ADVANCES IN PEDIATRIC RESEARCH

Put your ears on! Deaf children's embodied experiences with human and technological interventions

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Abstract

Background: This paper considers the voices of deaf children and their parents in Belgium's Flemish community.

Methods: This study is part of a larger longitudinal project on early interventions in families with deaf children. We open up questions of identity and belonging for empirical examination by exploring the unrecognized borderlands of a particular childhood in a particular society which is guided by the quest for physical, social and mental health perfection. Qualitative data were obtained from interviews with parents and children with congenital hearing loss but no other impairments.

Results: It is argued that children as meaning makers enact difference or sameness as a means of participating in wider social encounters. Changing contexts and social encounters, together with expectations of how a deaf child is supposed to behave, add an element of contingency, of fluidity to children's sense of self.

Conclusions: Dominant discursive practices of a fixed all-or-nothing position are challenged or rejected.

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Introduction

How do congenitally deaf or hard of hearing children think of themselves: of their identity and their belonging? In this paper we set aside the institutionalized binary notions which, for over a century, have constituted conflicting ideas of good care for prelingual deaf children. From a professional and policy point of view, the possibility to hear and speak is categorically set as the standard for a normal, happy and healthy child. Accordingly, the absence of these capacities creates a generalized identity construction of the child as deaf or disabled, with the implied risk of diminished personhood [1]. Listening to the voices of children themselves, and their parents, we open up questions of identity and belonging for empirical examination.

According to the World Health Organization's terminology, deaf children are categorized as "children with disabilities," and in need of prompt medical attention [2]. National policies should therefore provide for early detection of hearing

impairments and rapid intervention. This, it is suggested, is the best way of ensuring equal opportunities for deaf children in society [3]. In Western European countries, there is indeed a trend in diagnosing hearing loss in children as early as possible, and to intervene promptly in case any hearing loss is identified. Today, about 80% of western European children found to have profound bilateral hearing loss undergo cochlear implant surgery before the age of three years [4]. Cochlear implantation is considered the most effective treatment for deaf children and is said to give them access to the world of sound and spoken language, and to prepare them to participate in mainstream education and society [5]. Research has shown that early cochlear implant surgery is of great benefit to profoundly deaf children. As a consequence, parents are advised to have the operation carried out when their child is only a few months old [6].

All of these recommendations have been adapted into policies and practices in Belgium's Flemish community, where the present study was conducted. The neonatal screening program is well established, and diagnosis of a hearing impairment is followed by rapid medical intervention [7,8]. Present efforts to tailor public practices are said to correspond to the social, educational and communicative challenges facing deaf children in the 21st century [9,10]. Modern scientific assumptions and beliefs about the salvation of children [11] and about the need to act fast to normalize the child have created a public view of well-performing, autonomous, integrated and self-confident children who receive the necessary support [12]. The emphasis on oral language acquisition and development of conventional social skills serves societal demands, assigning individual and parental responsibilities and prioritizing the need and the obligation to speak and to participate in a hearing world [13].

There are however grounds for questioning, and the different framing of current practices. These practices rest on a very narrow understanding of deafness, to which "evidence-based" success stories of early medical and technological intervention are central. Evidence for the wider implications of deafness, for its profound influence on children's identities and on parental trust and sense of competence, is more or less ignored [14,15,16,17].

The concept of deafness on which current practices are based is also a profoundly ahistorical one. For some scholars, current practices have to be seen against the history of oppression and neglect of the deaf, and the transformation in deaf consciousness which emerged in the 1970s, partly as a result of research on the sign languages of deaf people [18,19]. Within this newer perspective, some use the term "deaf" to refer to membership of a distinctive sign language-using community: a community of people with a different linguistic and socio-cultural heritage and identity from hearing people. The term "deaf" is then used to refer to people who consider themselves as hearing impaired and as experiencing consequent disabling effects in society [20,21]. Here, for reasons that will become clear, we avoid making this deaf/non-deaf distinction.

