

"Growing up with a sibling who is deaf/hard-of-hearing like myself":
Retrospective accounts



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The ecological-familial context of D/HH (deaf/hard-of-hearing) children

- More than 90% of D/HH are born to hearing families (Mitchell & Karchmer, 2004).
- D/HH individuals may lack opportunities to socialize with other D/HH children/adults.
- Up to 20% of D/HH children have D/HH siblings (Marschark, 1997)

The ecological-familial context of D/HH children

- World-wide increasing number of mainstreamed D/HH children due to technological, medical, legislative and social developments (Leigh et al. 2009).
- Mainstreaming does not necessarily mean true inclusion – D/HH children may face socio-emotional difficulties related to communication difficulties, social isolation and stigma (e.g. Fellingner et al., 2008; Van Gent et al., 2012).

Can the relationship with a D/HH sibling provide source of support?

Importance of sibling relationships

- Sibling relationships influence children's psychological well-being and the development of social skills.
- They are associated with social-emotional, behavioral, cognitive, and educational adjustment (Dunn, 2007).
- In the face of low parental or peer support, warm and supportive sibling relationship protect against depression or loneliness (Milevsky & Levitt, 2005).
- Sibling relationships are a powerful source of support in adulthood and predict well being in old age (McHale et al., 2013)

Sibling relationships in the context of children with disabilities

- Most research focused on the impact of children with disabilities on the none-disabled sibling/family members.
- Relatively few studies focused on how the child with disability experiences his/her family.
- Deaf children may suffer from isolation in non-signing families (Macaulay & Ford, 2013; Berkowitz & Jonas, 2014)
- The presence of deaf siblings enhances communication accessibility in the family and the treatment of the deaf child as any other sibling (Marschark, 1997).

D/HH siblings: The perspective of D/HH children

- Deaf siblings reported feeling more close to their siblings when the siblings were deaf (Woolfe & Smith, 2001).
- Some depicted their deaf siblings as role models with whom they could consult, and mentioned that their deaf siblings could easily make a contact with them and understand them due to their own deafness (Woolfe & Smith, 2001).

There is lack of research on the meaning that D/HH children and adults ascribe to their relationships with D/HH sibling

Aims of the current study:

- To explore D/HH young adults' idiographic experiences of growing up with a D/HH sibling.
- To explore the meaning of these experiences to D/HH individuals' sense of self and identity formation.

Method

- **Participants:**

- Ten young D/HH adults (20-31 years-old).
- D/HH participants & siblings used oral communication.
- In all families the communication modality was oral.
- 7 participants had hearing parents, 3 had one hard-of-hearing parent.
- Participants & siblings had been individually mainstreamed in regular schools.
- 4 men, 6 women. 4 had older D/HH sibling (age gaps 6-14); 4 had younger D/HH sibling (age gaps 2-5); and 2 had a D/HH twin. Except for one all participants had also hearing siblings.
- Hearing level of the participants ranged from mild to profound deafness (bilateral 40-120 db).

Method

- **Procedure:**

- Participants were recruited via snow-ball method.
- In-depth interviews were conducted in face to face meetings (6), on-line video interview via Skype (2) and on-line written correspondence (2). Interviews lasted about an hour.
- In a half-structured protocol participants were asked to describe their relationship with their D/HH sibling since childhood and how the relationship influenced their coping and identity.

Method

- Qualitative study design
- Interpretive Phenomenological Analysis (Smith & Shinebourne, 2012).
- Dual interpretation process that involves both the meaning the participants give to their experiences, and the researchers' interpretation to the participants' meaning-making process (Pietkiewicz & Smith, 2014).

Method

- Five analytic stages:
 1. Thorough reading of transcripts + observations and reflections.
 2. Transforming initial notes into emergent themes.
 3. Looking for connections across the themes for each case including iteratively reviewing again earlier transcripts.
 4. Clustering the themes into superordinate themes.
 5. Iterative cross-case analysis resulting in final themes and verbatim extracts.

Results

Two super-ordinate themes were identified:

- *Each super-ordinate theme included sub-themes*
1. The impact of the sibling relationship on the interviewee's sense of self and the integration of the deafness in the self.
 - Unique twinship and a sense of belonging
 - Normalization and naturalization of the deafness or of the self-identity
 - Prevention of emotional and communicational isolation
 - Active emotional support: sharing, validation of experiences and consulting
 - Facilitating integration of deafness in one's self-identity
 2. Family dynamics related to acceptance and coping with deafness when there are two D/HH siblings in the family.
 - The impact of parents' attitude on the sibling relationship
 - The impact of older sibling on parents' coping with younger sibling
 - Parental differential treatment

Super-ordinate theme 1: The impact of the sibling relationship on the interviewee's sense of self and the integration of the deafness in the self.

