Old challenges, changing contexts: reviewing and reflecting on information provision for parents of children who are deaf or hard-of-hearing

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Old challenges, changing contexts: reviewing and reflecting on information provision for parents of children who are deaf or hard-of-hearing

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ABSTRACT

The provision of information is generally not a technical activity, but rather a contextualized social action. Previous research about informed-choice and decision-making for parents of children who are deaf or hard-of-hearing (POCDHH) has demonstrated this, highlighting the close relationship between contextual factors and the nature of information parents are provided with to support decision-making on behalf of their children. Such contextual factors involve human elements such as attitudes, values and beliefs of individuals involved in the transfer of information, as well as broader contextual factors such as changing information technology and changing markets. This paper reviews literature from a range of fields relating directly and indirectly to issues of informed decision-making for POCDHH. These studies provide an overview of issues such as current understandings of what type of information does (or does not) support decision-making, as well as highlighting the importance of considering how information is presented. Approaches used in other fields to address issues of reliability of information are also discussed. To complement this literature review, the article includes an auto-ethnographic component documenting my own attempts as a POCDHH to garner reliable information on behalf of my daughter within a discursive environment where the material often appeared inconsistent with best practice informed-choice and decision-making principles.

Introduction

Different methodologies allow varying access to areas of inquiry, providing researchers with different ways to ask questions in the social sciences (Adams, Holman Jones, & Ellis, 2015). Less traditional methods such as auto-ethnography, connect the 'personal' with the 'social', and have become increasingly popular in recent years. One benefit of auto-ethnography is that it can afford access to

information or experiences outside the purview of existing literature on a given topic (Cook, 2014). Auto-ethnographic approaches are also valued for the access they afford into lived experience which is often more messy and uncertain than more traditional forms of research convey (Chang, 2016). This article explores issues relating to information provision and decision-making for POCDHH through a combination of auto-ethnography (in which I reflect on my own experience and observations as a parent stakeholder), as well as through a traditional narrative literature review.

Reflections and recollections

When my daughter Melissa was born in NSW, Australia in 2010, the Universal Newborn Hearing Screening programme was in its ninth year of operation. Melissa was identified with what was then an unusual and little-understood form of hearing loss called Auditory Neuropathy Spectrum Disorder (ANSD). Most of the information we encountered at the time was in print form. The children's hospital provided a sheet of paper with basic information about ANSD and a bundle of more generic material about hearing loss. I was advised to avoid consulting 'Dr Google', as it was put, on the basis that what I read might cause alarm. Naturally, I ignored this advice and spent many hours in the middle of the night as I fed my baby, scouring the web for details on what this diagnosis might mean for Melissa's future. The hospital was right about the alarm caused by some of the things I read on the Internet, yet the act of accumulating knowledge also brought with it some sense of comfort. I felt that through knowing all there was to know, I would somehow arrive at a point where I would be able to execute informed choice, a process that sounded neat and methodical in the introduction of the Australian Government issued booklet entitled *Choices* (2005) that had been part of the information bundle. It read:

> This book is called 'Choices' because the information it contains will assist you in the choices you will be making. No one can tell you what is best for you and your family. To make an informed choice about educational options, we suggest you make an appointment to visit each facility and then make a decision as to which program best suits the needs of your family. (Australian Hearing, 2005, p. 5).

One of the first decisions that POCDHH are encouraged to make is choosing an early intervention service. At that time, there were a few options in Sydney. Each looked appealing in their brochures, though some were glossier and more attractive than others. Many featured 'success stories' about their 'graduates' with the apparent gauge of this success being the child's enrolment in mainstream school with age-appropriate spoken language.

Despite best intentions to make a considered choice, in the chaotic reality of daytime, and juggling a toddler, and newborn Melissa (who was also diagnosed with serious health issues), it became clear that off the page (i.e. in real life),

decisions are made more haphazardly. We signed up swiftly with the closest centre to home, an organization offering an auditory-verbal approach. The staff was lovely. When they told me that, with assistance, Melissa would be able to speak and attend a mainstream school, I wept with relief at the prospect that she may be able to live a normal life.