Kermit argues that two alleged antinomies distort discussion of the precise meaning of the deaf child's best interests [22]. One side tends to consider deaf children as needing repair and remediation by experts, both physically and socially. The medical (individual) model of disability is traditionally associated with this view, also supported by a hearing (speaking) majority. Within a social (constructionist) model of disability, deafness should be viewed as a function of the interaction between the individual and society. Remediation or repair of societal and structural barriers is the biggest challenge. A socio-cultural (deaf) perspective fits well within the second perspective on disability [23].

This is an ideological and essentializing debate, in which little attention is paid to everyday lived experiences in one society or another [24]. The deaf child is then either a candidate for prosthetization, or a potential member of a distinctive community. Excluded is the attempt to explore what it means to be a deaf child, or to parent a deaf child. Although access to healthcare, education and rehabilitative care in Flanders, Belgium, can be considered very equitable, deaf children's voices are mostly lacking or become decontextualized, as is the case more generally.

The few studies that do listen to and consider deaf and hard of hearing children emphasize the need to further explore identity issues and questions about

social wellbeing [17,25,26]. As Wheeler demonstrated in a study with young cochlear implant users, identity is a flexible concept and young people do not position themselves in fixed or one-dimensional categories such as either deaf or hearing [27].

The aim of this study was to explore deaf children's perceptions of their deafness, and give voice to their experiential knowledge in interaction with parents. In what ways do Flemish children's narratives refer to deaf or hearing identities, or to "something in between"? By foregrounding children's voices, we position this study within a micro-sociology of childhood with underpinning concepts of children's agency and figurations of social relationships [28,29]. Children's voices are then not separated from, or set against adult voices but are included in a broad spectrum of mutual context-dependence of children's, parents' and significant other's achievements [30]. Consequently, the use of specific theoretical paradigms is considered as hindering the researchers' open attitude of emergent listening which proves to be crucial in understanding meaning and experiences of participants.

We acknowledge Castro's [31] (473) delineation of children's subjectivities that:

… consist of ongoing processes decentred from the individual unit, the person as a whole, made to circulate among very diverse elements of the social world: symbols, language, norms, values, objects, tools and machines etc.

Methods

This study is part of a larger longitudinal project on early interventions in families with deaf children. In 2006–2007, 16 families with congenitally deaf or hard of hearing children (between 5 and 7 years old), living in Flanders (Belgium), and screened by a new hearing test, were included in the research. Flanders is a world pioneer in screening for hearing problems. The current hearing test is an adapted version of an existing Automated Auditory Brainstem Response Audiometry (AABR) test that is labeled the Algo test. This Algo test is administered by the preventive health nurse in all

infant consultation schemes to babies at age four to six weeks from 1998 onwards [32]. Since its introduction, more than 95 percent of all babies have undergone the Algo test. As a result of using these tests, figures reveal that one to two children per 1000 births are born with a substantial degree of bilateral hearing loss. For Flanders, this implies that approximately 70 children are born deaf every year. About 90 percent of these children are born to hearing families [8]. Recruitment of families for this study was executed by Kind&Gezin, the child welfare organization of the Flemish community of Belgium (for additional information about the research population, see Table 1 and Table 2) [32].

The first author conducted two interview rounds with the parents when their children transitioned from kindergarten to primary school. The parents were asked to recall their experiences and decisions since their child's birth [32]. Seven years later, the families were contacted again and, with their children's consent, five of them agreed to participate in this study. Two families had more than one deaf or hard of hearing child. During this second phase of interviews (conducted in 2014), the children (n=7) were 12 to 14 years old and transitioning from primary to secondary education. None of the parents were deaf. The children explicitly agreed to share their personal experiences.

Before the first author visited each family, the interviews conducted 7 years previously were re-studied and structured in order to start with a general impression and tentative knowledge of the family history. Parents and children were visited at home and given a general presentation of the results of the earlier research phases, giving them the opportunity to ask questions about the previous phase of the project. Most interviews with children were conducted in the presence of at least one parent, which turned out to be an additional strength in the mutual conversations. Children and parents were comfortable in each other's presence and shared their views with no sense of being tested. Only Kobe & Marthe's mother invited the researcher to do the interview in the children's own bedrooms in their absence. The interviews lasted between 60 and 90 minutes. Interviews were audio-taped with the parent's and child's consent and were

verbatim transcribed afterwards. All names are anonymized.

