembered how his older brother grew his hair to hide the hearing aids. This, in turn, created a dilemma about whether he should hide his own hearing aids. To our understanding, this example shows how even just observing the sibling's behavior generated self-reflection on one's own coping with HL. Participants also said they compared between them and their siblings in communication skills and relationships with hearing peers, particularly when one sibling experienced social difficulties. As one participant remarked, this could decrease self-confidence and the sense of being "normal", defined by this participant as being similar to hearing people. The construction of self-identity during adolescence and young adulthood is complex, and the comparisons mentioned by our participants included allusions to cultural affiliation (e.g. Deaf, hard-of-hearing, hearing, bicultural) and self-acceptance within the Deaf/hearing culture:

> What happens when I take off the hearing aid and my sister is with the hearing aid? She doesn't have so much patience, telling me – "put on your hearing aid, I don't want to talk with you" [...] We are hard-of-hearing who grew up in the hearing world, with parents that try to normalize us. But contrary to my sister, I have been going in the last years a change and today I see things differently. She does not see them like me. From my perspective, if she and I would take off the hearing aids, we could make our own language. But she is not open to it.

Interpreting participants' reflections, siblings could also facilitate inner thinking about deafness by *representing a denied or unwanted part of the self*. Within this category, we noted a subtler process, which we identified as a projection of a negative attitude to HL onto a DHH sibling. During childhood and adolescence, several participants were ashamed of being DHH or wished to have a hearing identity (i.e. to be "normal"). The DHH sibling represented an unwanted part of the self in this case. This elicited an emotional distance from or negative feelings about the DHH sibling. We interpreted these feelings as rejection of the sibling in an unconscious attempt to keep the HL away from their own self-perception. Rejections included a lack of communication about HL between the siblings, a lack of knowledge about each other's experiences, and a more general emotional distance in the relationship. As one of the participants told us, emotional distance and non-communication could begin during childhood:

> When I was a child, I took off the hearing aids, and it seems that quite quickly he was following me in this, and I think that since then until our twenties we didn't talk about it. The whole adolescence we didn't talk about it at all. It was like something that is in the past and you don't want to touch it. Maybe in adolescence we already started to move away from each other or kept moving away.

Another form of sibling rejection was the expression of explicitly negative feelings about the sibling's HL, such as impatience

toward his or her communication needs, disappointment that he/she could not repeat what other people had said, or feeling ashamed of his/her HL. As one of the participants put it:

> There were moments that I felt [. . .] when we didn't hear and follow what was going on, eh … what a shame that we are both behind. Not just me, but her too. So, it is a much more difficult shame, since I need to carry both my and her shame. Here we are both fucked up, double shame, unless I choose to say: you know what, go fuck you [. . .] but you can't, you can't, because she is connected to you. Once I cut her there appears the … compassion, the sorry feelings.

 It seemed that dissociating from HL and ascribing it to a sibling served the participants' need to feel normal in terms of hearing identity (see the Discussion for further clarification). Yet projecting the deafness onto the sibling also seemed to create a secure space to think about deafness. For example, one participant used to relate deafness mainly to her sister, who was "more deaf" then she was, yet she remembered being enthralled by how the sister's friends used sign language: "It was the cutest thing that I had ever seen!". As a child, she said, "It always belonged more to her than to me I think". However, as an adult, she more consciously reflected on her own HL: "Between us [in the family] we did not sign, we signed only with my sister, so it didn't help me too much in life. Like, it did not make things easier for me and all that kind of stuff, which could have been nice." The presence of sign language during this participant's childhood, although attributed to the sister, may have assisted her in the process of incorporating deafness into her own identity, being able in adulthood to reflect on her own communication needs.

Superordinate Theme II: Family Coping and Relationships

The theme *Family Coping and Relationships* included the unique familial patterns that emerged when there were two DHH siblings in the family. Here, the micro-context of an individual's perception of HL was viewed in the larger context of the mutual influences of parents' and siblings' perceptions and relationships. Three subthemes emerged: (1) the impact of parents' attitudes to HL on the sibling relationship, (2) the impact of an older sibling on parents' coping with the HL of the younger sibling, and (3) parents' differential treatment of the siblings' HL.

