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Analysing care-related decisions in parents of congenitally deaf children: introduction of an explanatory model

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Research into issues of deafness is characterised by the dominance of the medical model of disability. Although social and cultural-linguistic models have received increasing attention from scholars, they have been used mainly in theoretical debate. Empirical application has been limited. Based on our comprehensive research project into the care-related decisions of parents of congenitally deaf children in Flanders, Belgium, an explanatory model for care-related parental decisions was constructed, which transcends the specific findings generated by our studies. This model is presented and discussed in this paper. Illustrations are provided based on our empirical findings.

Keywords: deafness; decision-making; parents; disability models

Introduction

Since the development of modern medicine, an increasing range of tools has become available to define and treat illness and disability, thereby assigning persons who are ill or have a disability to a certain position in society. New medical technologies carried the promise to liberate people with disabilities from their unfavourable position and integrate them into society (Conrad 2007). This explains why its advocates have long succeeded in presenting their approach not simply as a model, but as the only imaginable conceptualisation of the issue (Lane 1995). Fuelled by Foucault's social constructionism, by the end of the 1960s opposition to the medical model of scholars and activists in the United States, the United Kingdom and Scandinavia resulted in the development of a social model of disability (Thomas 2002). In this approach disability is not considered as an inevitable result of bodily dysfunctions, but as a consequence of the social and political environment. Hence the level of analysis is not the human body, but the social structure (Thomas 2002). In the field of deafness, advocates of yet another approach, the cultural-linguistic model, reject the notion of disability – and as a consequence a basic assumption of

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the social model – altogether (Humphrey 2000). In their view, deafness is not a disadvantage, but a characteristic on which a particular identity, language and culture are based (Padden and Humphries 2005, 2010). Social and cultural-linguistic models have struggled to establish themselves in research while widespread implementation of technological innovations such as cochlear implantation (CI) has strengthened the position of the medical model.

Research into care-related experiences and decisions of congenitally deaf children's parents is interesting in this respect, because it touches the heart of the conceptual debate in the field of disability (Calderon and Greenberg 2003). In a recent contribution to scientific literature, Sparrow (2010), while taking a cultural-linguistic point of view, warns those who advocate Deaf culture that they should take swift action against new genetic technologies, such as pre-implantation genetic diagnosis (PGD), because they pose a threat to the future of the Deaf community. He states that the slow reaction in the past from advocates of Deaf culture and language against CI has undermined their chances to oppose to large-scale implementation and further biomedical development of the technology. Authors like Sparrow – and also Barton (1996) and Lane (2005) – not only consider the medical model as oppressive, but extend their critiques to the social model of disability as well.

Scholars like Lane (2005), Ladd (2003), and Padden and Humphries (2005, 2010) have argued that constructing deafness as a disability category reflects a misunderstanding of the issue, because it is not perceived as such by Deaf people. In their view, treatment within a disability approach implies needless medical risks, threatens the persistence of the Deaf community, and suggests inadequate solutions to problems experienced by Deaf people. This perspective is contested by other scholars, for instance Balkany, Hodges and Goodman (1996) who defend parents' right to surrogate decision-making with regard to CI. Regardless of the value of these scholars' arguments, disability studies in general and deaf studies in particular have directed much attention to conceptual issues connected to medical definitions and technological innovations. Empirical research, on the other hand, is following at much slower pace. For example, theoretical arguments for a cultural-linguistic approach to issues of congenital deafness such as CI and PGD have been provided (Sparrow 2005, 2010; Lane 1995, 2005), but never is empirical insight presented about parents' experiences in these issues.

This lack of empirical evidence for confronting conceptual frameworks is an issue with many cultural-linguistic and social model studies regarding deafness, not limited to the work by Sparrow, Lane, Ladd, Padden and Humphries. Admittedly, empirical research findings based on a non-medical approach have been reported on, for example with regard to initiatives in early care intervention that aim to increase the role of elements that fit in a social or cultural-linguistic approach such as the development of Deaf identity (e.g. Young 1999; Beazley and Moore 1995). Nevertheless, most authors' emancipatory research efforts touch issues that involve parents, without involving these parents in empirical research. This is illustrated by the references that Obasi (2008) cites to support the contention that 'it is well documented that medical intervention in the form of cochlear implantation is opposed by Deaf people.' All cited works – by authors as Anderson (1994), King (2004) and Lane (1994, 2005) – present arguments based on a personal account and/or a theoretical perspective on the issue. The value of these works for advancing the field should not be underestimated, but is it possible to consider this as adequate empirical evidence which will have emancipatory political impact?