Unique twinship and a sense of belonging

a. Alikeness:

- Special sense of alikeness, belonging and identification connected to a feeling of sharing a common difference.
- The sense of alikeness was expressed regardless of age-gaps, gender-differences or none-communication about deafness.

Unique twinship and a sense of belonging (aliqueness)

" I remember how... after he was born [...] I saw that he.. that my parents were extremely worried about him [...] and then I realized that... there is one more person in the world that is... alike me and... we are different from the rest of the world. I think that then I realized it."

Super-ordinate theme 1: The impact of the sibling relationship on the interviewee's sense of self and the integration of the deafness in the self.

Unique twinship and a sense of belonging

b. Closeness:

- For some (but not all) likeness feeling was combined with a close relationship: spending time together, being good friends, feeling very connected especially during childhood.
- The relationship was described as a unique and special bond, fostered by the shared deafness.
- One participant mentioned that the oral communicational needs created a sense of totality that facilitating both sibling closeness and isolation from other people.

Unique twinship and a sense of belonging (closeness)

"The impairment in itself gave us our own unique patterns of communication, which are based on vision, on reading lips like any other hearing-impaired person. And I think that the impairment connected us more [...] It is funny because we can be in a social situation and.. we talk and it is as if we are not with them at all, we talk between us and they look at us and I feel that she and I talk and they are watching. It means that there is a detachment here."

Super-ordinate theme 1: The impact of the sibling relationship on the interviewee's sense of self and the integration of the deafness in the self.

Normalization and naturalization of the deafness or of the self-identity

- The sibling made the deafness more natural in the family.
- Sibling normalized one's identity in relation to both hearing and deaf people.

((Normalization and naturalization of the deafness or of the self-identity))

"I personally had a great difficulty with that [afternoon meetings with deaf children], very much. Why am I going to the school of the stupid? [...] I am not a moron, a stupid, I am normal [...] [describing how she and her sister were laughing at one of the children there] We did not accept them. We said: we are not you [...] we are with the hearing, with the ordinary people, and you are a bunch of morons [...] we also have hearing aids but we are not like you. [Is it the way how she helped you to feel normal?] Exactly [...] I know how I perceived it that time – you are helping me, you are with me, we are the normal against... the deaf"

Super-ordinate theme 1: The impact of the sibling relationship on the interviewee's sense of self and the integration of the deafness in the self.

Prevention of emotional and communicational isolation

- Family's conversations: D/HH sibling was the person to turn to when it was hard to follow – for a joint play or for receiving explanation about what the conversation was about.
- The sibling's presence helped to heighten the family awareness to communication needs.
- In the social sphere: playing together in school; playing together after school when there is lack of hearing friends, even when there was a significant age gap.

Prevention of emotional and communicational isolation

"I come from an English family and when the 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 that it was difficult for us [...] We always had our own haven ."

((Prevention of emotional and communicational isolation))

"In family meals eh... many things pass the tables, people talk about many things and sometimes he is not following. So eh he feels most comfortable to ask me what, what did they say. And then I will tell him from the beginning until he understands, and other people not necessarily will understand how to explain it to him, like what exactly he missed, how backwards one should go [to explain] [...] how much is needed to emphasize the things in the funny punch [...] sometimes I tell him: listen, I did not hear that too. Which means [for her brother] that it is alright, if she didn't hear then what my chance is [smiling] [...] I understand what he is going through, so like... I have more patience to help him than other hearing people"

Super-ordinate theme 1: The impact of the sibling relationship on the interviewee's sense of self and the integration of the deafness in the self.

Active emotional support: sharing, validation of experiences and consulting

- Explicit sharing, supporting and advising – especially between young brothers and older sisters.
- Childhood conversations focused on social coping.
- In adulthood – with a growing independence and separation from parents – focused on practical coping (university, fitting hearing aids, etc.).

Active emotional support

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

Super-ordinate theme 1: The impact of the sibling relationship on the interviewee's sense of self and the integration of the deafness in the self.

Facilitating integration of deafness in one's self-identity

a. Role model and mutual influence:

- An older sibling can serve as a role model for how to cope with deafness, as well as influence in directions opposed to parents (taking hearing aids off, dislike for speech therapy).
- A younger sibling can also influence by making the older sibling more socially close to the Deaf community and more accepting of deafness.

