Empirical Articles

Congenitally Deaf Children's Care Trajectories in the Context of Universal Neonatal Hearing Screening: A Qualitative Study of the Parental Experiences

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Received June 25, 2010; revisions received November 11, 2010; accepted November 15, 2010

The objective of this study is to examine the early care trajectories of congenitally deaf children from a parental perspective, starting with universal neonatal hearing screenings. The analysis using a three-dimensional care trajectory concept is aimed at developing a basic typology of postscreening care trajectories. Children with severe/profound hearing loss, registered in the Flanders' (Belgium) universal neonatal hearing screening program, born between 1999 and 2001. Thematic content analysis of qualitative data collected retrospectively from participant's parents. Two basic types of care trajectories emerged; based on differences in care-use in the phase of further diagnosis and related parental experiences. Subtypes resulted from events related to cochlear implantation. Five trajectory phases were identified: screening, further diagnosis, care and technology, cochlear implantation, and reduction of care and were characterized by specific parental experiences such as confusion, disbelief, disappointment, and uncertainty. Those experiences relate to care professionals' acts and communication and the child's functional evolution. Early care interventions could benefit from coordinated transition between phases, parent support throughout the care trajectory, and a broad approach to deafness in professionals' communication.

Universal neonatal hearing screening programs (UNHSPs) are considered a major step forward in the early detection of congenital deafness (Grill et al., 2005). Literature shows that such early detection generally also leads to earlier care intervention (Declau, Boudewyns, Van den Ende, Peeters, & van den Heyning, 2008; Uus & Bamford, 2006), which is beneficial to the child's development (Nelson, Bougatsos, & Nygren, 2008). As a result, UNHSP acts as a gateway to early care interventions.

The issue of early care intervention is influenced by both developments in hearing loss (HL) detection and by new techniques, such as cochlear implantation, which has become a common intervention for young children with a severe or profound HL. Due to technological advances, the age of first implantation has been reduced to 4–6 months (Anderson et al., 2004). This is supported by scientific evidence on the effectiveness of early cochlear implantation in terms of oral language development and educational achievement (Eisenberg et al., 2006; Geers, 2004; Hehar, Nikolopoulos, Gibbin, & O'Donoghue, 2002; O'Donoghue, 1999; Stacey, Fortnum, Barton, & Summerfield, 2006).

Scientific research has been addressed, against this background, to elements such as educational aspects of deafness and language development (e.g., Hermans

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doi:10.1093/deafed/enq055
Advance Access publication on March 2, 2011

et al., 2008; Kluwin, Stinson & Colarossi, 2002; Marschark, Rhoten & Fabich, 2007; Meronen and Ahonen, 2008; Powers, 1999), rehabilitation care (e.g., Brown, Bakar, Rickards, & Griffin, 2006; Fitzpatrick, McCrae, & Schramm, 2006; Fitzpatrick et al., 2007; McCracken, Young, & Tattersall, 2008; McKellin, 1995; Storbeck and Pitmann, 2008), attitudes and perspectives of deaf parents (e.g., Christiansen & Leigh, 2004; Stein, Barnett, & Padden, 2001; The cyber-deaf, 1999), the evaluation of UNHSPs from a parental perspective (e.g., Tattersall & Young, 2005; Young & Andrews, 2001; Young and Tattersall, 2005) and ethical aspects, as evidenced in the articles by Balkany, Hodges, & Goodman (1996), Marschark (1996), Lane & Grodin (1997), and Nunes (2001) which focus on ethical views opposing cochlear implantation. Furthermore, in our previous research, we analyzed decision-making processes regarding hearing assistive technologies (Hardonk et al., 2010a) and multidisciplinary rehabilitation care (Hardonk et al., 2010b). Apart from the specific decisions and events characterizing care trajectories, literature also shows evidence for parental distress and reduced psychological well-being during the early care trajectory (Burger et al., 2005; Spahn, Burger, Löschmann, & Richter, 2004).

Research is often limited to the analysis of specific components of care trajectories, resulting in little being published on these trajectories as a whole. Nevertheless, a care trajectory has been defined as "a multidimensional sequence of care-related events" (Strauss, Fagerhaugh, Suczek, & Wiener 1997). The first dimension concerns the type of care that is employed: parents make decisions about the care and assistive technologies that their child is to receive. Scientific literature shows a limited number of studies into the decision-making processes regarding cochlear implantation, which transpires to be the most investigated care-related event. Examples can be found in the studies by Kluwin and Stewart (2000), Incesulu, Vural, and Erkam (2003) and Okubo, Takahashi, and Kai (2008). The second dimension is the evolution of the hearing-loss–related functional limitations of the child. It refers to the child's developmental evolution as a result of care and assistive technologies. These aspects of the child's development can be measured at certain points in the care trajectory, using validated instruments, or they can be reported after observations by parents and/or health care professionals. The third dimension reflects the parental experiences related to the care trajectory. Provision of care/assistive technologies and the development of the child induce different experiences, perceptions, and emotions. These aspects are a crucial part of the care trajectory as they can shape care-related decisions and influence parenting and parental well-being. Examples of empirical research in which parental distress related to cochlear implantation was analyzed—however independent from the notion of care trajectories—are the investigations by Spahn, Richter, Burger, Löhle, and Wirsching (2003) and by Burger et al. (2005), which show heightened levels of parental psychological distress related to cochlear implantation.

There are several elements that emphasize the need for a comprehensive investigation of the care trajectories of congenitally deaf children. First of all, a better understanding of the characteristics of the care trajectories could support the implementation of a program for early detection and care intervention, as well as practice among health care professionals. Second, generating relevant findings regarding parental experiences, related to early detection and intervention, supports the recognition of the perspective and needs of families, who are confronted with a congenitally deaf child, as an important aspect in professional practice. Third, extending the concept of care trajectories into the field of congenital disability not only offers new perspectives for research in this field, it can also act as a framework to assess priorities for future research.

Flanders, the Flemish speaking region of Belgium, offers an attractive setting for the analysis of deaf children's care trajectories. Primarily, in 1998, Flanders became a pioneer in implementing a Universal Newborn Hearing Screening Program based on automated auditory brainstem response (AABR) assessment (Verhaert, Willems, Van Kerschaver, & Desloovere, 2008). Evidence for the effectiveness of this procedure for testing is found in the systematic literature review by Thompson et al. (2001). In addition, the program has a high ratio of coverage in the target population—that is, the ratio tested versus non-tested newborn children in the period 1999–2001 was constantly above 90% (Van Kerschaver & Stappaerts,

2000, 2001, 2003). Second, in Flanders, different services for early care are widely available. Many of them are registered in the UNHSP certification program. Among these services, multidisciplinary rehabilitation centers (MDRCs) and ear-nose-throat (ENT) departments in hospitals are key actors. The MDRCs provide some further diagnosis alongside the multidisciplinary care, administrative support, fitting of traditional hearing aids, and referral for cochlear implantation (Hardonk et al., 2010a). The ENT departments focus on diagnosis, audiological care, and cochlear implantation. Third, from a financial point of view, cochlear implantation is highly accessible because it is fully covered by the Belgian Public Health Insurance. Fourth, as a consequence of the organization of the UNHSP and its collaboration with certified referral centers, early care interventions have become widespread, leading to an increasing number of children with a congenital HL being implanted in the first 12 months after birth (De Raeve, 2005).