Moreover, often different models of deafness are treated as opposing each other and mutually incompatible frameworks that need to be advocated or criticized. It is true that empirical research shows that the influence of the medical model on parents' care-related experiences and decision-making is strong (e.g. Kluwin and Stewart 2000), which is hardly surprising given that over 90% of congenitally deaf children are born to hearing parents, who – as opposed to deaf parents – have no experience of deafness or Deaf identity (Vaccari and Marschark 1997). But should we conclude that the distinction between medical and social/cultural-linguistic models aligns perfectly with the dividing line between hearing and deaf parents? Although some qualitative studies on parental values and decision-making regarding CI have given us some indication of the complexity of this issue, the available evidence looks insufficient to provide a comprehensive answer to this question (Steinberg et al. 2000; Li, Bain, and Steinberg 2004). Consequently, social and cultural-linguistic models risk being considered by some as mainly theoretical constructions, which depend on the dominance of the medical model to legitimise their very existence.

This situation has inspired our empirical research project that was aimed at the analysis of parents' experiences and decisions related to their congenitally deaf child's care trajectory. This project revolved around three research questions: (1) how do parents arrive at care-related decisions, more specific with regard to CI?; (2) which experiences, preferences and decisions are found in parents with regard to the trajectory between universal neonatal hearing screening (UNHS) and multidisciplinary rehabilitation care?; (3) how can parents' experiences throughout the care trajectory of the first years of life (minimum of five years) be clustered into phases in order to develop a basic care trajectory typology? To address these questions a qualitative study design involving hearing parents of congenitally deaf children was implemented. With regard to the first research question an additional qualitative study was undertaken involving deaf parents. In the following paragraphs we describe the main characteristics of these studies, which were approved by the Brussels University Hospital Ethical Committee (references 2006/139-2010/002). Full methodological accounts and results have been published elsewhere (Hardonk et al. 2010a, Hardonk et al. 2010b, Hardonk et al. 2011a, Hardonk et al. 2011b).

Methodological notes

For both qualitative studies data were collected in the Flemish community of Belgium, among parents of children referred through the UNHS programme, having a congenital hearing loss of minimum 41dB and no multiple disabilities. Consequently, the age criterion for inclusion depended on the first year of full implementation of the programme (1999), and was set to between five and seven years for the children of hearing parents; between five and nini years for the children of deaf parents. The latter is explained by the fact that the second data collection effort was done two years later. Families were recruited through collaboration with the organisation in charge of the Flemish UNHS programme (Kind en Gezin), the Federation of Flemish Organisations for the Deaf (Fevlado), the Flemish Organisation of Parents of Children with a CI (VLOK-CI), and the Centre for Flemish Sign Language (Vlaams Gebarentaalcentrum). All families received written invitations to participate in the study; non-responders were sent reminders three months later. At that point, purposeful sampling based on socio-demographic information available in the UNHS-database was applied, to include information-rich cases and achieve

maximum social diversity in the sample (Patton 1990). The criteria used were 'province of residence,' 'ethnicity' and 'poverty.' In total, the hearing parents of 17 children and the deaf parents of six children participated in our studies.

Thematic content analysis from a phenomenological approach (Schwandt 1998) was applied to verbatim transcripts of in-depth semi-structured retrospective interviews conducted with the participating families at their home (Miller and Glassner 2004). Two hearing interviewers were present at each interview, one leading the conversation – supported by a checklist of relevant topics – the other supporting the first interviewer. For the interviews with three families who used sign language a certified Flemish Sign Language interpreter was present to translate between spoken and sign language. At the onset, parents were asked to tell about their experiences with regard to screening and diagnosis. Next, they were asked to go into detail about events, experiences and motivations throughout the care trajectory. As a result of the more limited scope of our data collection among deaf parents, those parents were asked to focus on the decision-making process concerning traditional hearing aids/ CI. With the sample of hearing parents a second round of interviews was done to go into detail on topics for which first analysis had revealed lacunas or inaccuracies.

Furthermore, the life grid method – involving a chronological registration scheme – was implemented in interviewing to avoid gaps and inconsistencies in parents' accounts concerning past events (Hardonk et al. 2010a).

Both researchers participated in an observer triangulation procedure using open thematic coding, i.e. creating codes to label text fragments that contain different thematic elements reported by respondents as meaningful events or experiences. Text fragments containing information on more than one topic were labelled with multiple codes. The coding scheme which resulted from this procedure was used to modify or expand the interview check list in the course of data collection, resulting in a high degree of saturation (Green and Thorogood 2004). At completion of data collection the coding scheme was reconstructed into a logical tree of codes, representing different (sub-)topics, to finalize labelling of transcripts.

Thematic analysis was continued by selecting text fragments based on their labels, using so-called coded text queries in the NVivo7® software package for qualitative data management. The acquired information was classified, further labelled when necessary, and interpreted into thematic clusters that allowed for answering the research questions. This resulted in rich and highly detailed insight into parents' experiences during the care trajectory, and into the interplay between different factors in their care-related decision-making processes.

Given that the identification of lacunas in existing knowledge was at the basis of our empirical research project, these qualitative findings enabled us to make a contribution to the conceptual debate on different approaches to deafness – and disability in general. More specifically, using the insights with regard to: (1) how parents arrive at decisions with regard to CI; (2) how parents and professionals play a role in the care trajectory from screening to multidisciplinary rehabilitation care; and (3) how parents' experiences throughout the entire care trajectory are clustered into different phases, we have developed an explanatory model for parents' care-related decisions which includes social and cultural-linguistic model concepts. The different components and relationships of this model will be presented in the next paragraphs. Furthermore, different types of parental stances will be related to our explanatory model.