Table 1. Characteristics of the children interviewed in 2007

Families contacted	First announcement	69
	Reminder	23
Respondents (households)	After first announcement	15
	After reminder	1
Parents participating in interview	Mother	10
	Mother and father	6
Included deaf children per family	1	15
	2	1
Gender of child	Male	8
	Female	9
Age of child at time of interview	5	1
	6	9
	7	7
Hearing loss of child	Moderate (41-70dB)	4
	Severe (71-90dB)	2
	Profound (>91dB)	11
Type of hearing aids[1]	Bilateral traditional hearing aids	8
	Unilateral cochlear implants	3
	Bilateral cochlear implants	6

The interviews were semi-structured, providing flexibility to adapt to the situation. We translated research questions into interview question that could provide thematic knowledge and also contribute dynamically to a natural conversation flow to generate spontaneous and rich descriptions [33] (132-133) (for more information on the interview guide, see Table 3, and on the craft of qualitative research interviewing, see the work of Kvale and Brinkmann [34]). Each session began by situating the interview in the framework of the larger study and recalling some basic aspects of the previous interview. The parents were then asked a general question about their experiences since then. The interview with the child started with general questions about their identity and how this related to their hearing impairment [35]. An example of such a question is: "How will you present yourself when entering a new group of people? Do you consider yourself as different than other children? How?" The interview also included questions about how others reacted to the child (e.g. "How do other children react to your hearing aids?") and questions about their possible belonging to different sociocultural worlds (e.g. "Do you know sign language? When/where do you use it? Would you like to have more contact with other deaf children?").

Transcription and coding of the narratives was executed using NVIVO® software and this supported the exploratory first steps in the analytical phase. Texts were written and read with background information about previous experiences with the same families in mind. An inductive coding process yielded a collection of themes which served as meaningful guides during the iterative, analytical phase. The themes emerging from this first interpretative process were: presentation of self, perception of hearing aids, use of frequency-modulated (FM) devices, experience without sound, description of deaf or hearing status, reactions from the environment, experiences at school, interventions of special educators, and thoughts about future deaf children.

Children's experiences were catalogued according to a summative content analysis [36] but showed insufficient and fragmented experiential meaning. A second analytical stage of deconstruction yielded a more complex, detailed description of the interactive meaning of children's and parents' perspectives. The analysis of deconstruction is marked by an attention strategy, which suggests forgetting about the idea that responsiveness can be directed. Trying to cling to specific reference frameworks almost certainly leads to a loss of sense [37].

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[1] Traditional hearing aids and cochlear implants are both hearing aids but with the substantial difference that the former refers to assistive technology that does not require surgery.

Table 2. Characteristics of the children interviewed in 2014

Child interviewed	Anna	Dieter	Dorien	Kobe	Marthe	Sien	Lara
		Siblings		Siblings			
Age at time of interview	13	14	12	14	13	13	13
Interview context	- Living room - Mother present	- Living room - Mother present	- Living room - Mother present	- Bedroom - private	- Bedroom - private	- Kitchen - Mother, father and sister present	- Living room - Mother and father present
Diagnosis as described by parent	Deaf	Hard of hearing	Hard of hearing	Deaf	Deaf	From severe hearing loss to deaf	Deaf
Type of hearing aids	Cochlear implants	Hearing aids	Hearing aids	Cochlear implants	Cochlear implants	Hearing aids/cochlear implants	Hearing aids
Age at time of first use of hearing aids	Both CI at 6 months	2 years	6 months	First CI at 18 months; second CI at 6 years	First CI at 8.5 months; second CI at 2.5 years	First HA at 3 years; first CI at 11 years; second CI at 12 years	6 months
Number of children in the family	3	2	2	4	4	3	1
Education (Primary/Secondary)	Mainstream/ Mainstream (socio-technical)	Special school for the deaf/ Mainstream (technical)	Special school for the deaf	Mainstream/ Mainstream	Mainstream/ Mainstream	Mainstream/ Mainstream (vocational)	Special school for children with learning disab. Mainstream (vocational)
Sign Language	No practical knowledge	Good practical knowledge – no longer used at home or at school	Good practical knowledge – used at school, not at home	Very good practical knowledge – no frequent use at home; no longer used at school	Very good practical knowledge – no frequent use at home; no longer used at school	Limited knowledge of basic signs	No knowledge
Parents	Mother: cleaning lady; father: employee in elevator company	Mother: cleaning lady; father: no more contact. Divorced	Mother: cleaning lady; father: no more contact. Divorced	Mother: educated speech therapist/ audiologist working at home; father: independent creative	Mother: educated speech therapist/ audiologist working at home; father: independent creative	Mother: Early childhood worker at kindergarten; father: disabled by work accident	Mother: housewife; father: employee in public railway company