Aim of the study

The central aim of this study was to examine the parental experiences with regard to their congenitally deaf child's early care trajectory, starting with the universal neonatal hearing screening. Using a parental perspective on the issue, descriptive qualitative analysis was used for the investigation of experiences related to the early care trajectory, which is aimed at developing a basic typology of postscreening care trajectories. Findings from the analysis support professional practice and assessment of priorities for future research.

Methods

Study Design and Data Collection

This study used a qualitative design, based on descriptive analysis of interviews with parents of a population of children with a congenital HL and free from additional disabilities, in the Flemish community of Belgium. Two additional inclusion criteria were defined.

First, because social factors and factors related to the care process itself were of primary importance in our study, we were attentive to possible interference by biomedical elements shaping the care trajectory. Therefore, the research population was selected based on three clearly defined categories of HL: (a) 41–70 dB (moderate HL), (b) 71–90 dB (severe HL), and (c) >90 dB (profound HL).

Second, a specific age interval was defined as an inclusion criterion. Initially, due to the fact that for data collection, parents were asked to recall past events and experiences, only children age 5 years and over at the time of the interview (thus born before 2001) were included to allow for the analysis of sufficiently long postscreening care trajectories. Later, based on the aim of our study, the upper age limit at the time of interview was set to 7 years, to coincide with the fact that the Flemish UNHSP was first implemented in 1999 (Van Kerschaver, Boudewyns, Stappaerts, Wuyts, & Van de Heyning, 2007). Using trajectory durations of between 5 and 7 years, all fundamental early care-related events were included in the analysis.

The clinical and sociodemographic information gathered by the UNHSP is the basis of recruitment for our sample. Considering the success rate of the program, the database can account for over 90% of the population of children with a congenital HL in Flanders (Van Kerschaver and Stappaerts, 2000, 2001, 2003; Van Kerschaver et al., 2007).

The population corresponding to the inclusion criteria was relatively small ($N = 69$), due to the low prevalence of congenital HL (approximately 1.4 per 1,000 births (Mehl and Thomson, 2002). Therefore, the whole population was contacted in the first wave of recruitment. To guarantee their privacy, all families were contacted personally by the organization responsible for the UNHSP and the UNHSP database (Kind en Gezin). Upon approval, the researchers were allowed to contact the collaborating families directly. Collaboration with Kind en Gezin was approved by the organization's Scientific Committee, based on the research protocol.

Nonrespondents were contacted again in a second wave of recruitment 3 months later. At that point, intentional sampling (Bunne, 1999) based on the sociodemographic information, available in the database of the UNHSP, was applied in order to allow for a maximum of social diversity in the selected cases (Arber, 2001). This supports the aims of our descriptive

analysis. The relevance of the criteria for intentional sampling was assessed through a study of the literature and interviews with experts. The selected criteria of differentiation were "province of residence," "ethnicity," and "poverty". The latter was defined based on six indicators: low household income, low parental educational level, no professional activity, low parental intellectual stimulation of children, poor housing, and poor health of the household members. A household was considered "poor" when three or more the conditions were fulfilled (Lammertyn and Luyten, 1990; Hardonk et al., 2010a). In total, 17 cases were studied ($n = 17$). An overview of the characteristics of the research population and the respondents is shown in Table 1.

Two methods were combined in the data collection phase. First, for each of the 17 cases two in-depth semi-structured interviews were conducted, using a check list of relevant topics based on the literature and interviews with several experts. In-depth interviewing is an adequate method for acquiring information about the social world (Miller & Glassner, 2004). Parents were asked to reconstruct events, decisions, and experiences in the care trajectory chronologically, whereas the interviewers asked additional questions from the check list, which included topics on the three care trajectory dimensions (Silverman, 1993). Second, because the care-related events had taken place maximum 5–7 years before the time of the interview, recall bias was an important concern in the design of the study. Therefore, a life-grid method was used in order to minimize recall bias while collecting information on the care trajectory (Berney and Blane, 1997; Blane, 1996). The life grid is a chronological scheme in which the onset and ending of care-related events are represented. Because this study is part of a broader research project, 4 grids were developed for different aspects of life: "care for the child," "child's education," "parents' occupational activities," and "family and the home." Every grid counts eight columns, each representing 1 year between birth and the time of interview. Different types of events are noted in rows, such as "outpatient rehabilitation care" or "care at home," on the "care for the child" grid. Events were then registered in a cell according to the aspect of life, the type of event, and the date it occurred. This scheme was used in facilitating and validating the chronology, dates, order of events, and general consistency of retrospectively collected information. This leads to a double check on the recalled information, at the time of both the interview and the analysis. Two researchers were present at each interview, one leading the conversation and the other filling out the life-grid and supporting the first interviewer. The interviews were recorded using a digital audio recorder, and the life grid was in full view during the interview. All interviews were transcribed verbatim for detailed analysis of the parental accounts (Silverman, 1993).

The research protocol as described above was approved by the "UZ Brussels" University Hospital Ethical Committee (reference 2006/139).

Analysis

The analysis was based on a phenomenological approach (Schwandt, 1998), which enables the researchers to acquire insights into how the parents made sense of their experiences during the early care trajectory. This approach emphasizes the role of the social context and the attribution of meaning by the respondents. It is respectful of the way individuals perceive the reality within a given context and it can show both similarities and differences between experiences of different persons (Silverman, 1993).

After the first round of interviewing, an intersubjectivity check procedure was implemented, based on open coding (Lewins, 2001). This means that a set of codes was used independently by the researchers to label fragments of text containing different elements that were reported by respondents as meaningful factors in the decision process. The set of codes was partially based on our topic list, although new relevant codes were later added when new topics emerged during the open coding process (Fielding, 2001). The life grid was used to support the open coding. Text fragments containing information on more than one topic were given several codes. The open coding process was followed by further discussion on differences between the researchers with regard to the definition and application of codes.