Explanatory factors

Adding to the largely reductionist perspective of the medical model, the results of our analyses indicate that parents' care-related decisions are influenced by several factors that can be linked to social, ethical and cultural linguistic approaches. Our model departs from eight explanatory factors to explain care-related decisions (see Figure 1). A direct influence originates from 'Ethical aspects of surrogate decision-making.' The influence of the cluster 'educational aspects' on care-related experiences is mediated by 'parents' preferences concerning communication mode.' Finally, within the 'construction of deafness'-cluster social support has an influence on: (1) parents' preferences with regard to social participation, and identity and culture; and (2) information and knowledge. This cluster influences care-related decisions through three interrelated factors: 'adjustment,' 'parents' preferences concerning communication mode,' and 'care-related experiences.' In the next paragraphs these factors will be discussed using results from our empirical studies, supported by findings from literature.

Ethical aspects surrounding surrogate decision-making

When a person is unable to make care-related decisions, a surrogate can take on this responsibility. In bioethical literature consensus exists that a clear locus of authority is necessary to achieve coherence, continuity and accountability in decision-making (Buchanan and Brock 1990). Balkany et al. (1996) have argued that this authority is located in the first place with parents. They furthermore have rejected criteria such as
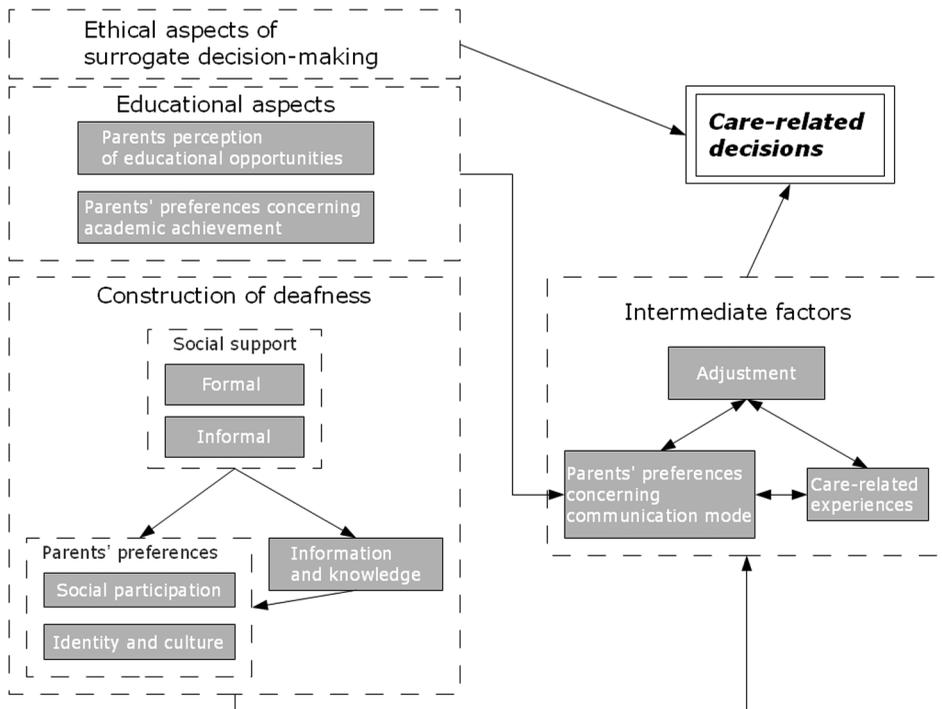

Figure 1.   Explanatory model for care-related decisions.

advanced directives and substituted judgement, because both are based on the assumption that the person for whom decisions are being made, has been able to express preferences in the past. Therefore, in issues of congenital deafness Balkany et al. (1996) consider only one additional ethical criterion as relevant: the best interest of the child, which should underlie any decision. This has been criticised by other scholars (e.g. Lane and Grodin 1997), who have emphasised the role of the Deaf community in decision-making on CI as part of the horizontal acculturation of the deaf child. This refers to the idea that Deaf role models should be given the responsibility to teach hearing families with congenitally deaf children cultural, social and language aspects of the Deaf community. Some authors have gone so far as to suggest that a culturally Deaf role model should be appointed to make decisions on CI.

In care-related decision-making for a congenitally deaf child, the fact that deafness is not a life-threatening condition has been central in the ethical debate. Some parents in our studies (Hardonk et al. 2010, 2011b) felt that – given these circumstances – it was ethically wrong to make decisions that involve medical operations on the child's body – such as CI.

Other parents believed that it was their responsibility to act on the child's behalf and make decisions in the child's best interest, more specifically to seize every opportunity for achieving optimal outcomes in language development and academic achievement. For example, some parents were convinced that they had a moral obligation to decide on early cochlear implantation, because they had received information that this improves spoken language development in the long term (see also Okubo, Takahashi, and Kai 2008).