Impact of parents' attitudes to HL on the sibling relationship. This subtheme was raised mainly by participants who experienced difficulties in their sibling relationship, such as emotional distance, lack of communication, and feeling ashamed of each other. As these participants saw it, these difficulties were related to their family climate. When parents denied HL or perceived it in a negative way, siblings' ability to accept their HL was hindered, and they were less likely to openly communicate about it. This, in turn, challenged their ability to create a close and intimate relationship:

> We grew up in denial […] power, power, power, be a man, be a man. In two words – no problems [. . .] In the relationship between me and my big brother, there is repression and denial. Our father told us: "There is no hearing problem. Be a man". It is a very high price to pay. I am not sure that from the emotional perspective

we knew how to manage a relationship that is open and intimate, which means: "Brother, it is difficult for me." [. . .] So our communication is with masks too, many times it is normal instead of simply talking.

Impact of an older DHH sibling on parents' coping with a younger sibling's HL. Several participants noted that their parents reacted negatively when they had a second DHH child, sometimes delaying or avoiding having a third child because of the fear that the next child would also be DHH. Parents' expectations and worries were, to a large extent, informed by their experience of parenting the older DHH sibling. Sometimes, according to the participants, previous experience intensified their parents' negative reactions:

> From what I know at least my mother took it very hard. My older brother has a serious hearing loss [. . .] they immigrated here when he was a child. There they didn't really have tools to cope with it. And it was very difficult for my mother to take care of him, so she thought she would go through the same thing with me [. . .] okay, but I think that I am completely different though.

 Yet most of the time, the older sibling paved the way to more informed parental coping with the second sibling's HL. According to the participants, parents had increased awareness of the HL of the younger siblings. They tended to examine siblings' hearing early on and started the rehabilitation process, sometimes deliberately compensating for not doing so with the older sibling. Consequently, some of the younger siblings displayed better oral communication abilities and used hearing aids, and they accepted these much more readily than their older siblings. Furthermore, when parents saw that HL did not prevent the older sibling from getting along well, they had a more positive and accepting attitude to the HL of the younger sibling:

> I felt that they accepted me. I don't think it was very hard for them [. . .] also because they know that it can be handled. I think that maybe with my older brother it was a bit more difficult for them. They were extremely worried about him but eh … I think that once they saw that it is getting alright with him, then they were less worried about me in this respect.

Parental differential treatment. This third subtheme focused on the experience expressed by participants who, due to differences in gender, age, hearing, or communication status, felt that their parents treated them differently from their DHH sibling. Older sisters of younger brothers described their parents as being more over-protective, indulgent, or overly tolerant of the younger sibling's requests or complaints. They described themselves as receiving less parental attention, less likely to expect that other people would adapt themselves to accommodate their communicational needs, and less inclined to reveal difficulties caused by their HL. We felt that this differential parental attitude, or family dynamics, elicited resentment. This resentment was sometimes expressed by the participants saying things that only they, as DHH, could say, for example, telling their parents not to worry too much about the sibling, or telling the sibling to adapt him/herself to spoken communication: "I was all the time bothering my brother by telling him to put on the hearing aid because he liked to disengage in the most improper times

[...] I felt convenient to tell him because I have hearing loss myself."

A more complex experience was described by participants whose siblings had more severe HL or more difficulty with spoken communication. It seemed that in these families, the sibling who was less proficient in spoken communication took the role of the "problematic" child, while the other was considered as "regular" and "getting along" well. This could be reflected in the child's identity, as one of the participants explained: "You see someone who hears worse, then you feel that you are alright [...] now that she is [in the family] then I am suddenly like hearing relatively, no longer the hard of hearing of the family." As we understood it, the more "oral" DHH children tended to focus less on their own HL, to put their own difficulties "into proportion", and to avoid sharing these difficulties with their parents. One of our participants said:

> Our parents were always more bothered with my younger brother than me. To say the truth, I have never ... delved in it too much [the deafness]. I have always thought more about my brother in respect to how he is getting along. I talk about it a lot mainly for him, less for me, I think.