This procedure resulted in a first nonexhaustive set of relevant codes that were used as a check list revealing lacunas in the interviews of the first round. This in turn inspired the topic list of the interviews of the second round. Consequently, a high degree of

Table 1 Characteristics of research population and respondents

	N
Families contacted	
First announcement	69
Reminder	23
Respondents (households)	
After first announcement	15
After reminder	1
Parent(s) participating in interview	
Mother	10
Father	0
Mother and Father	6
Hearing characteristics of parents	
Moderate to profound hearing loss	0
No hearing loss	22
Total number of children included in research population	17
Included 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 (41–70 dB)	4
Severe (71–90 dB)	2
Profound (>90 dB)	11
Type of hearing aids	
Bilateral cochlear implants	6
Unilateral cochlear implant and unilateral traditional hearing aid	3
Bilateral traditional hearing aids	8
Poverty	
Yes	1
No	16
Province of domicile	
Antwerpen	4
Limburg	1
East-Flanders	6
West-Flanders	2
Flemish-Brabant	4

saturation with respect to the content could be reached in the second interview wave.

Furthermore, the set of codes that resulted from the open coding procedure led to the construction of a coding tree that was subsequently used to label all interview transcripts. The coding tree was conceived as a logical scheme of codes, representing different topics that were present in the interviews. Different levels in the tree represented the hierarchical structure into main topics and subset topics that can be identified from the content of the transcripts. All first-level codes in the coding tree contained at least one subset of codes, covering different aspects of the higher level codes.

The coding tree was further adapted in the process of coding all transcripts, resulting in several consecutive versions. Substantial input into the adaptation of the tree was given both by researchers and members of the project's interdisciplinary steering committee.

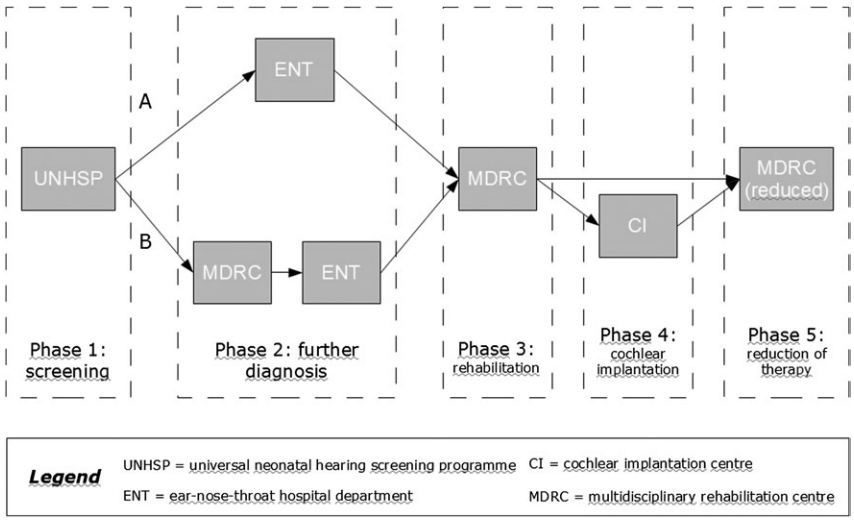

Figure 1

Thematic content analysis was conducted starting from a longitudinal perspective on the care trajectories. This method was implemented within the framework of a phenomenological approach of the research issue as it allows for a detailed thematic classification of parental experiences related to specific events. Therefore, coded text queries were made to classify all relevant text fragments for further analysis. In addition, contextual information was collected by adding surrounding parts to the selected, the text fragments resulting from our queries. This information was supported by the information registered in the life grids. All coding was carried out using NVivo7 software.

Consistent with the aim of this article and the components of our qualitative study design, we had explicitly chosen to describe relevant dimensions and phases in care trajectories without suggesting any causal relations other than those reported by parents themselves (Fielding & Thomas, 2001). The parental perception was considered the basis for our descriptive analysis. Consequently, information on the inclusion criteria and the criteria of differentiation applied in our recruitment strategy, were not part of the analysis or the interpretation of our findings, unless the parents reported on causal relationships.

Finally, all information in the text fragments was classified, recoded where necessary and subsequently interpreted into a basic typology of care trajectories, which provides the structure for reporting our results in this article.

Results

Because our descriptive analysis was aimed at the development of a basic typology of postscreening care trajectories, this typology is presented to support the findings that will be reported in this section.

Figure 1 represents two basic types of care trajectories that follow from our analysis: Type A is based on referral from neonatal hearing screening to an ENT department at a hospital, whereas in Type B, this referral is directed toward an MDRC. Within these basic types, care-use related to cochlear implantation is an optional event in the trajectory. In a number of cases, cochlear implantation was part of the trajectory, and this had no fundamental influence on the dimension of parental experiences in preceding or following events. Consequently, trajectories that include a cochlear implantation event are included as an optional event, leading to a subtype of the main trajectory types, rather than as a different type.

In the next paragraphs, the parental experiences shall be described as they are positioned within different phases with regard to care-related events and the child's functional limitations.

Phase 1: Screening

In this first phase of the trajectory, all care-related events are uniquely aimed at acquiring a clear diagnosis. At the

onset of this phase, the child's functional limitations, due to the HL, are unknown to both the parents and the screening program nurses. When the AABR assessment returns "refer" as a result, the procedure is repeated at least twice. As far as the parents' experiences are concerned, testing and retesting induced two different emotional responses: confusion and disbelief. This appears to be connected to the communication of the result by the UNHSP nurse. No differences were found between trajectory Type A and B cases as far as the phase of screening is concerned; therefore, this distinction was not be made in this section.

Confusion. Due to the characteristics of the screening method, the UNHSP nurse cannot provide a clear diagnosis to parents. Although the test has a high reliability, a "refer" result indicates little more than the necessity of further examination. Moreover, most of the parents shared the experience that the UNHSP nurse interpreted the "refer" result as a "strange result," possibly due to malfunctioning of the testing device. The testing and re-testing procedure is often experienced by parents as unclear and confusing. Jolien's mother reported:

> The nurse said, 'Yea, it must be the device.' That was a Tuesday. She went on, 'I'll make a house-call Thursday and then, err, I'll bring another device' Right then, we didn't suspect a problem, I didn't know the ALGO test and no one in our family has a hearing problem; we were innocently ignorant. Then it was Thursday and she came to us with another device, and there it was again "referral". And then; (clears throat) then she calls the ALGO helpdesk and … so she did the test another three times and then I started to worry because now I was confused, and I wanted to know 'What now?'. The very next day, she was back with yet another device …

Tinne's mother experienced the testing and retesting procedure in a similar way. The UNHSP nurse's interpretation of test results as a matter of the device malfunctioning, while not mentioning that the test results could also point towards an actual HL, was perceived as unprofessional by this mother:

> I went back again the next time, which was a week later. And then it (the device) didn't work, again! Still she (the baby) was peaceful and so on. And then, a week later, she made a home visit and this was the third test already. And again it looked like the device wasn't working properly. During all the testing, she never once mentioned that my daughter could be deaf or have a hearing loss.