CI: cochlear implant; HA: hearing aid

Instead, inverting the stories and themes, confronting the two voices while forgetting about the initial questions and tailoring creative and critical concepts of human experience, yielded two central ideas of the embodied experiences of deaf children. These two themes were about a temporal way of expressing who the children are and what they need. The two meta-themes were discussed with the second and third authors and used to structure this article and we emphasize that the purpose of this study is not to generalize findings for deaf, cochlear implant or hearing aid users. Rather, this study is an exploration of the unrecognized borderlands of a particular childhood in a particular society which is guided by the quest for physical, social and mental health perfection.

Results

Who we are: identity, technology, contingency

The teenagers to whom we talked were rarely inclined to present themselves as deaf. When entering a new peer group (e.g. during the transition from primary school to secondary school), their deafness was only mentioned if others made remarks or asked questions about the condition.

Marthe: I just tell them who I am but I never say "I am deaf," actually. I never say it. Sometimes they really stare at my hearing aids. And if other children start asking questions such as "What is that by your ears?" or "Why do you often say excuse me?", I will try to explain it as well as possible. Then I just say I am deaf, that it happened at birth and that I am not responsible for it.

Lara is diagnosed as hard of hearing and wears her hearing aids mostly covered by her long blond hair. She doesn't like to talk much and hesitates during the interview, waiting for her mother to jump in with possible answers.

Lara's mother: It is mostly the extra attention she receives, that unconscious attention she gets, from more people, isn't it? (Lara hums, waits…) That is something she finds annoying, she doesn't think it is much fun.

Interviewer: Can you describe why this isn't much fun?

Lara: Well, there was something like, "What are you doing here? You shouldn't be here, shouldn't you go to another school?" I had that kind of feeling once, but now that is completely over. When I said, "I have hearing aids, I can hear but not that well," I said that. Then they told me, "If someone bothers you, you should come to me" […] Like my best friend, I was playing with her one day and we bumped into two boys who were making comments like "Uh, what is that?" Then my best friend said:

"Don't you laugh at her or you can choose between the cemetery and the hospital."

Not all children sought approval from their peers. Insecurity or shame about looking different is not something that bothered Sien. On the contrary, her new cochlear implants were presented as funny, unique accessories which made her all the more acceptable and special as a young teenage girl.

Sien: I think it is fun, it is just a device. I tell them right from the start and they think it is nice and start asking questions. And I just say, "Well, I am deaf so you should pay more attention to me and speak clearly." Then they understand it right away and start making it cool. […] I can feel it you know. Here, there is a hole and over there is a bump (laughing and showing the difference on her skull), you should feel it, there is a hole in my head.

Sien's mother: She is constantly playing with it, you know, and uses it to her advantage, like "I have this and you don't have it." She exploits it to make it more beneficial, you know, which is really nice.

Except for Sien, being like other boys and girls is what preoccupies most children. The tangible situations in which they most often consider themselves as deaf are when they are in bed or in the bath – private, intimate places where hearing aids are left aside and sound is necessarily excluded. Since most Flemish deaf children with cochlear implants attend mainstream schools, they rarely have deaf peers to relate to and must adjust to situations where they are the only one with a different perception of sound. Visiting a public swimming pool, for example, was a challenging situation where they had to depend on lip reading,

gestures and/or sign language to be able to participate and did not really feel safe. All the children we talked to characterised noisy environments such as the school playground as the most difficult place to interact and be just like others. These were places where there are no teachers, therapists or parents to evaluate or help if communication is difficult. Open spaces with a lot of background noise make it hard for deaf children to be included in interactions, heard or seen by others. In this often neglected environment, no cognitive learning is going on yet it contains all the more micro situations of real life in which children like to participate. The use of a local dialect or the presence of larger groups of children chatting around them are also excluding factors for deaf children. Or as Marthe puts it:

Then I don't understand what they say and I repeatedly have to say "Excuse me" and I really don't like that.