This is also illustrated by a diagnostic event in the early care trajectory: the necessity of bringing the child under sedation for Brainstem Evoked Response Audiometry posed an ethical concern to some parents. They had their doubts whether it was right to sedate a newborn on the grounds of a *suspicion* of hearing loss. Some parents believed that the means – a medical testing procedure involving sedation – was disproportionate to the end – the diagnosis of hearing loss (Hardonk et al. 2011).

In our model we did not link parents' ethical considerations to the intermediate factors, as it appeared that elements such as adjustment and preferences with regard to communication mode were not influenced by parents' ethical position with regard to surrogate decision-making and the use of medical technology (Hardonk et al. 2010).

Educational aspects

Parents' perception of educational opportunities

This fundamental factor is related to social and educational policy and issues of equal opportunities for people with disabilities, and therefore fits within a social model approach of deafness. The way in which mainstream and special education programmes are organised has consequences for the opportunities that education offers. More specifically, educational policy in which special education for the deaf is considered equal to mainstream education in creating future educational and employment opportunities, implies that special education offers the same high level of quality and a broad spectrum of options. By contrast, when special education is treated as a secondary type of education, fit for children with a disability who are

expected never to attain the same results as children in mainstream education, this is likely to have an impact on the level of education and the number of options to choose from. Differences can also arise at the level of the school, more specifically in the emphases that are placed in the curriculum on language development and academic achievement. Parents' perceptions of quality and available opportunities in different types of educational placement and curricula provide the background for preferences concerning the child's communication mode, from which care-related decisions follow. In our empirical studies (Hardonk et al. 2011b, 2011c) many parents associated special education with low levels of academic achievement and limited opportunities for higher education. Most parents believed that mainstream education offered higher educational levels and a wider range of opportunities.

Parents' preferences concerning academic achievement

Given their perceptions of educational opportunities, whether parents choose for their child to attend special or mainstream education, with curricula that focus on oral/aural or manual communication, depends upon their *preferences* concerning academic achievement. Parents who favour for their child high educational levels and a wide array of possibilities regarding higher education will prefer educational placement and curricula that – in their perception – can provide these opportunities. Following the empirical findings presented in the previous paragraph, choosing special education would imply that these parents settle for fewer opportunities in the future, at a moment when their child is only just starting to attend school. The parents in our studies carefully considered the impact of educational placement in terms of their long-term preferences, including employment-related opportunities (Hardonk et al. 2010). Decisions with regard to educational placement in turn affect their preferences concerning the communication mode of their child: when parents decided that mainstream education based on oral/aural communication fits with their preferences and perceptions of educational opportunities, this resulted in their giving priority to the development of spoken language in the care trajectory.

Although parents' perceptions and preferences concerning educational opportunities are to a certain extent related to their preferences regarding social participation, their positions in both issues do not necessarily align with each other. This is illustrated by the position of many deaf parents in our studies who pursued the participation of their children in the Deaf community. However, they did not choose special education based on sign language – which offers that opportunity – because they had the impression that mainstream education offered better educational opportunities. The parents explained this by the higher value they placed on academic achievement and employment opportunities (Hardonk et al. 2011b, 2011c).

Construction of deafness

This cluster represents the role in parents' decision-making processes of different perspectives on the concept of deafness. Parents' construction of the reality of deafness is a process that starts with UNHS, in which views, knowledge and preferences interplay to become a framework for parents' perspective of their child's deafness and related needs (Young and Tattersall 2007).

Social support

This subset contains two factors that refer to the role played by support from formal and informal sources in parents' construction of deafness. *Formal social support* is provided mainly by care professionals, e.g. doctors, nurses, audiologists, speech therapists, and social workers (Dunst and Trivette 1990; also McKellin 1995). Our studies indicate that starting from screening and throughout attendance of rehabilitation centres and ear-nose-throat (ENT) hospital departments, most hearing parents placed deafness within a medical framework, because they became confronted with professionals trained to operate in issues of deafness from a predominantly medical perspective (Hardonk et al. 2011c). This was also found by Matthijs et al. (2012) in their discourse analysis of professionals' support after screening. However, Young (1999) has demonstrated that, depending on how early intervention is organised, the influence originating from formal social support can also fit within a social or cultural-linguistic perspective.

Support to parents included many instances of explicit advice based on what professionals considered as the most adequate care for the child. In our model, the role of formal social support should be understood not only as connected to intentional acts of advice, but also as the unintentional influence that arises from professionals' approach. For example, our studies demonstrate that when professionals systematically emphasize the importance of assisting the newborn child to wear hearing aids at all times when he is awake, they unintentionally provide a framework for parents' experiences of their child's deafness, which in turn affects parents' care-related decisions.