The feelings of confusion were also reported by Bram's mother:

> Yes. Actually, yes, you …, you really can't diagnose with an ALGO. It gives an indication, of something, but what … they just don't know.

Disbelief. The fact that the UNHSP nurses were in many cases unclear about the meaning of a "refer" result, also led to a second type of emotional response: disbelief. In all these cases (which fit into this type of trajectory), the parents had no experience with deafness and they felt that the idea that their child might be deaf was strange and difficult to believe. As Dieter's mother reported:

> Yes, and they knew, right away that there was unquestionably he was hard of hearing, that something was wrong, you know. But we couldn't to accept that, we thought, 'It's not true.' I guess our reaction was because of the shock.

Even though the mother reported that it was mainly her husband who rejected the results, she was not only confronted with her husband's refusal, she had, moreover, no means of transportation to follow up after the referral had been made and visit a rehabilitation center. It should be noted that this family lived in poverty and had limited financial means.

The account of Jonas' mother shows her disbelief in connection to the fact that she and her husband were unfamiliar with deafness:

> Third time, yes it really took that long, after the third time you begin to ask yourself questions, 'How could this land on us?' and 'It doesn't run in our family, nothing, absolutely nothing'.

The suspicion of an HL often came as a complete surprise because most of the children were otherwise

medically healthy. It is equally almost impossible for some parents to detect HL without testing as it is almost unthinkable, as in the case of Jolien:

> And, I called by husband right away, he was at work, and he came home. We both told the nurse, 'That's impossible, she can hear.

Phase 2: Further Diagnosis

Trajectory Type A: referral to ENT department. In the first trajectory type, which is very common among the families participating in our study, the child is referred to an ENT department at a hospital after testing by the universal neonatal screening program. This referral is primarily aimed at further diagnosis, using specialized techniques. ENT specialists use extensive testing to develop an audiogram and to acquire a clear view on the degree of the HL. Brainstem Evoked Response Audiometry (BERA) is used in all cases to measure HL at higher frequencies and to obtain information on the functioning of the acoustic nerve. This technique is complemented by other tests. Both the diagnostic actions by medical professionals as well as the communication of the diagnosis lead to feelings of disappointment and uncertainty among the parents.

Disappointment—. The BERA testing procedure is of major importance in the parental experiences. For many parents, the fact that the test involves sedation has a considerable emotional impact. The testing itself acts as a demarcation between the lack of clarity during screening and the confirmation of an HL. The test is presented to parents as reliable and precise and offers the prospect of a clear diagnosis. The parents are, when the diagnosis is presented by the ENT specialist, in many cases disappointed. To be confronted with previously unknown problem their image of a healthy newborn child is shattered. The following quotes from the Bram and Dieters mothers clearly illustrate the parent's feelings:

> [Bram's mother] And then it dawned on me, and my world came crashing down on me, and I knew it, this is something very serious.

> [Dieter's mother] When we drove home from the hospital for the first time, then it really hit us.

In Jolien's case, the disappointment was connected both to the diagnosis itself and the way it was communicated:

> I also did that, uh yes, there I was with a trainee doctor I think, because I was absolutely not satisfied, certainly not satisfied, and then they did the test again and indeed the child is not responding. Uh, and they just told me right out, in my face, yes he will be deaf, and so I'm left to deal with that and for me that process was very upsetting.

Uncertainty—. Feelings of uncertainty were reported with regard to three different aspects.

First, the diagnostic procedures themselves were a source of uncertainty. Parents with no experience in deafness were suddenly confronted by tests performed on their newborn child and in some cases this was perceived as disturbing, as illustrated by the case of Lara:

> What it was all about, we knew pretty much nothing. And then we were suddenly, taken to a lab. And Lara had to have her feed. And there they put tubes, all sort of electrodes on her head. And that was the ABERA test. But yes, I mean, sorry but you were thrown into it, you know basically nothing. You're told by Child and Family, you need to go to Leuven for some tests, and that's all right. And then they come there with machines and tubes, and band-aids and commotions, and that was actually very intimidating, then.

Second, uncertainty also appeared in some cases between the testing and communicating the diagnosis. This was a result of the fact that the BERA, scan images, and other tests were done by audiologists, whereas the diagnosis, based on the test results, was presented by the ENT specialist. As a consequence, some parents had to wait for a week or more to receive the diagnosis. During this time, these parents felt uncertain about what could be wrong with their child, whether they should be worried or not, and what the future could bring. Bram's mother reported on these experiences:

> And, yes there were people who did the BERA—test but didn't tell us anything. So when we went

> home. Then we were left with … yea we still didn't know anything. Until you were allowed to consult the … They said nothing immediately after the test. Then we had to go back again. Because I remember asking myself, when we drove home the first time, 'Was is good news or bad news?'

It was only after all diagnostic tests had been complete that she and her husband received a diagnosis:

> Only after the MRI-scan, and when all test results, from BERA, were put together did I ask myself, 'Why did we have to have two BERA tests?'. Well it was all so long ago. And yes, you survive it, I mean …

Third, the diagnosis itself was a source of uncertainty in terms of the child's future care and the development. In the case of Tinne, the mother described this uncertainty:

> And then, I tell you, as we came out [of the hospital], he [the doctor] had just told us, 'Your child is deaf …' we really had to sit down for a moment. 'What did he just say? What was the word he just used? [The centre] What is that? What do they do there?' We really didn't know anything at all.

The parents are confronted with a very new experience. The characteristics and consequences of deafness, the terminology used by health care professionals and the available care are completely unknown to them. The cases of Jonas and Jolien provide examples of how difficult it is for parents to assess the consequences of HL:

> [Jonas' mother] What you are going along with, I mean… You know practically nothing, they've tested him, and he's at 110 dB. You know that's nothing, beyond the vibration, but … You don't realize…
>
> [Jolien's mother] "And they didn't tell us, now that is seems that your daughter is deaf, that there is always something, hey, like a cochlear implant. They just left us, until the following Tuesday, thinking 'Yes, this will be a child condemned to a lifetime of using sign language.' And, and …"

Kasper's mother stated that the meaning of the terminology used by the doctor was unclear:

> And then they had found out that he did not have [Organ of Corti] hairs… hair cells or something like that. They explained it to us in detail, but for us the language was difficult to understand.