The particular experience of the absence of sound felt boring for some and comforting for others. The children had an additional skill to manage the disturbance caused by noise and they used this in flexible ways according to their mood, feelings of self and interpretation of the situation.

Sien: It is very quiet then because you don't hear anything. You do "hear" the beating of your heart. But I turn them off [the hearing aids] if I am not feeling comfortable, when I have a headache and if I don't want to listen.

In the morning, Kobe waits as long as possible before putting his hearing aids on, which causes distress for his mother. He compared his behaviour to his deaf sister's habits, who wears them for longer, puts them on earlier and is fascinated by the different sound of a voice, with or without hearing aids. In Kobe's case, the hesitation to use his technical tools immediately had something to do with his sense of being by himself:

Kobe: […] of course when I am asleep I don't use them or if I want to read or study. Sometimes when I am using the vacuum cleaner I turn them off as well.

Interviewer: You do these kind of jobs in the house, nice. And what exactly is disturbing for you then?

Kobe: It doesn't disturb me but I would rather do these things quietly. Marthe puts her CI [cochlear implant] on immediately after she wakes up in the morning. I don't do that and I postpone it as long as I can, but Mum doesn't like that. Now, with my little brother J., I try to do it more often because he knows sign language but he doesn't understand everything.

Interviewer: … And why do you like your hearing aids being turned off?

Kobe: … Yes, well, it is much quieter then and I don't have to pay as much attention to my environment.

Most of the children wore their hearing aids all day long and the daily action of putting them on in the morning only differed in terms of the time taken to organize things before going to school. Components like batteries, FM tools or accessories for the cochlear implant were additional objects, making the organization of family routines more challenging for families with a deaf child. The task of checking if their children had all the items and tools they needed during the day was troubling for mothers:

Mother of Kobe and Marthe: Well, yes, in the morning it is a real rush, everything is timed to get everyone out of the house in time. And with Kobe it is a fight sometimes, yes, to … get up in the morning, come down and put your ears on. And everything will go smoothly, well, for me I mean, because communication will be easier. In the morning you always have something in your hands, putting things on the table, making coffee, having J. (youngest child) in my hands and then… having to use my hands to communicate is not natural for me (laughing). So, with Kobe, I regularly have to struggle and ask "Please, during the week, put your ears on immediately and I will try to complain less."

Children were creative in adapting to their technological devices and often saw themselves as no different from everyone else. Nevertheless, they wanted people around them to be considerate about their condition. If they talked about it or presented themselves as hearing or deaf, they decided when, where and why they did so. Probably, because none of these children were born to deaf parents, the

cultural divide of relating more to a deaf or a hearing world was absent from the interviews. In these cases, there is no reason to assume that the children are somewhere "in between worlds" because of their hearing impairment. They expressed no wish to have more contact with other deaf children or receive more information about deaf culture or the use of sign language. Since these children received an early diagnosis (before the age of one) and were prepared and trained to use their assistive technology from infancy, oral communication became part of the world they belong to and this was seen as the easiest way to connect with others.

Marthe: There still is a difference between hearing and deaf children [positioning herself as hearing in this case], especially when it comes to making friends. With sign language, you can't always express what you mean and who you are. You can show other children a lot by the way you behave, telling them things etc., but with deaf children it isn't as fast. […] But there are a few advantages of being deaf you know [positioning herself as deaf in this case]. The funny thing, although in fact it is very impolite, is that when Mum is complaining, I can turn my hearing aids off. But I don't do it, I am too ashamed to. Apart from that, we sleep very well. And you can fool people by like turning it off and letting them tell you a whole story and when they have finished you just say "I don't hear anything."

In trying to understand the children's perspective on deafness we asked for their opinions about a hypothetical situation of having a deaf baby in the future. This question turned out to be thought-provoking for some and very odd for others. Except for two children, who didn't know how to respond, the other five children had a common perception of a situation that would be regrettable but by no means a tragedy.