The more "oral" DHH children sometimes had a special duty in the family, namely consulting their parents about the problems experienced by the deaf sibling, as they could give advice based on their own experiences. As one participant described it, this could elicit both a feeling of competency and a sense of being overburdened:

> They came to share with me what they had with my sister, so that I will give them some advice because I ... also I have already passed this age, and I am also considered as having a hearing loss. If they didn't share with me, I would have felt much less heavy, why do I need this on me, I am just a child myself. It was a lot of burden.

Parental differential treatment could also be felt by the DHH sibling as being harmful to the other DHH sibling who received more "special" parental attention. As they told us, this elicited empathic feelings for the DHH sibling and a feeling of being "saved" from the DHH sibling's "doom":

> The advantage is that I was not the poor child of the house. It allowed me to grow up like a regular child [...] perhaps if I were the only one with hearing loss then they would have been worried about me all the time. It influences your personality if they worry about you all the time or not. You can become more mature or less mature.

As these examples make clear, familial patterns in coping with deafness influenced the siblings' relationship and development of self-identity and also were influenced by them.

Discussion

This study explored DHH young adults' retrospective, idiographic experiences of growing up with a DHH sibling. As with any other sibling relationship, the relationships were complex and ranged from closeness to emotional distance, from mutual identification to jealousy or rejection. However, they were always colored by the unique context of the shared experience of HL, and its impact on the construction of the self.

We identified six themes under two overarching themes: sibling relationships and the sense of self and family coping and relationships. Both themes reflected the potential of the DHH siblings to provide significant emotional and communicational support to our DHH participants and indicated the familial conditions under which this potential could be fulfilled. To interpret the interview data, we used Kohut's (1984) theory on universal needs in the development of the sense of self and the importance of relationships with close others in fulfilling these needs. We also applied the relational understanding of identity formation (Flum, 2001; Josselson, 1994), whereby identity is a psychosocial construct that synthesizes individual and social aspects and evolves in relatedness with other people. Thus, as Josselson comments, "Although identity is in part distinct, differentiated selfhood, it is also an integration of relational contexts that profoundly shape, bound, and limit but also create opportunities for the emergent identity" (Josselson, 1994, p. 89). To relate our anlysis to the deaf context, we applied current perspectives on the formation of deaf identity as fluid and context dependent (Leigh, 2017; McIlroy & Storbeck, 2011; Ohna, 2004).

DHH sibling fulfills the universal need of twinship experience in the development of the self. Most of the participants and their siblings grew up in hearing families, used spoken language, were individually mainstreamed with hearing peers, and did not have contact with other DHH children. In the interviews, they conveyed a strong sense of being similar to their DHH sibling. This sense sometimes appeared very early in life, right after the sibling's birth in the case of a younger sibling, and was expressed regardless of age gaps and gender differences. Kohut (1984) defines the need for essential likeness or a twinship experience as a universal need in the development of the sense of self. From the baby who is surrounded by human voices and smells to the adult who shares similar interests with friends or co-workers, the self is sustained by the presence of someone experienced as essentially similar. This basic alikeness allows the child to obtain "a vague but intense and pervasive sense of security as he feels himself to be a human among humans" (Kohut, 1984, p. 200). The twinship experience implies not only a sense of belonging but also a feeling that one is understood by others. In cases where this need is not fulfilled, both children and adults may compensate by fantasizing about an imaginary twin or sibling (Klein, 1963; Kohut, 1984; Vivona, 2010).

DHH children are similar to their hearing family members and friends in many respects, yet our interviewees told us that, at times, they felt they were different and were not always understood or accepted. The sibling's presence helped to mitigate this sense of being alone. Even in the absence of explicit communication between the siblings about their coping, they felt they were going through similar experiences. This sense of "understanding without words" may attest to the human need to have someone onto whom we can project our experiences and with whom we can identify.

DHH sibling's presence fulfills the need to feel that one's self-identity is normal and natural, not exceptional. Participants expressed the need to feel unexceptional, whether their identity was D/deaf, hard-of-hearing, or "hearing with hearing aids".