Additionally, testing of other aspects, which could be related to HL, lead to uncertainty, as Lara's mother recalls:

> Then we had to go and see an eye doctor. We had to go to the doctor to do with hereditariness. And he, the eye doctor, I remember it very well, asked us, 'What have you come here for?' So we said: 'We have to because we have an appointment, we have to come here for an eye test for our child'. Yes, but why. Yes, because she apparently can't hear very well.

Feelings of lack of support—. The feelings of disappointment and uncertainty lead the Karlien's mother to suggest a type of support that she felt was missing:

> Well, the local support, really, from the moment that they told us there should have been some sort of in-between step, somewhere that you could turn to for some support.

Trajectory Type B: referral to multidisciplinary rehabilitation care services. This type of support appeared to be present in cases of children who followed a second type of care trajectory, in which they were referred from neonatal hearing screening to an MDRC. In centers equipped for the BERA, the assessment was done shortly after referral and parents were informed about the meaning of the screening results and further diagnosis. As in the case of Elise:

> On Tuesday we were referred to the rehabilitation centre, and next Friday the BERA assessment was done.

Not only was the time between referral and further diagnosis very short, the parents also reported extensive support from the multidisciplinary team, as reported by Elise's mother:

> We felt that the people there were concerned about us, there were psychologists present at that moment, and they were very kind and considerate, yes, we really received very good support.

However, in some cases, the MDRC was not equipped for BERA and therefore referred the parents to an ENT department at a hospital. In a few cases, this lead to a longer period between referral and BERA assessment. This was reported by Gella's parents:

> We went to the centre and they told us that he needed a BER assessment, so they made an appointment at the hospital, but we had to wait one and a half months. So we said, 'One and a half months, do we have to wait that long?'.

Furthermore, these parents did not experience close and extensive support during further diagnosis (Gella's parents):

> At the rehabilitation centre, they simply told us straight out 'She's deaf' and that we had to get a BERA assessment. Just like that. They didn't give any information. When we left we thought 'Our baby's deaf', but we knew nothing beyond the fact. We knew nothing about implants; we didn't even know anything about hearing aids.

Sien's parents were also referred to a rehabilitation center without equipment for a BERA assessment, so they were sent to a hospital, which lead to a similar experience of inadequate support. These parents responded by resisting the sedation necessary for the testing procedure:

> And then the answer came, 'look, what can you do, you can go to the hospital, and there they'll do a BERA test and that's done under sedation. I said, 'I'm not letting you sedate a baby of five-six weeks just for that. (Said emphatically) But they thought so, so they can test during the time she sleeps. Still, we had to go to the hospital. When we eventually got to the hospital, I had said to the man who took the intake test, 'I want to try, but you're not anesthetizing her, I'm sorry but you're not anesthetizing her and certainly not just for an investigation.' and certainly such a small child, my, my, my.

Subsequently, the test results were ruled invalid and were of little value to the care professionals at the rehabilitation center because no conclusions could be drawn. The parents were advised to observe their child intensively and report anomalies in the behavior and development of their child:

> Back at the rehabilitation centre they said that because the BERA assessment failed it was impossible for them to continue their work. They said: 'If you really don't want to put her under sedation, observe her and look closely at her reactions. Whether she responds to you or not, if she starts 'blah, blah, blah …' and if she starts babbling, then that is a good sign'.

The parents followed this advice, and two years later they found out that their child's oral language development was slow, leading to a diagnosis of HL. This led the parents to blame the multidisciplinary team for not supporting them more intensively:

> They should have pushed us more, at least I think so, they should have insisted 'Look, narcosis or not, you have no choice, it must happen ….' Maybe they were too easy going. Maybe they gave us too much room… the choice … I don't know.

We cannot conclude from these experiences that the absence of equipment for further testing at the rehabilitation center always results in a lack of support and even delay in further diagnosis because in other cases, a referral, from the rehabilitation center to an ENT-department and back, was well supported by the rehabilitation professionals. Jelle's mother reported this:

> I have to say that we received a lot of information on the next steps and options. They really supported us very well and explained everything.

With respect to the feelings of disappointment and uncertainty, related to further diagnosis, we did not find different experiences among the families who were referred to a service for multidisciplinary rehabilitation care.

Phase 3: Initiation of Rehabilitation Care and Use of Assistive Technology

In both trajectory types, diagnostic activities were followed by referral to a center offering multidisciplinary

rehabilitation care—in the second trajectory type, this meant "returning to the rehabilitation center." The multidisciplinary rehabilitation team provides audiological care, speech/language therapy and physiotherapy, which is aimed at optimizing the child's functional development. As we shall demonstrate, rehabilitation care is primarily focused on the acquisition of oral language. In addition, support is also provided by social workers and psychologists. The parents arrive at the rehabilitation center after the diagnostic phase, which induced many emotional responses. However, the onset of rehabilitation care introduces a new phase in the care trajectory, in which three major aspects were found: Advice regarding development and care, parent support, and stability.

Advice regarding development and care. The uncertainty that resulted from the diagnosis was in all cases, addressed by care professionals from different disciplines at the rehabilitation center. Audiologists, speech/language therapists, and physiotherapists focused on providing the parents with advice on audiological management and parent-child interaction. Advice on audiological management includes explanation of language development and the consequences of hearing loss, the importance of sound stimuli for the development of hearing and oral language, the importance of traditional hearing aids in offering these stimuli, and the care by speech/language therapists. As reported by Bram's and Wouter's mother:

> [Bram's mother] They told us in general about the audiometry, about how he'd start babbling, and about the speech/language therapy. They told us things like how important the baby-babbling was.
>
> [Wouter's mother] We didn't have a problem, because all aspects of care and hearing loss were explained at the centre.

Dieter's mother reported on how the advice regarding the use of hearing aids made her feel responsible:

> It was all new to me and a bit of a shock too. They said that it was enough if I managed to make him wear the hearing aids a few hours every day. They said that the child needs some time to get used to this. So I put on the hearing aids from the moment he woke up until he went to bed again, and they (care professionals) told me that I was doing a good job. That it went so well.