Sien: I think it would be a pity, but not too much. I would teach them everything and I would contact someone who could do a cochlear implant, yes, because the sooner the better. Because they say then you will be used to it for later. I would immediately go to rehabilitation as well, so they can learn how to speak sooner and better. And I would say [meaning

to her partner], that you shouldn't feel sad about it, you should be happy instead.

We witnessed multiple voices in one child. One was the voice of a young citizen in society, confronting the barriers that deaf children still have to face. Another was the voice of a girl or boy trying to find out what love is all about. There was even a third voice, that of their parents, transmitting parents' feelings of trust or grief.

Need and belonging: dependence and free space

When their children are confronted with judgments or questions about their sensory difference, or the way they talk or behave, parents often help out by interpreting the situation. The voice of the child is coloured and shaped by the words, sentiments, and interactions he or she encounters at home. Asking children whether they consider themselves simply as deaf or hearing offers them a dichotomized split that fails to reflect the complexity of the children's sense of self. Parents add to this complexity by assigning specific qualities to their children's behaviour.

Anna's mother, for example, contrasts her two deaf children in terms of the ways in which they adjust to particular situations, how they relate to others, and even how they fight. She describes her 19-year-old son C. as a "real deaf" person and Anna as a "hearing" child. Both the children are cochlear implant users and both have approximately the same degree of hearing loss:

Anna's mother: For her, it is really hard if she cannot hear. She feels much more lost than her brother, who adapts more easily. In fact she is even more deaf than he is but she does more with her devices. She always looks for "hearing deaf" who are talking at the same level. On trips organized for parents with deaf children, she is one of the better "hearing" children.[…] When they were younger, the way they fought drove you crazy, it was a kind of "deaf fighting." They yelled at each other very loudly; they didn't understand each other because they were not looking at each other's lips, not realizing that they didn't have their hearing aids on, then they became more and more frustrated, not

recognizing that they couldn't hear each other. It was really hilarious.

Even in families that are convinced of the benefits of using sign language and have experiential knowledge of having more than one deaf child, things weren't always that clear or similar to families with hearing children. The mother of Kobe and Marthe describes the difference as follows:

I have the feeling, how should I put it, that they are more on a little island, a little bit trapped in their cocoon; auditory, emotionally too, but certainly on a social level. By this, I don't mean that deaf people aren't social, not at all, but […] There seems to be a kind of subtlety about seeking contact with others, knowing how to react. And yes, other children, you should teach them how to share and be thoughtful of others too, but I have a feeling that it is much more fine-tuned in comparison to them [meaning her deaf children], it is less obvious, not that easy…

The family of Kobe and Marthe can be considered a well-off professional family, well-educated and well connected. This is not the case for the mother of Dieter and Dorien, who is struggling much more to receive recognition for her role as a supportive mother dealing with a social environment, including her family, who have not always been respectful towards her children:

They see it as something really simple, like," OK, they are deaf, they wear hearing aids" and otherwise nothing is wrong, when there is so much more to it. […] My father always says "It's a lot better now isn't it?" I say, "Nothing is better, it's exactly the same." There's a kind of taboo and you get the feeling that you're always trying to cope by yourself when everyone continues to think like that. Always denying things, not wanting to see it as just the way it is.

Dieter and Dorien appeared more dependent on their mothers' voice to articulate their thoughts and feelings about the hearing impairment. They covered their hearing aids and were susceptible to critical remarks or questions about their condition. Professional or parental support seemed to be more appreciated and more frequently requested than in the other families. All the parents were occupied with their children's future in society but the ways

in which they expressed these concerns differed significantly. The mother of Dieter and Dorien was more anxious about her children's future, their safety and ability to function independently in society. As long as her children's hearing ability was not declining, she said she felt OK. Kobe and Marthe's mother was more self-assured about her children's opportunities if only "They put their ears on"; but critical of the public policy on child healthcare in Flanders because interventions are narrowed to a medical narrative that never fits the real-life experiences of particular families.

Critiques and questions about the future development of deaf children are easily linked to the parents' responsibility.