The need to feel ordinary has been identified in previous qualitative studies on children and adults with disabilities (Connors & Stalker, 2007; Watson, 2002). Postmodern theory sees identity as fluid and nonessential, thus challenging the clear-cut boundaries between D/deaf and hearing identities. The extent to which deafness is felt to be central to identity (as with other identity attributes) is context dependent, making self-definitions dynamic and changing (Leigh, 2017; McIlroy & Storbeck, 2011). However, in the context of hearing families, many DHH individuals who only have hearing siblings describe themselves as being perceived by family members as exceptional and special, with deafness their main defining attribute (Berkowitz & Jonas, 2014). Our findings suggest that having a DHH sibling can contribute significantly to a more holistic, integrated, and "ordinary" self-perception.

DHH sibling plays a role in preventing isolation. In cases when feelings of similarity and identification occurred in a close and warm relationship, our participants' DHH sibling provided a significant source of emotional and communicational support. Supportive sibling relationships have been found to be associated with children's positive social and emotional development, as well as their behavioral, cognitive, and educational adjustment (e.g. East & Rook, 1992; Feinberg et al., 2012; Milevsky & Levitt, 2005). When both siblings are DHH, this closeness seems to create a special bond, which, according to our participants, is fostered by the deafness itself. Even the need to read each other's lips fosters a sense of closeness, as siblings must focus on one another to do so. For some of the participants, the DHH sibling compensated for or prevented feelings of social, emotional, or communicational isolation in the family or at school. Their descriptions strikingly contradict the sense of isolation felt by deaf children in hearing families (Berkowitz & Jonas, 2014; Woolfe & Smith, 2013). Our findings join those of studies conducted with signing children (Marschark, 1997; Woolfe & Smith, 2001) and highlight the importance of the DHH sibling in the prevention of loneliness and isolation for non-signing siblings.

Communication with the sibling about HL fulfills the need of mirroring and validation in the development of the self. Most of the participants in this study did not discuss their experiences or their feelings about their deafness with their siblings during childhood. Arguably, this situation reflected an initial "taken for granted" stage, in which DHH children know they are deaf or have a HL, but do not really understand or think about the meaning of deafness (Ohna, 2004). This stage usually changes when the child starts to have communication difficulties with hearing people (Ohna, 2004). According to some of our participants, the ability to communicate about deafness with a DHH sibling increased with their growing awareness and acceptance of deafness. Other facilitators for communication mentioned in the interviews were growing up, a greater capacity for in-depth dialogues, and a need for independent handling of deafness-related issues.

Conversations between the siblings about coping with HL served the important function of mirroring and validating each other's experiences. This function seems especially important as hearing parents do not always provide such validation (Eichengreen & Hoofien, 2017). Every child needs someone who can admire, see, and approve his or her presence, abilities, and inner world (Kohut, 1984). The recognition and validation of the child's experiences are important in the context of identity formation at any developmental stage, but are particularly crucial during adolescence (Flum, 2001; Josselson, 1994). DHH children who grow up in a hearing environment need someone who can emphatically understand, give meaning to, accept, and confirm their experiences with deafness, and the DHH sibling has the potential to be that person. When our participants discovered their experiences resonated with those of their DHH siblings, it seemed to create what Josselson (1994) calls "a bond of affective mutuality", providing "a necessary sense of vitality that mitigates existential aloneness" (Josselson, 1994, p.97).

DHH sibling facilitates the integration of deafness into self-identity. Our participants described processes of comparisons to, identification with, and differentiation from their DHH siblings; these processes facilitated self-reflection and helped them integrate deafness into their self-identities. The formation of self-identity is a life-long, dynamic process that is essentially inter-subjective. Identity develops in a relational matrix, and identifications with others are the building blocks of this process (Flum, 2001; Josselson, 1994). The development of interests, values, and even careers is embedded in relations with parents, teachers, peers, and other identification figures (Flum, 2001; Josselson, 1994). DHH children who grow up in a hearing environment do not have many opportunities to socialize with other DHH children and adults. However, these peers could serve as role models or as focal points for comparisons, self-reflections, and self-assertions about coping with deafness, and self-definition (Israelite et al., 2002; Moeller, Carr, Seaver, Stredler-Brown, & Holzinger, 2013). DHH siblings fill this empty space, and they can do so even without any explicit communication about deafness.