Jolien's and Wouter's mother reported a strong focus on the importance of sound stimuli in the professional advice:

> [Jolien's mother] The only thing they kept saying was that we had to make sure that we offered as much sound to her as possible, preferably different kinds of sounds, and that we spend a lot of time with her.
>
> [Wouter's mother] Well really, a child, a baby with hearing aids, is that really necessary? I've thought a lot about this, but at the centre they really convince you 200 percent. Because the child has to learn to speak, he has to … And if we would wait two or three years, then he won't be able to speak, he'll keep burbling .... They kept arguing that I should make Wouter wear the hearing aids all day, except when he went to sleep …

In the account of Jonas', Wouter's and Kasper's mothers, the multidisciplinary team was constantly willing and able to answer questions regarding the child's care:

> [Jonas' mother] The audiologists, speech/language therapists, psychologists, all of them, were great, whatever question we had, and we always received a complete explanation .... And they knew what they were talking about. That reduced the stress significantly.
>
> [Wouter's mother] There was a time when I wrote down all my questions, things I had to ask and things I had to say .... And they were there for us, they helped us constantly. Whenever we had a problem, we could just pick up the phone …
>
> [Kasper's mother] They explained lots of care-related things, even though they sometimes used medical terminology. But anyway, we always received sufficient information. Actually, we had weekly meetings with the team that was responsible for Kasper's therapy.

The approach by the multidisciplinary team was in many cases experienced by the parents as "reassuring," after the uncertainty caused by the diagnosis. Lara's mother and Tinne's mother described this feeling:

> [Lara's mother] Now we knew what was going on, what we could do about it, how we should do it, yes, that is how we felt.
>
> [Tinne's mother] The center explained everything to us. Even so someone from the centre came here personally to provide all information on her hearing and how these things work. So then I knew how it all … what was in store for me, what we could expect, which steps we would take …

Parent support. In most cases, the multidisciplinary team at the rehabilitation center provided support to both the child and the parents. As was reported in Dieter's and Jonas' case:

> [Dieter's mother] Whenever I have questions .... After a while, you really develop a relationship with the care professionals .... I just call them when necessary …
>
> [Jonas' mother] From the beginning we could contact the psychologist, and that was a solution, which was good, because sometimes you really need that.

Support for the parents, who were confronted with a diagnosis of hearing loss, appears to be valued by the respondents, who furthermore stress the importance of not only social and psychological but also administrative support. Lara's mother and Tinne's mother stated:

> [Lara's mother] They really supported us .... Through conversations and also … how should I say, social and legal matters, paperwork, everything actually.
>
> [Tinne's mother] They also offered social support. And the people from the social department also took care of all the paperwork. Whenever I said, "Gosh, what the heck is that all about?' I could always just call them.

Only in two cases—Kobe and Bram—was it reported that the parents received little or no support.

> [Kobe's mother] Well, it was purely technical; they focused on getting Kobe's audiogram. It was purely and solely for the child.
>
> [Bram's mother] There was a lot of attention to the way we cared for our child, but for us .... At the time we didn't realize it was important. All conversations were about our son and everything that related to what was happening to him.

Stability. The third aspect that was identified—"stability"—is best described as attainment of equilibrium in care-use. After initial meetings, refinement of the diagnosis and the provision of information on development and care, the multidisciplinary therapy is provided with a fixed frequency and recurring evaluations. In most cases, the parents quickly adapt to this new situation of frequent care-use. However, for some parents, the necessity of some aspects of care was not clear in the beginning, as reported in the case of Wouter:

> I gave up my Saturday mornings to Wouter. I told them that I didn't want to come for a bit of gymnastics, but they said that was not for me to decide, this is included in the multidisciplinary care-package, so it's part of the deal.

Other parents needed some time to go through all the information and the emotions, as in Karlien's and Jonas' case:

> [Karlien's mother] Well, the support we received …. It's a lot of information, we had to go through a lot of stuff, and we received lots of it …. But from then on, we really knew something, which meant a lot to us. So we could move on, find some peace of mind.
>
> [Jonas' mother] We received good support at the rehabilitation centre. But the people there, that's where it stopped. They couldn't do more. They couldn't tell us that it would be alright in the end and things like that. But …

The timing of the parents reaching equilibrium in their experiences of their child's care use was closely connected to the evolution of the child's functional

limitations. Wouter's mother reported how she and her husband eventually reached this point:

> You'd think that a deaf child can't learn to make sentences of more than two or three words … without any care; that would be it. But then, after two or three years of care we had a result and then we were very satisfied, we had made sacrifices, driving him to the rehabilitation centre and back three or four times a week …

Bram's mother's account illustrates remaining unrest and uncertainty related to the negative evolution in her child's functional limitations:

> Two whole years we went to therapy, and then they told us one day that the hearing loss in both ears had gotten worse. After two years, then they told us… Why could they not have told me earlier? I went there every Monday, my husband every Friday, we have been driving back and forth there for two years, and what for?

Phase 4: Cochlear Implantation

Different elements play a role in parental decision making regarding cochlear implantation (Hardonk et al., 2010a). The availability of cochlear implant centers with experience in implantation in young children, and the full coverage by Belgian Public Health Insurance, creates a context in which this option is broadly accessible. As a result, it constitutes an important care-related decision in the care trajectories of congenitally deaf children, even though in a number of cases, this decision making did not lead to a cochlear implantation care event. The cochlear implantation phase encompasses the discussions between parents and care professionals about adopting or rejecting the implant, as well as the discussions about the implantation and fitting of the device. In this section on the phase of cochlear implantation, no distinction has been made between Types A and B because differences between the two trajectory types was not evident. Three aspects emerged from the analysis: "provision of information and advice," "hope and disappointment," and "support and expectations."

Provision of information and advice on cochlear implantation. All parents experienced the first aspect of this phase: provision of information and discussion regarding the possibility of cochlear implantation, resulting in referral in a number of cases. Care professionals play a very important role because often they are the first to mention this option and subsequently they are important information providers. In many cases, audiologists at the rehabilitation center bring up the subject by explaining the technology and offering preliminary advice on whether the parents should take the initiative in this matter. Jelle's and Dieter's mothers reported:

> [Jelle's mother] They gave us a lot of information on hearing aids and cochlear implantation, and then they told us that he could achieve enough with the hearing aids. A cochlear implantation wasn't necessary.

> [Dieter's mother] In the rehabilitation centre they once talked about cochlear implantation, but they said it wasn't necessary for Dieter. Recently he received new and better hearing aids and cochlear implantation is there, just in case his hearing loss deteriorates significantly.

In some cases, rehabilitation care professional told the parents that their child was not eligible for cochlear implantation due to clinical contraindications. In Sien's case, this was done as a response to the request of the father:

> I said to them: 'You have to implant her. I saw this once on television and it was possible to implant them.' But then they said that it was not possible for Sien, because she had a problem with her acoustic nerve, which is the main cause for her hearing loss. So an implant couldn't offer a solution.

In all cases, the option of cochlear implantation was considered against the possibilities it would yield for the child in terms of oral language development. In cases where rehabilitation care professionals expected an extra value over the use of traditional hearing aids, they advised in favor of implantation and they referred the parents to an implantation center. As reported by Kobe's mother:

> They told me that it would become easier for him with an implant to hear, especially in noisy environments.