Parents not only interact with care professionals and other sources of formal social support, they are also supported by family, friends, colleagues, peers and other informal contacts (Dunst and Trivette 1990; see also McKellin 1995). The influence of *informal sources of social support* on the way parents experience the deafness of their child and on care-related decisions shows similarities with the role of formal social support in our model. Through informal social support, the parents in our studies sometimes received explicit advice with regard to how they should understand the deafness of their child, what it means to get 'adequate care' and which steps they should take in care-use. But from our findings we have also learned that a less explicit and more fragmented influence originates from informal social support, which was also found by Li et al. (2004) with regard to decision-making for CI. In our study parents' feelings of losing their 'perfect child' because of deafness were reinforced when grandparents expressed concerns over the child's inability to hear and the consequences for spoken language development, which could affect their interaction and relation with the child. This stimulated parents to place minimum value on sign language and to undertake all possible medical action to make sure the child will 'fit into the family' (Hardonk et al. 2010). Among deaf parents (Hardonk et al. 2011b) we found more than once that strong rejection of CI by friends in the Deaf community fuelled parents' ethical doubts. Although these examples demonstrate how informal social support is connected to care-related decisions, parents emphasised their autonomy stating that informal contacts were not entitled to give any advice and to have a direct influence in care-related issues (cf. Incesulu, Vural, and Erkam 2003). This influence nevertheless remained, because parents' perspective on their child's deafness was in part built on elements of their interactions with informal contacts, e.g. with regard to expectations, preferences, feelings, etc.

Parents' preferences

In our studies, care-related decisions appeared to be related to parents' positions in issues of *social participation*, more specifically whether they wanted their child to participate in hearing or Deaf social environments, or in both. The first priority of most hearing parents was to give their child all opportunities to participate in the nuclear and extended (hearing) family, and to integrate in mainstream education. At the same time they did not place much value on participation in deaf education or the Deaf community (Hardonk et al. 2010, 2011c). Vice versa we found that deaf parents were equally preoccupied with participation in the – mostly deaf – family, and although they had given participation in hearing social environments more thought than hearing parents had done with regard to the Deaf community, they generally did not give priority to it (Hardonk et al. 2011b). These social participation preferences are influenced by provision of information and through formal and informal social support, nevertheless we have included it separately in our model, because it appeared that parents' preferences with regard to social participation had already been established before the birth of their child, and regardless of the influence of other factors in our model. Parents' preferences are at least in part dependent upon past experiences within a certain social context, i.e. whether the family historically belongs to a hearing or Deaf community.

Many culturally Deaf people and researchers – in particular scholars from the cultural-linguistic school – regard deafness not as a characteristic that defines disability, but as a precondition for membership of a minority that has its own language and culture. Although referring to the culture and identity of the majority, Young (1999) suggests adding 'hearingness' as a conceptual equivalent to deafness in cultural-linguistic terms: being able to hear can be considered as necessary for membership of the 'hearing community.' A person's *identity* is developed in interaction with other members of the family and the community, and whether one looks at him/herself as a Deaf or hearing person is closely related to the *cultural* values and predominant discourse in the community, and the language(s) adopted (Calderon and Greenberg 2003). The factor *identity and culture* in our model refers to parents' cultural background, their views and preferences with regard to future Deaf/hearing identity and community membership. Although this factor is related to parents' social participation preferences and their expectations concerning educational opportunities, we found evidence for its autonomous effect. For example, although favouring the development of a Deaf identity was for some parents associated with a preference for emphasising sign language in the child's education, this was not necessarily so for other parents (Hardonk et al. 2011b).

Information and knowledge

Over 90% of congenitally deaf children are born to hearing parents (Vaccari and Marschark 1997; Moores 2001), which implies that most families are unfamiliar with the issue. But also among parents with earlier experiences in deafness *information and knowledge* plays a role – both enabling and confining. Information is necessary for parents to understand care-related issues – e.g. diagnosis, rehabilitation care and hearing assistive technology – but it also creates – often invisibly – a framework for parents' experiences and decision-making processes. At the basis of describing the reality at hand lie assumptions concerning the meaning of deafness and its

implications for care and future development. Sources of information depart from such assumptions – models of deafness – and as a result (un)intentionally provide partial information. When formal or informal sources do not expose the assumptions underlying their information, we might even call this 'biased' information, because it *represents* the reality of deafness without describing itself as a representation (Lane 1995). Consequently, our model assumes an association of information and knowledge with formal and informal social support. The latter can be considered as gatekeepers to information on deafness, first of all for parents who are unfamiliar with the issue and in need of information – especially in the period after first screening. This emphasises the relevance of the challenges identified by Young et al. (2006) concerning informed choice in issues that involve deaf children. We found parents' information-seeking initiatives outside support relations to be of secondary importance (Hardonk et al. 2010, 2011c), for instance aimed at adding missing details to information received from formal or informal sources.