Anna's mother: I think parents sometimes have too much information and are still hoping to get a hearing child back. When I see new parents like this I think "Man, just have some patience." You know, they get the diagnosis "Your child is deaf" and want to turn them into a hearing child. Tomorrow. It's technically possible, right? Give it time, take time to deal with it, make space, find out for yourself what it means to be deaf.

The way this responsibility is formulated by Anna's mother gives the impression of a secure and self-confident position in raising her children. According to the way she put it, deafness became "a hidden disability," making it all the more important that parents try to communicate all necessary information when deaf children are participating in public spaces. This is very different from Dieter and Dorien's mother, who was more confused, articulating feelings of guilt and a sense of being burdened with responsibility.

Dieter and Dorien's mother: One day, I told a friend, that it is somehow a double feeling. On the one hand, I still don't know where it comes from, and on the other hand, I know it can't get any worse. I kind of have peace about that.

Interviewer: Suppose you knew the cause of their hearing impairment, would it be different?

Dieter and Dorien's mother: Yes, because I would know the cause, I think that is important for them as well. Later, if they have a family of their own. One day they will become self-conscious about their

deafness and I would be able to answer their questions because a mother is supposed to know everything, isn't she? In the beginning I said, "I have created a deaf family…"

Some children require more intensive professional or parental involvement, as is the case with Dieter, who is afraid to talk about the technical aids he needs during class. At the beginning of secondary school, his mother had to intervene:

Dieter's mother: During that first year, he had a special educator. He was so nervous, really anxious that he wouldn't be accepted because of his hearing aids. He was so worried that he became ill and had to stay at home. So I talked to her and explained that he was too ashamed to ask the teacher to use the FM tools. We told them they would get things that had to be hung around their neck. So, she decided to talk in front of the whole classroom (Dieter was absent) and explained that Dieter was hard of hearing and needed different tools and that the teachers should pay attention to it. After that he seemed more at ease.

The presence of others who are not friends or family members was just one of the unquestioned interventions that demanded flexibility and perseverance from both children and parents. Professionals sometimes gave advice guided by personal beliefs or opinions about a "generalized" deaf child. Even if children expressed their thoughts about not wanting further assistance or guidance with schoolwork or other tasks, they still received implicit messages or predictions of future problems. For example, Kobe received two hours of support a week from a special educator but doubted if this was really helpful.

Kobe: The special educator told me that children who don't know me would start talking louder to me. She said they would sometimes do that and it would be more difficult for me to deal with the rest of society. But that is not the case with me; other children will not behave in deviant ways.[…] In fact, she doesn't do that much. Sometimes we make a plan or prepare a presentation for busy weekends, or I ask a question if there are things I don't quite understand. It is OK, but if I didn't have that, it wouldn't be a disaster.

Wearing hearing aids makes deaf children appear slightly different from other children, and in private situations, they adapt to this in flexible ways. At school, however, they preferred not to be special and the presence of assistive technology and professionals was considered as mostly intrusive or too visible to others. Especially the FM system, an assistive listening device which improves sound clarity and eliminates background noise, makes concentration for deaf children easier but at the same time it restricts their ability to escape from duties. It demands constant attention to the teachers' voice and limits their engagement with the whole class situation, in which other children have more freedom to decide to listen or not. Whereas parents had been decisive and compliant with professional advice on always using this tool during primary education, their teenagers in secondary school started negotiating about where and when they wanted to use it. Most of them were bothered by it and they searched for ways to either eliminate it or would forget about handing it to the teacher or find other excuses.

Anna's mother: […] They often forget that she is deaf. The thing we experience at school at the moment is that she doesn't like using her FM tool. Last year it was obvious that she needed it, especially for French and writing exercises, she really needs it. And we pushed and pushed just like we did with her brother C. and told Anna 'Please, tell the teacher to use that FM." But recently we discovered that she practically never uses it. […] So, this year we are giving her the benefit of the doubt. Who are we to decide that she should use it? Maybe, in comparison to her brother, she is doing better than before with her hearing aids, who knows. […] For her, it is extremely important to belong to the group, and with the FM, the social element is eliminated and she can't hear what the others say.