Deterioration in the child's hearing loss can trigger the advice, Lara's and Jelle's mothers stated:

> [Lara's mother] They started talking about cochlear implantation right after the first big drop in her hearing.

> [Jelle's mother] They said: "He has frequent infections in his ear, which is causing an increasing hearing loss, so it would be better to give Jelle an implant.

Hope and disappointment regarding cochlear implantation. Opportunities for development of oral language appear as a basis for referral by care professionals at the MDRCs. As a result cochlear implantation creates new hope for the parents, it allows them to expect better results in oral language development. This is illustrated by Tess' mother:

> They gave me hope by telling me that she was eligible for cochlear implantation. And those children achieve better results. (…) They concluded that it would be very hard using traditional hearing aids; she would never learn how to speak with hearing aids, never.

Hope is an emotion that also appeared in the case of Bram, where it was closely associated with disappointment. Bram's parents reported that initially nothing was said about cochlear implantation at the rehabilitation center, until the care professionals were sure that the potential of hearing aids for oral language development was inadequate:

> I asked her, 'Why have you not told me before about the implant?' and she answered, 'Well, the implantation requires surgery, so we wanted to try to stimulate his residual hearing using hearing aids. But his language hasn't developed'. I said, 'You should have told me this earlier. Then I realized, hey, we've waited a year too long here.

Bram's parents had received information from relatives and colleagues that earlier implantation would lead to better results, so they blamed the rehabilitation care professionals for the lack of functional improvement. This experience was shared by Arthur's mother:

> [Bram's mother] I think the referral was done far too late. I'm not sure who should decide this. They should've noticed that his audiogram pointed in the direction of a cochlear implant and that more testing and therapy would result in delay. Now that we have to test for another year, we've a year behind.

> [Arthur's mother] I had the feeling that they tried to slow me down at the rehabilitation centre. I wanted an implant, because I had the feeling that he wasn't making progress with his hearing aids.

Implantation and fitting: support and expectations. The third major aspect of this phase—which is only found among families who decided to have their child undergo cochlear implantation—is the parental response to the implant surgery itself and the support they received from professionals. For most parents, the implantation was an emotionally charged event in the trajectory; most parents were satisfied with the support that they received from the rehabilitation care professionals, as Elise's mother reported:

> We got a lot of support from everyone. The therapist who provided therapy at home accompanied us on the day of the surgery and she was there during the surgery. She was the first to tell us that 'Elise is awake' again and that everything went well.

Support was also provided during the fitting of the device, one month after the surgery:

> We were constantly supported, also during the fitting of the device. The first fitting was overwhelming, her eyes as she responded to the stimuli …

This was also reported by Jelle's mother:

> Everything went well, I stayed with him and we received a lot of support, I'm very satisfied with that. After the surgery, I noticed that he was couldn't keep his balance, so I felt a bit of a panic because I thought they'd damaged something during the operation. But we stayed a day longer and it was OK, so then we were reassured.

Support during fitting of the device was also important to Bram's parents, although they were given unrealistic expectations of the implant's potential:

> They had said (the surgeon, before the surgery) that he would be able to hear and be able to speak six months after the surgery …. But it was more than a year before he spoke his first words.

Phase 5: Reduction of Rehabilitation Care

The last phase of the care trajectories in our analysis was experienced by most parents. When the multidisciplinary rehabilitation therapy has become a continuous element in the child's care—in a number of cases complemented by the extra event of cochlear implantation—both parents and care professionals focus on the developmental progress of the child. In many cases, the intensity of therapy is measured in relation to the functional (developmental) dimension of the care trajectory. Our analysis showed that therapy is often reduced at the moment when satisfactory oral language development is reached and/or the beginning of school. Another factor is the perception of the burden of therapy by the child and/or the family. Gella's father and Kobe's mother reported on the aspect of development:

> [Gella's father] Recently, we've stopped the speech therapy for a couple of months, because she achieved a level that's normal for her age. And her nasal pronunciation has gone. Also the speech therapist said that she didn't think it was necessary to keep coming, we could wait until she's five or six and then it depends on what progress she's made.

> [Kobe's mother] They [rehabilitation care professionals] said that everything is going well and so we agreed to reduce the therapy.

The beginning of primary school attendance, at the age of six, also marked a reduction in the intensity of therapy. This is illustrated by Bram's mother's account:

> If we hadn't reduced care, he would be out of class too often. I think that he's taken out of the class for therapy too often right now and because of that he can't fully join in the social life at school.

The burden of therapy for both the child and the family is an aspect that was also reported in many cases. Jolien's mother explained a reduction in parent support as follows:

> We said we didn't need care any longer. If we had doubts or questions, we could just as well write them down and ask the therapists when we could take Jolien to the centre.

Kobe's mother felt that the therapy made it difficult to lead a normal family life:

> You know, at a certain point, when I started feeling better and when I knew how to handle things, we also needed time to ourselves and for our child, like; it's my turn now. We had so many therapy sessions to attend and surrounded by other people. I wanted to be left alone with my family, in my own home, that's just the way I am.

The burden of therapy, as far as the child is concerned, was reported by Jonas' mother and Sien's father as a reason for reducing the intensity of therapy:

> [Jonas' mother] After a while my child couldn't take any more, he really became aggressive because it was too much. They kept demanding intellectual effort from him, but playing and relaxing was never part of the schedule.

> [Sien's father] She already spends six hours at school, behind a desk. Three hours in extra therapy plus the extra school support would have been just too much. That wouldn't be good for her.

Discussion and Conclusion

This study demonstrates how a qualitative study design can complement quantitative research in the field of care-use among deaf children. By analyzing the early care trajectory, using three dimensions—care-related events, the evolution of the functional status of the child, and parental experiences with regard to care and decision making—we were able to provide in-depth information on the parental perspective with regard to these dimensions. Moreover, through our analysis we have gained insight in the interplay between the dimensions. Such detailed knowledge illuminates earlier work on parental needs in the care trajectory, by Yucel, Derim, and Celik (2008). It should also be noted that our study included the complete early care trajectory, in contrast to

previous studies which were limited to one type of care event (Archbold, Sach, O'Neill, Lutman, & Gregory, 2006; Fitzpatrick et al., 2007). This is necessary to assess the reality of care trajectories that has emerged after the implementation of UNHSPs and the widespread early intervention as a consequence.