Intermediate factors

Parents' adjustment to their child's deafness

Traditional conceptualisations of adjustment focus on elements such as loss, grief and mourning (Young 1999). Laurenzi and Hindley (1994), and Beazley and Moore (1995) have argued that this is a consequence of the underlying medical and psychological models. According to Beazley and Moore (1995), the definition of adjustment as individual and inevitable human reactions to deafness is also reflected in the service provision of early intervention services. Hence, they suggested that approaching adjustment as a social construction allows for redefining the concept from a cultural-linguistic perspective. Different – more adequate, in Beazley's and Moore's terms – responses from early intervention services to parents' needs will result in a different type of adjustment, characterised by feelings of motivation to discover Deaf identity and culture, instead of grief and loss. It follows that parents' construction of deafness influences their adjustment, which in turn has consequences for care-related decisions. The position of adjustment in our model is furthermore based on our empirical findings, in which the issue of virtual timetables in parents' care-related experiences is illustrative. In their study on parents' experiences regarding early audiological management, McCracken, Young, and Tattersall (2008) found that parents used virtual timetables for decision-making, which was explained by the pressure arising from the *framework of a deficit-model* underlying care professionals' provision of information. In our studies (Hardonk et al. 2010) parents also reported that most care professionals focused on the absence of sufficient hearing capacities that allow for the development of spoken language, and swift medical treatment was presented as a solution. For example, in discussing treatment options with parents, care professionals stressed that scientific evidence supported the effectiveness of early implantation. Particularly for hearing parents the phrase 'the sooner, the better' reflected not just an aspect of the decision-making process with regard to CI, but a perspective on care characterised by feelings of loss, and hope for successful treatment (Hardonk et al. 2010, 2011c). In sum, a virtual timetable was imposed by care professionals on the parents, who incorporated this with their sense of responsibility for maximizing their child's chances for spoken

language development. Meanwhile, *fear* of possible failure was brought into their adjustment process.

Parents' preferences concerning communication mode

This factor represents the role played by parents' preferences with regard to learning oral or sign language or any combination of these. The importance of this factor has been recognised in earlier research, such as the studies by McKellin (1995), Steinberg et al. (2000) and by Li et al. (2004), however it has never been accurately described as part of a model in relation to other factors. Li et al. (2004) for example concluded from their study that parents' decisions concerning CI can be condensed into this one factor – which they state is to be used for assessment of parents' decision-making – summarising the role of other factors as 'other domains playing a lesser role' (Li et al. 2004).

From our empirical research it has become clear that parents' preference concerning communication mode is influenced by their position on the construction of deafness-cluster, however this is not a one to one relation (Hardonk et al. 2010), as we have already demonstrated that another association exists with the educational aspects-cluster. This is illustrated by our earlier description of many deaf parents in our sample (Hardonk et al. 2011b) who discursively advocated a construction of deafness that is best described as cultural-linguistic, but nevertheless expressed the preference that their child should develop spoken language as an important secondary language, not because they adhered to a medical model of deafness, but because they expected that mainstream placement offered the best educational opportunities. In sum, education and participation preferences influenced their care-related decisions through preferences concerning communication mode.

Parents' care-related experiences

This factor covers a broad range of experiences with regard to quality of care, effectiveness of therapy/hearing assistive technology, interaction with care professionals, burden of care for the child and family, and practical aspects of care-use.

In our studies (Hardonk et al. 2010, 2011c) we have demonstrated that the effectiveness of traditional hearing aids was an important element triggering intense parental experiences. When hearing aids were successful in terms of the child's oral/aural development, many hearing parents expressed feelings of accomplishment – because of the hard time that they had had in making their baby wear the hearing aids – and hope – because the child was developing in a way that fitted their expectations. These experiences resulted in many cases in the continuation of the use of traditional hearing aids instead of initiating a process for CI. But when the effect of hearing aids was poor, parents experienced uncertainty about the future and feelings of failure, resulting in a preference for CI. Moreover, parents' confidence in rehabilitation care professionals decreased when they perceived continuation of the use of hearing aids and further testing as contradictory to their virtual timetable (Hardonk et al. 2010). McCracken et al. (2008) similarly found that care professionals induced a sense of urgency in parents' experiences, and at the same time they were held responsible when parents believed that the way care was provided could compromise achieving spoken language development. It is evident that also formal social support had a direct impact – e.g. ENT specialists' advice for/against

CI – nevertheless these findings illustrate the intermediate role of parents' experiences in-between the 'construction of deafness' explanatory factors and care-related decisions.

Associations between intermediate factors

Our research demonstrates that care that is based on a medical model leads to parental experiences such as satisfaction with the possibility of medical treatment and feelings of responsibility in terms of offering the child aural stimuli (Hardonk et al. 2011c). More generally, we found that the type of care that parents receive and the assumptions with regard to deafness on which it is based induce a framework for parents' adjustment process (see also Beazley and Moore 1995). Vice versa, the character of the adjustment processes has an influence on how parents experience care provision. Therefore an association between adjustment and care-related experiences was included in the model. This is further illustrated by Young (1999) who demonstrated that support at home based on a cultural-linguistic model induces a different kind of experiences in parents: they realise that there is a (Deaf) world out there and that they are unfamiliar with it. This creates a confrontation with their own 'hearingness' – a notion that refers to the fact that they have been acculturated in a hearing culture – resulting in greater awareness of cultural-linguistic aspects of deafness in their care-related decision-making.