Facilitating integration of deafness in one's self-identity (role model)

“Because they [her big brother and her father] were hearing impaired and I saw that they... are okay and... they don't have problems in... areas in life, so ... it gave me more confidence in my life, i.e. that I am hearing impaired it is... different though but.. it can be handled with“

Super-ordinate theme 1: The impact of the sibling relationship on the interviewee's sense of self and the integration of the deafness in the self.

Facilitating integration of deafness in one's self-identity

b. Comparisons:

- Sibling served as a point of reference that facilitated self-reflection with regards to coping with deafness, even when there was no explicit communication (e.g. should I lengthen my hair and hide the hearing aids like my brother does?).
- Comparisons in the social domain when one of the siblings had social difficulties: feeling that I cope better, or putting my difficulties into proportion; or alternatively jealousy and low self-confidence
- Participants built their self-definition in relation (similarity or contrast) to their sibling's identity.

Facilitating integration of deafness in one's self-identity (comparisons)

"As a child I didn't see myself too much as a hard of hearing [...] because everything is relative. You see someone who hears worse, then you can feel good [...] 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"

((Facilitating integration of deafness in one's self-identity (comparisons)))

"I all the time compare myself to her. She is successful from the social perspective, I get frustrated, my self-confidence goes down. And I follow her [...] imitate her in social situations, 'cause I all the time compare myself to her. [During childhood and adolescence] I always had the will to show that I am normal [...] by being involved in conversations, talk, talk, voice something, show high involvement in the interaction, even if it comes at the cost of shoving my sister away from the conversation aggressively [by not explaining to her what she didn't hear]"

Super-ordinate theme 1: The impact of the sibling relationship on the interviewee's sense of self and the integration of the deafness in the self.

Facilitating integration of deafness in one's self-identity

c. The sibling as representing a denied or unwanted part of the self:

- Especially during childhood and adolescence, shame of deafness could result in projection of negative attitudes towards deafness into the sibling.
- Denial, total non-communication about deafness between siblings and emotional distance.
- In adulthood – sorrow and regret.
- Feeling that only the sibling is deaf, wishing that the sibling were not deaf, disappointment, impatience for the sibling's communication needs, shame of the sibling.

((Facilitating integration of deafness in one's self-identity
(sibling represents unwanted part of the self)))

"When I was a child I took off the hearing aids [...] and it seems that quite quickly she 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 [laughing], eh but in a more meaningful way because each of us had her own occupations and social circles"

Facilitating integration of deafness in one's self-identity (sibling represents unwanted part of the self)

"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 him too. So it is a much more difficult shame, since I need to carry both my and his shame. Here we are both fucked up [...] double shame [...] unless I... yes, choose to say: you know what, go fuck you [...] but you can't, you can't, because he is connected to you. Once I cut him there appears the... compassion, the sorry feelings "

Super-ordinate theme 2: Family dynamics related to acceptance and coping with deafness when there are two D/HH siblings in the family.

The impact of parents' attitude on the sibling relationship

- Participants who identified some difficulties in the sibling relationship related them to the familial atmosphere in which they grew up.
- Siblings internalized or suffered from parental negative perceptions of deafness, denial, misunderstanding and pressure for normalization.
- Parental attitudes resulted in emotional distance, non-communication or non-acceptance in the sibling relationship.

The impact of parents' attitude on the sibling relationship

“...In the relationship between me and my brother there is repression and denial [...] Father said: there is no hearing problem. Be a man [...] [I am] so mad at father [...] because 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. [...] We are hard of hearing that grew up in the hearing world, with mother and father that try to normalize us [...] So that our communication is with masks too, many times it is normal instead of simply talking”

Super-ordinate theme 2: Family dynamics related to acceptance and coping with deafness when there are two D/HH siblings in the family.

The impact of older sibling on parents' coping with younger sibling

- Parents were worried/negative when younger sibling was born. Sometimes delaying or avoiding having a third child.
- However usually older sibling 'paved the way' for younger one: parents were more aware of deafness, started rehabilitation earlier, compensating for earlier mistakes, less anxious and more accepting of deafness.

((The impact of older sibling on parents' coping with younger sibling))

"I felt that they [parents] accepted me [...] I don't think it was very difficult 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 more alright with him, then they were less worried about me in this respect."

Super-ordinate theme 2: Family dynamics related to acceptance and coping with deafness when there are two D/HH siblings in the family.