Dependence on technology is an important part of care for deaf children in society today. It becomes increasingly integrated into the child's sense of self [38]. For the deaf/hearing impaired children in this study, their distinctive reference to sound and to the human voice is shaped by these artificial aids. Apart from the financial cost of these items, which in Belgium is commonly covered by the health insurance system, there is a large amount of human

and technological intervention to be added to deaf children's list of duties. From birth, they are invited and urged to use the hearing aids constantly, practice oral language, have surgery for a prosthesis (sometimes more than once), and rehabilitate through speech training, social skills and balance exercises etc. These children are prepared for an experience of childhood determined and influenced by additional obligations and a sense of hard work rather than simply growing up like any other child. By the time they arrive in secondary school, it seems that they need more free space to decide and act for themselves.

Discussion

Essentialist notions of deafness and hearing underpin both medical-technological interventions in the lives of deaf children and their families, and the views of those who oppose these practices in the name of the deaf community [20,38,39]. In this study, we have sought to go beyond these notions, allowing deaf and hearing impaired children, and their parents, to speak for themselves. How do these children see themselves? Unsurprisingly, the answer is complex and contingent. Their heteroglossic voices constitute unfinalized identity negotiations that are resistant to theoretical categorization. In line with the work of Kermit and McIlroy [17,21,22], the recognition of intertwined discourses in socio-pedagogical practices for deaf children opens up new perspectives on appropriate care for deaf children and families, and indicates the limitations of relying exclusively on medical notions of "evidence" [40].

This account of five families with deaf children can be read as a journey through the challenges involved in trying to live an authentic life as an adolescent in Flemish society. For some children, this means that silence is appreciated and intrusive questions are avoided. For others, the absence of sound is scary whilst questions about a different appearance with technological aids are welcomed. Some deaf children like to be looked at and listened to, whereas others do not. While most people today make use of communications devices such as cell phones, deaf children have a more intimate relationship with their

hearing technology [41]. In playful ways they demonstrate agency by choosing to connect to or disconnect from external sounds and stimuli. Or, as formulated by one of the mothers, the question of "putting your ears on" serves as a parental request to relate to the child, regardless of assumptions about spoken or signed languages. We should not interpret the child's relationship to his or her technological aids or to his or her parents or caring professionals in terms of overcoming physical impairment or transforming the child's nature. Rather we can say that these children enact difference or sameness, as they feel appropriate, as a means of participating in wider social encounters. The barriers that they may come across are located both in their (developing) bodies and in their social and cultural life worlds. So swimming pools or playgrounds challenge their strategies of participation [9].

Children resist a unitary identity as deaf or hearing [39]. But it is not sufficient to simply add a third stable "in between" identity, as Bat-Chava proposes [20]. Rather, changing context and social encounters, together with expectations of how a deaf child is supposed to behave, add an element of contingency, of fluidity, to children's sense of self [17,39]. Consequently this position will change over time and context, and in many cases deaf and hearing statuses may coexist.

Freedom to decide when and where to belong is what connects (deaf) children. For some, perhaps especially those coming from vulnerable families, choices may be reliant on parents' and professionals' assistance and guidance. For others, freedom of choice means searching for unique, educational paths that resist default positions. In seeing deaf children as meaning-makers, capable of forming their own views on what constitutes a (deaf) identity, dominant discursive practices of a fixed all-or-nothing position (e.g. screened and diagnosed, deaf and disabled, implanted and cured, speaking and integrated, hearing and normal, signing and different etc.) are challenged or rejected. In the negotiated borderlands of children's embodied experiences, silent questions arise about spaces of emancipation that interrupt unified scientific conceptions of the deaf child's best interests. What if we could start by conceptualizing

dependency as a human gift instead of a regrettable weakness? [42]. What if we could make responsibility a shared choice rather than an individual burden? In the current debate on legitimate interventions in the deaf child's life world, these questions remain "Oh, so quiet" [43,44].

Ethical approval

The initial research protocol was approved by the ethical committee of the "UZ Brussel" university hospital (reference 2006/139).

Author contribution

The first author takes full responsibility for the collection of the data and for the overall content of the manuscript. Each contributor was equally engaged in the process of conception, design, analysis, revision and final approval of the study.

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