The association of parents' preferences regarding communication mode with adjustment and care-related experiences is particularly useful for explaining changes in parents' care-related decisions. Under the influence of less-than-expected success in the use of hearing aids or CI, some hearing parents received formal and/or informal social support pointing out the value of sign language for deaf children (Hardonk et al. 2011c). When these parents included some sign language in their preferences with regard to communication mode, this did not represent a shift towards another construction of deafness – sign language was clearly represented as 'plan B.' Instead it reflects the association of the intermediate factors.

Care-related decisions: end of all pathways?

Our model allows for explaining parental decisions in such issues as hearing assistive technology, rehabilitation care and educational support at home. As we have pointed out, care-related decisions can induce new events in the child's care trajectory that might ultimately lead to a new decision. Therefore 'care-related decisions' should not be considered as the end of all pathways. Nevertheless, we have explicitly chosen not to attach bidirectional causal links to care-related decisions, because our findings demonstrate that any subsequent effect would not be a direct one, but instead pass through the explanatory and intermediate factors as described. This finding is a result of the application of the care trajectory concept (Strauss et al. 1997) as a central element in our research (Hardonk et al. 2011c). This implies that care-related events and experiences were ordered within a chronological multidimensional sequence, in line with McKellin's (1995) rigorous trajectory concept termed 'careers of hearing impaired families.' In our research the care trajectory dimension were ordered as follows: (1) events concerning care and hearing assistive technologies; (2) parents' perspective on their child's developmental evolution; and (3) parents' experiences and decision-making processes. The explanatory model is the result of

sociological analysis based on analytical classification of care trajectories in this multidimensional concept. Consequently, parents' advances in the care trajectory can be understood by multi-iterating the explanatory model for every subsequent care-related event.

Transcending simplistic classifications of parental perspectives on deafness

In matters of care many scholars depart from archetypically distinct approaches, which can be analytically classified using our model. On one hand, the oral/aural perspective – based on the medical model – focuses on overcoming functional limitations regarding speech/language development. In our model this is reflected in *formal and informal social support* in which application of hearing assistive technologies and therapy aimed at spoken language development are emphasised; in *information and knowledge about deafness* that covers mainly medical, technological and oral communication aspects; and – with regard to the factor *'identity and culture'* – in parents preferring for their child to be part of the hearing community. The Deaf perspective on the other hand applies a cultural-linguistic minority approach, rejecting the notion of deafness as a treatable disorder. In our model this is reflected in *formal and informal social support* aimed at supporting parents to acculturate their child in the Deaf community; in *information and knowledge* concerned with Deaf culture and identity, and sign language; and in an emphasis on *participation* in the Deaf community. Following the logic of our explanatory model, the consequences of these two archetypical stances are found in parents' adjustment, care-related experiences, and preferences with regard to communication mode, and subsequently in care-related decisions.

However, this Deaf-hearing dichotomy is challenged by some authors, e.g. Woll and Ladd (2003) have attempted to conceptualize Deaf communities in a way that represents existing diversity. In addition, empirical findings by Bat-Chava (2000) indicate that the archetypical perspectives do exist in some families, but that many parents combine elements that can be attributed to the oral/aural and the Deaf perspective. We found that among hearing parents it was not uncommon that *formal and informal social support* attached some role to sign language as 'helpful on certain conditions' – e.g. when hearing aids run out of batteries or in interaction with deaf children who sign – but it was never considered a priority (Hardonk et al. 2010). Furthermore, most parents considered *participation* in the Deaf community as an 'interesting option,' not as an essential goal. Many hearing parents had only received fragmented and superficial *information* on cultural-linguistic aspects of deafness (Hardonk et al. 2011c), and those who had tried to obtain more information reported that they became confronted with a Deaf community that was not welcoming to 'outsiders.'

On the other hand, many deaf parents received *formal social support* in which some attention was given to deafness as a cultural-linguistic issue and they experienced restraint among professionals to focus strongly on therapy aimed at spoken language development (Hardonk et al. 2011b). In contrast, *informal social support* mostly reflected a Deafness-position with emphasis on sign language and identity, although hearing grandparents were reported to give more attention to goals such as spoken language development. These parents mostly preferred *participation* in the Deaf community, but they also wanted their child to be able to participate in the hearing world. These parents were well *informed* about Deaf culture, identity and

language as well as about hearing culture, spoken language and medical interventions such as CI.

We conclude that the perspectives of hearing and deaf parents in our studies do not comply with the archetypical Deaf versus oral/aural distinction, and could therefore be considered as 'blended perspectives'; they can generally be described as 'pragmatic' or 'ambiguous' – see also Bat-Chava (2000). Our explanatory model allows for representation of the specific components of all – not only the archetypical – perspectives, reflecting the richness of parents' positions.