It seems that growing up with another DHH person makes it harder to deny deafness or separate it from one's sense of self. The participants in our study said that witnessing their sibling's coping with deafness made them reflect on their own coping. When the sibling was seen as successfully coping with deafness, identifying with the sibling improved their own self-confidence and acceptance of deafness. Alternatively, as in any sibling dyad, comparisons could cause jealousy and decreased self-esteem. Another study has noted DHH siblings' rivalry when parents are hearing and one sibling is more skilled in spoken language than the other (Woolfe & Smith, 2001). We found that our participants' comparisons of their social competency in the hearing culture could merge with a subtler and more painful question of who was more "normal", at least when participants defined normality in terms of similarity to hearing people. This question can appear in familial and social environments that explicitly or implicitly transmit negative perceptions of deafness, weaknesses, or differences in general.

Potential of the sibling dyad to form a d/Deaf micro-community. Comparisons to and differentiations from siblings in coping with deafness can serve the need for self-differentiation and formation of a unique self-identity during the process of separation-individuation (Verona, 2010). However, we found that our participants often looked for similarities rather than differences. When they felt their deafness was an accepted and meaningful part of themselves, it was especially difficult for them if the sibling did not share this point of view. Having so few other sources of validation of their identity as DHH, their dependency on their sibling for supportive mirroring and identification was relatively high.

The descriptions of participants' identity formation as DHH persons could not be categorized into fixed phases or stages (see Leigh, 2017, for an overview of the development in research on deaf identities). The participants dynamically synthesized affiliation with hearing people, awareness of their HL, and affiliation with DHH people which changed in intensity over different life periods. Yet for some participants, the DHH siblings mitigated a sense of alienation, often generated in relation to the hearing community (Ohna, 2004), and increased their sense of affiliation by creating an alternative sibling micro-community. In one case, a sibling who was immersed in deaf culture facilitated our participant's affiliation with the larger deaf community.

DHH sibling enables dissociation from deafness in the search for self-validation. Some participants described what we interpreted as a negative projection of their feelings about deafness onto their sibling, e.g. being ashamed of the sibling's deafness. As young adults, they often looked back on this aspect of the relationship with regret. Yet projection serves to protect a person from intolerable parts of the self (Klein, 1963). In this respect, we suggest that distancing themselves from their siblings served their need to feel validated at times of their lives when the self was not strong enough to face social and familial pressures for normalcy, associated by the dominant society with a hearing identity. In the socio-cultural context of mainstream schools, many DHH children develop a hearing identity to increase their sense of belonging and avoid stigma (Leigh, 2017). By distancing themselves from deafness and relating it to a close family member instead, these participants could "safely" think about deafness and indirectly process it as part of their experience.

Parents' attitudes influence the siblings' communication and mutual support. Our findings indicated that although DHH siblings' relationships sometimes provided invaluable emotional support, this was not always the case. Some participants identified conditions that hindered siblings' support. For example, they described their parents' coping with deafness as influencing their own coping and, by extension, their relationship with the sibling. When parents' attitudes to deafness were negative or denying, participants felt distance, non-communication, and negative feelings in their sibling relationship. According to these participants, their parents' attitudes hindered the ability to accept HL and to communicate with the sibling about HL; this restricted communication and intimacy in the sibling relationship more generally. Previous studies on sibling pairs where only one is DHH or has a disability indicate that parental attitudes, such as decisions about the communication mode used by the family or stigmatic views of the deaf/disabled child, have an impact on the siblings' closeness and acceptance (Aronson, 2009; Bat-Chava & Martin, 2002; Berkowitz & Jonas, 2014; Dardeen, 2008; Wennick & Huus, 2012). We found a similar yet more complex pattern when both siblings were DHH: On the one hand, a familial atmosphere lacking in acceptance and not adapted to the siblings' communicational needs might strengthen the siblings' bond, compared to the bond with hearing family members. As one of the participants said, "It is me and her [the sibling] against all the rest". However, at the same time, the siblings may internalize their parents' attitudes, leading to detachment or rejection, both in relation to themselves and in relation to their DHH sibling.