A few methodological considerations need to be discussed. First, recall bias related to retrospectively collected data is an important issue. This study design was based on parental perspective on past events; data collection was aimed at collecting parent's accounts of the care trajectory. These accounts sometimes represent the past as a consistent reality, even though this is not necessarily the case. Therefore, methodological measures were taken to minimize recall bias: implementation of a life grid method and a second interview, based on first analysis, was conducted. Although the life grid method has been predominantly used in quantitative studies (Berney & Blane, 1997), its application in this qualitative study design proved to be particularly useful.

Second, it should be emphasized that our findings have to be interpreted as part of a descriptive qualitative study design. Whereas for this qualitative information, saturation was reached on all major criteria, clearly a qualitative design is aimed at acquiring rich and detailed information regarding specific events and experiences, situated within different particular contexts, and not at representativeness in the quantitative sense. Our aim was to reveal the parent's perspectives on the complete early care trajectory of their deaf child, within a population of maximum diversity.

Finally, our study design does not enable for testing of causal relations with contextual variables, apart from the description of relations reported by the parents themselves. However, to guarantee the comparability of the parental accounts as far as the clinical condition is concerned, our sampling approach was based on minimum HL and the exclusion of multiple disabilities. Relevant qualitative findings with regard to social aspects and experiences can only be generated when the research population is also clearly defined on clinical criteria. Moreover, this approach is complemented by a multidimensional definition of care trajectories, which is in line with integrative efforts in literature on the conceptualization of disability (Desnerck, Bosteels, & Hardonk, 2008; Tøssebro, Gustavsson, & Dyrendahl, 1996).

As we have demonstrated, the two basic types of care trajectories—initiated by referral to an ENT department versus an MDRC—are characterized by differences as well as similarities on the dimension of parental experiences, which are a result of differences in care-use in an early stage of the trajectory. From our findings, we derive three main points of discussion. First, it is apparent that screening and early intervention are more than an opportunity for better developmental outcomes. As we have demonstrated, all events have a significant impact on the child and parents and the early intervention is a challenge for care professionals in terms of communication and provision of support. Our results show that adequate support is necessary to give parents a clear perspective on screening, testing, and further care. Without this perspective, parents can feel uncertain about or reject diagnosis and/or care. The way in which professionals, in screening, diagnosis and multidisciplinary rehabilitation care, act and how they communicate with parents also has an influence on the level of stress experienced by parents and on their well-being related to their child's care trajectory. Our results show the role of care professionals in this matter, thereby adding to the care trajectory perspective of investigations by Meadow (1968), Kurtzer-White and Luterman (2003), Spahn et al. (2003), Burger et al. (2005), Young and Tattersall (2005), and Archbold et al. (2006). Furthermore, these insights can support the operational protocols for professional intervention in all events with regard to screening, diagnosis and care, aimed at minimizing parental distress, and potential delay in or early termination of the necessary care-use. Such protocols should include aspects of emotional, instrumental, and informational professional support (Dunst and Trivette, 1990).

A second point of discussion is the aspect of transition between the phases in the care trajectory. The different phases are based on the events and experiences that take place in time intervals. The specific nature of these events can cause parents to experience difficulties, distress, or hesitation in making the

transition to the next phase, which in turn can lead to delay in the trajectory. Moreover, we have demonstrated that shifts between different care providers can create additional barriers to the transition between phases. UNHSPs and services for early care intervention should be aware of a possible negative impact on the progress in the trajectory, on the level of parental distress, and on the future development of the child when parents receive inadequate support in between trajectory phases. The implementation of UNHSPs and the organization of early care interventions could benefit from a coordination of transitions between phases is followed through the trajectory in each case. Based on our results, Type B of our typology of care trajectories offers the most suitable opportunities for this kind of coordination. We conclude that referral from universal neonatal hearing screening should be directed toward MDRCs because these teams are trained to offer support to families in issues of deafness. Moreover, they can act as a direct link to adequate therapy which is provided at the center or to diagnostic care at ENT departments, which are highly specialized in issues of diagnosis and cochlear implantation. Optimal coordination of care trajectories can also be achieved through formal case management, which can be appointed to a specific support team immediately after neonatal hearing screening (Maes and Goffart, 2002; Maes et al., 2001).

Finally, although universal neonatal hearing screening is aimed at early intervention, our results show beyond doubt that these interventions are focused on a specific type of care: multidisciplinary therapy aimed at oral language development. Consequently, the parent's experiences are fitted into a "personal tragedy" model, in which the child's hearing loss is perceived as a tragic happening that should be overcome with adequate therapy and technology (McCracken et al., 2008; Mercer, 2002; Oliver, 1996; Young & Tattersall, 2007). The range of alternatives with regard to communication mode offered by professionals was very limited, and aspects of deaf culture and communication through sign language were notably absent in the parent's accounts of the services offered in all phases of the care trajectory. This confirms findings by Young (2002) and Young, Jones, Starmer, and Sutherland (2005). We found that diagnosis and care are focused on achieving oral language development, in which the factor "time" is perceived as crucial by parents and professionals alike. These findings confirm those of Young and Tattersall (2007) in relation to UNHSPs and of McCracken, Young, and Tattersall (2008) with regard to the use traditional hearing aids. This medically focused decision-making context can negatively affect the parent's well-being (cf. Spahn et al., 2003) and it raises concerns with regard to informed decision making (Young et al., 2006). Because most parents have little or no experience of deafness issues at the time of screening, and given the importance of professional advice (see also Hardonk et al., 2010a), the use of a wider perspective on deafness in professional multidisciplinary rehabilitation can have a positive influence on the decision-making context. Broadening the personal tragedy perspective to an approach that incorporates all relevant ideas and concepts—including sociocultural and ethical elements—could result in lower levels of parent's distress and a wider array of care options for parents to choose from when confronted with deafness. Moreover, the application of a wider perspective on deafness in scientific research can extend the current body of evidence—for example, with regard to language/educational achievement and psychosocial well-being. This in turn can reduce the uncertainty in evaluative information on deafness and care, which was described by Young et al. (2006) as a challenge to scientists. It could be argued that it appears that parents themselves are often fundamentally motivated by the desire to achieve oral language development for their child; implementation of professional support from a wide perspective on deafness should offer an adequate framework for care and informed decision making rather than being aimed at changing parents' minds (Young et al. 2006).

Funding

The data collection for this study was funded by Howest University College, Bruges, Belgium.

Conflicts of Interest

No conflicts of interest were reported.

Acknowledgements

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper. The conceptualization, data collection, and part of the analysis in this study have been funded by Howest University College. Recruitment of respondents was made possible thanks to the collaboration of Kind en Gezin (Child and Family), the children welfare organization for the Flemish Community in Belgium. We would like to express our gratitude toward both organizations and to our participants for their willingness to support this study.

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