Discussion and conclusion

Given their important role as decision-makers and partners in care-related issues of congenital deafness, it is surprising that parents' perspectives have received little attention in research. This was recognised by DesGeorges (2003), who focused on professionals' impact on parents' experiences throughout the process of early hearing detection and intervention, emphasising the importance of listening to parents – the 'consistent, long term case manager for their child' – to achieve successful outcomes for the child.

Starting from empirical findings from our own research project and reports in literature, we have constructed a model including several explanatory factors and their interrelatedness, and we have demonstrated how different parental positions fit into this model. As a strength of the model we note that it represents not only the archetypical positions found in discourses on deafness and care, but also combinations of elements that cannot be placed on neither end of the classical Deaf versus hearing divide, but are nevertheless found in the reality of families who are confronted with congenital deafness (see also Christiansen and Leigh 2004). This is achieved through inclusion of a 'construction of deafness'-cluster in our model representing parents' position with regard to their child's deafness. The importance of how parents construct deafness was mentioned by Young and Tattersall (2007) in their analysis of the impact of UNHS on parents' adjustment to their child's deafness. In their study the authors focused on the role of professionals during early screening and intervention in parents' – predominantly medical – construction of deafness. Based on our empirical studies we have further developed this concept, which resulted in the 'construction of deafness'-cluster that includes several additional factors besides professionals' support.

The construction of the explanatory model allows for identifying challenges in social and educational policy. For instance, if policymakers want to give priority to informed decision-making and equal opportunities, they will find in the model indications that action could be taken with regard to critically assessing the medical focus in formal social support and improving the opportunities offered in special education. The model gives care professionals more insight into their role in parents' decision-making processes by demonstrating how incorporating more attention for cultural aspects of deafness in their interaction with parents could have an effect on adjustment processes and decision-making.

On a conceptual level the model is a basis for future debate. It carries in itself an invitation for further investigation of the parental decision-making processes, the interrelatedness of factors and different pathways – either related to one care-related event such as cochlear implantation, or in the perspective of a care trajectory. At least three issues remain with regard to further development of the model, providing

challenges for future empirical research. First, there has been little attention in deaf studies for cultural-ethnic differences other than those between Deaf and hearing communities. In literature Deaf culture is often described in contrast to the majority who uses spoken language and considers hearing as necessary for social participation. This dualist representation is reductionist in that cultural differences between the Deaf and hearing communities are overemphasised and differences within these communities neglected. Woll and Ladd (2003) have argued that the representation of Deaf communities as a reaction to the oppression by hearing culture does not adequately reflect the dynamic qualities of Deaf communities. This is in line with scholars who have argued that in social model theories and research not enough attention has been given to applicability across different cultural contexts (Priestley 2001; Mercer 2002). Some attention has been directed to this issue by Steinberg et al. (2003), Foster and Kinuthia (2003), Smiler and Locker McKee (2007), however their empirical contributions with regard to the role of cultural-ethnic aspects on the level of parents' construction of deafness is limited. Operationalisation of cultural-ethnic elements in care-related decision-making, for example within an ethnographic approach of the subject, is an empirical challenge that when met will contribute to the further development of our model by refining or addition of factors/relations.

Second, the attention of disability studies in general and deaf studies in particular for issues of socio-economic deprivation and social inequality has been limited in its scope; by some scholars the issue was neglected as a result of an emphasis on aspects of community/culture. Empirical studies have been aimed at the unfavourable socio-economic position of people with disabilities as a group, but little is known about the effects of socio-economic differences *within* this group. This has recently been pointed out in Calton's (2010) analysis of the memoirs of parents of children with disabilities and it is equally true with regard to deafness. With regard to cochlear implantation, some authors have reported on the role of economic costs in parents' decision-making – for example Okubo et al. (2008) and Hardonk et al. (2011b) – and on the economic costs incurred by families – for example Barton et al. (2006). However, through analysis of care-related costs these studies have reduced socio-economic aspects to a separate factor in decision-making. Therefore, with the development of the explanatory model also comes the challenge to direct further attention to the role of families' socio-economic position in care-related decision-making. More specifically, families' socio-economic position and relevant class relations need to be operationalised in empirical study designs to allow for analysis on the level of all different factors and relations in our model.

A third challenge involves international validation – both qualitative and quantitative – of the model. Although findings from literature have been used to support the construction of our model, it remains necessary to transcend the influence of specific characteristics of the setting of our empirical research. Parents' care-related decisions take place within a context characterised by specific policy, for example concerning early intervention services and availability of educational opportunities. International validation through empirical studies can shed light on how discourses related to different social and welfare policies influence parents' decision-making and whether this demands modifications of our model.

We conclude that in a sociology of deafness the value of social and cultural-linguistic model concepts becomes apparent in providing a better understanding of the full complexity of families' decisions, which cannot be achieved using exclusively a medical model approach. Our findings clearly demonstrate that parents'

conceptualisations of deafness and their decisions with regard to care cannot be confined within the conceptual boundaries of one model of disability. A sociological approach that incorporates social and cultural-ethnic models of disability has the potential to generate middle-range theory relevant to policy, professional practice and scientific research, because it is more adequate for understanding the *reality of disability*.

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