The influence of parental differential treatment on sibling relationship and self-identity. Some participants described their parents as more involved with or protective of one of the siblings, while dedicating less attention to the other. For example, older sisters described their parents as more involved with the rehabilitation and social aspects of their younger brothers with HL, or they said their parents showed more understanding of their younger brothers' needs. This could lead to resentment in the sibling who received less parental attention, but at the same time, it could encourage a feeling of being more competent, mature, and responsible than the younger sibling. These findings join the more general expectations of older siblings, and older sisters in particular, to take on the role of caregivers and supporters of their younger siblings (McHale et al., 2013).

Parental differential treatment also occurred when there were gaps in the siblings' hearing level or skills in spoken communication. In Woolfe and Smith's study (2001), one participant talked about his experience as a signing sibling. This child felt that his hearing parents preferred to speak with the oral DHH sibling, leaving him isolated. Interestingly, the perspectives given by our participants were of those siblings who were skilled in spoken language. In a different way, they too felt disadvantaged. They described their parents as more involved, worried, and over-protective of the sibling who was considered more deaf or less "oral". The less hard-of-hearing or more "oral" sibling was then considered more hearing or "regular", which our participants felt freed them for a "normal" growing up in terms of maturity and autonomy. At the same time, as can happen with hard-of-hearing children (Meadow-Orlans, Mertens, & Sass-Lehrer, 2003), this advantage can be a double-edged sword, since the child's own difficulties may be overlooked. This pattern bears similarity to what is known in the literature about siblings without disabilities or hearing siblings. Hearing/non-disabled siblings may be expected to take care of or watch over deaf/disabled siblings and, depending on family dynamics, can feel enhanced empathy or overprotectiveness, along with feelings of over-burden, resentment, jealousy, or guilt (Aronson, 2009; Berkowitz & Jonas, 2014; Wennick & Huus, 2012). According to our findings, when these siblings are DHH themselves, they can identify with the DHH sibling based on their own experiences, while also feeling saved from the attitude of the family toward the sibling. The unique empathic understanding of the DHH sibling can even lead to taking the role of counselor in the family, a role which can foster a feeling of competency, but also be a significant burden.

Implications

As some of the participants indicated, parents who already have one DHH child may feel overwhelmed when another DHH child joins the family. They may react with shock, feel overburdened, worry about the children's future, or simply feel disappointed. However, having a DHH sibling may make a significant contribution to the well-being of the first DHH child, e.g. by relieving feelings of loneliness and difference or by providing special understanding that the parents cannot give. At the same time, it is important for parents to be aware of the need to foster support between the siblings by encouraging an open and positive familial dialogue on deafness. Parents and professionals also need to be aware of potential comparisons that siblings may make about coping with deafness and the implications for both self-perception and self-confidence. Potential implications of parental differential treatment should be noted as well, for

example, if parents are over-protective of one of the siblings, while over-looking the needs of the other. Finally, while we focused on sibling relationships, our findings are relevant to DHH children who do not have a DHH sibling, as they indicate the various ways these children can benefit from close relationships with other DHH individuals.

Limitations and Future Research

To the best of our knowledge, this was the first qualitative study designed to examine sibling relationships among siblings who are both DHH. Due to the voluntary nature of participation, a potential bias should be taken into consideration; e.g. we might be missing the experiences of siblings who had particularly bad relationships or who were reluctant to reflect on deafness. As the interviews contained the retrospective and current accounts of young adults, future research would benefit from examining the experience of children and older adults. In addition, our participants did not use sign language as their main communication mode and all attended mainstream schools; hence, the findings represent only a subset of experiences of the DHH population. Future studies should explore sibling relationships among signing siblings, siblings who study in schools for the deaf or co-enrollment programs, or siblings who have signing deaf parents. It is unknown, for instance, to what extent deafness is perceived as an important part of the sibling relationship, or how the relationship influences self-identity when a person has a much broader socio-cultural context to validate his or her deafness, or how experiences in schools for the deaf and the use of sign language interact with siblings' communication and emotional relationships. The findings of this study highlight some unique experiences, such as parental differential treatment, which call for research on the dynamics of families of children with HL. Finally, IPA is an idiographic approach concerned with the particular experiences of individuals (Smith & Shinebourne, 2012); hence, the study has limited generalizability.

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