Parental differential treatment

- Some participants described that the parents were more protective or involved with their sibling comparing to them, and they were more holding difficulties for themselves: Older-sisters to younger brothers; HH siblings to D sibling.
- HH sibling considered 'regular' comparing to the D sibling, sometimes even advising the parents with regards to the D sibling – feeling competent + overburdened
- Mixed feelings in the HH of: resentment, feeling sorry for the D sibling, identifying with the D sibling, escaping from D sibling's 'doom'

Parental differential treatment

"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 hearing impaired 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."

Discussion

- Unique rich and complex accounts of D/HH sibling relationships, both retrospective and ongoing.
- Significant potential of D/HH sibling to provide emotional support by influencing the development of the self and the inclusion of deafness in the self.
- Some aspects (like twinship experience) are present almost by default. However, development of closeness, active support and intimate communication depend on acceptance of deafness in the family.
- Parents influence the acceptance between hearing and deaf siblings (Bat-Chava & Martin, 2002). So is the case when both siblings are D/HH.

Discussion

The mechanism by which the D/HH sibling provides significant mental support:

- Sibling fulfills the basic emotional need for twinship. Kohut (1984): the sustenance of the self is kept throughout life by the presence of someone who is felt to be essential similar. It allows since infancy "a vogue but intense and pervasive sense of security as [the child] feels himself to be a human among humans" (*How does analysis cure?*, p. 200).
- Sibling fulfills the need to feel one's identity as natural and ordinary (Watson, 2002), whether it be 'D/deaf', 'hard of hearing' or 'hearing with hearing aids'.

The mechanism by which the D/HH sibling provides significant mental support:

- Sibling can compensate and prevent feeling of social, emotional or communicational isolation. Widens finding from other studies (Marschark, 1997; Woolfe & Smith, 2001) to none-signing siblings as well.
- Supportive communication: sibling serves an important function of mirroring & validation (Kohut, 1984; Josselson, 1994) of the other sibling's experiences and identity as a D/HH person in a hearing world.

The mechanism by which the D/HH sibling provides significant mental support:

- Providing identification figure in the process of identity formation (Josselson, 1994).
- Integration of the deafness in the self, first by simply making the deafness attend.
- Sibling can be a role model, or provide a point of reference for self-reflections and definitions.

NOTE: When sibling is seen as coping successfully it can foster self-confidence and acceptance of deafness; or alternatively lead to jealousy and low self-confidence.

Social comparisons may cover internal question with regards to who is more 'normal' or 'hearing', especially in families who value normalization.

(((The mechanism by which the D/HH sibling provides significant mental support)))

- Sibling can represent the unwanted part of the self when there are negative feelings towards deafness (e.g. emotionally distancing from the sibling, wishing sibling were not deaf, shame of the sibling).
- Projection is an unconscious attempt to get rid of intolerable parts of the self (Klein, 1963).
- Projecting negative emotions into the sibling served the child's need to feel normal and 'alright' at times of life when his/her self was not strong enough to face social and familial pressures for normality.
- Distancing from deafness and relating it to someone close may have allowed the child to 'safely' think and make internal processing of deafness.

((Facilitating integration of deafness in one's self-identity))

(sibling represents unwanted part of the self)

*"I don't remember when she was born, [but] when she started to go to kindergarten and afterwards she had the deaf friends, that was very cute. **That is what I remember, that it was the cutest thing that I had ever seen.** [...] They [the deaf children] can tell you if they want to eat, drink, play. They say: come come, I want to play [laughing] [...] **[so you remember that you were enthralled by that then?] Yes, it was very cute. [But you felt that it was something that belonged more to her?...] More eh.. yes. It always belonged more to her than to me I think ."***

*"The whole family we learned a bit sign language at the beginning when she was small, until she stopped signing [...] It was very nice. The parents eh... like... we were not signing between us too much. I think that... it's a shame, because had we signed maybe [her sister] would have related to it more. [And do you remember how it was for you when you started with the signing?] [...] **between us we did not sign, we signed only with [her 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 ."***

Implications

- Parents may initially feel devastated when having a second child who is D/HH. It may help them to know that this ‘addition’ can contribute significantly to the well-being of their deaf child, given that parents enable such development (e.g. allowing open and positive familial communication about deafness)
- Important to pay attention to potential comparisons that siblings make and their implications for their self-perception and confidence.
- Implications of parental differential treatment with respect to birth order, gender or differences in hearing level: More involved and over-protective with one of the siblings, overlooking the needs of the other.
- The findings highlight also the needs of mainstreamed D/HH who do not have a D/HH sibling. By the same mechanisms children can benefit from a close identification figure who is D/HH (such as in “older sibling” projects).

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Thank you