As time passed, the initial shock of finding out that Melissa was deaf wore off and her health issues resolved. Life was a little less chaotic. We continued to attend weekly auditory-verbal sessions at the early intervention centre. My two daughters and I enjoyed these sessions. We even featured briefly in a short segment on the breakfast television show 'Sunrise'. Nine-month-old Melissa made a little squawk while the cameras were rolling which was later edited to appear a momentous event; the reporter declaring her vocalization 'a miracle'.

I continued to gather all the information I could. I read articles online, attended conferences and seminars, spoke to professionals and other parents, joined online forums, and liked the Facebook pages of organizations as a way of keeping in touch with deafness-related activities and news. I became aware of the existence of different perspectives on deafness, and was interested in the debates about communication modes; in particular, the benefits that signing could bring for children. I wondered why no one had raised the option of Auslan (Australian Sign Language) with us. I was troubled by what I read about the potential of language deprivation, the lower psycho-social outcomes in adolescents and adults who were deaf. I was saddened by the stories of adults who were d/Deaf, some recalling the difficulty and isolation they felt at school and the regret at having missed out on the opportunity to connect with the Deaf community. Partly because of my exposure to these different perspectives, and partly because by this time we had discovered that Melissa's hypo-plastic (narrow) auditory nerves meant she would be one of the small group of children unlikely to gain benefit from a cochlear implant and hearing aid, I enrolled my two daughters in a bilingual Auslan/English preschool and noticed at once the ease with which both daughters picked up a new language.

For reasons which I could not precisely lay my finger on, I started to question some of the material I was encountering. First, there was the large billboard displayed in bus stops around Sydney, commissioned by an early intervention service for children who were deaf and blind (see Figure 1). It featured a teddy bear with no ears or eyes slumped against a wall, with the title above the bear reading, 'We need your help'.

Then there were the cochlear implant switch on videos shared on YouTube and Facebook, and the ubiquitous success stories in video and print form, a staple of newsletters and newsfeeds, enthusing about 'the miracle of cochlear implants', 'the precious gift of speech', 'the power of speech'. The mother telling the camera: 'We got a life back that we never thought we would.' There was the post that appeared daily at the top of my Facebook feed for weeks: a montage of photos of the life of a little girl (a cochlear implant recipient)
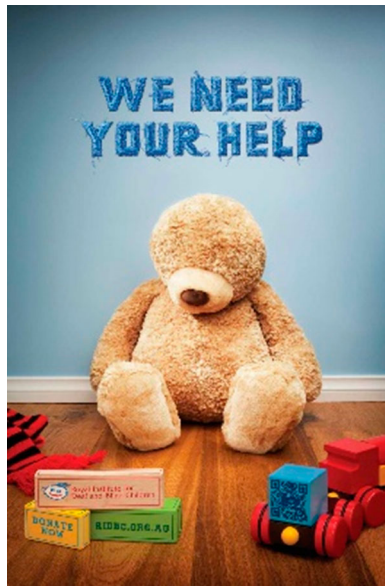
Figure 1. Early intervention billboard 2013.

from birth to school. The clip was set to Stevie Wonder's 'I just called to say I love you', accompanied by the following caption:

> Picture this; your child is hearing impaired. How would you feel if you NEVER heard the words "I love you" coming out their little mouths?

Not only did these texts seem overly simplistic in their representations of hearing loss and hearing technology, but, on top of this, they seemed to share a common element that hinted ominously at the negative trajectory the life of a child like Melissa might easily take, given the wrong circumstances. A seed of fear planted in parents' minds. Without 'help' would Melissa be destined to lead her life metaphorically slumped against a wall? Without the power of speech would she be powerless? Is it a tragedy that lies on the other side of a miracle? If not a success story, what did that leave?

And then there was the book about Mellie the elephant that resurfaced in our bookshelf one evening last winter (selected pages shown in Figure 2). Published by a cochlear implant company, it had been part of an information pack we were given in the lead up to Melissa's cochlear implant surgery. The book follows a basic narrative structure. The orientation is Mellie's birth (a time of great happiness), the complication is the discovery that Mellie is deaf (a cause for sadness), followed quickly again by happiness when the parents learn about cochlear implants. The story resolves predictably. Mellie receives cochlear implants and learns to listen and speak, making her parents 'so proud'. The final page shows Mellie playing with her friends and essentially being the same as all the other elephants.

> The ear doctor said: 'Mellie does not hear well.' At first her parents were sad. But then the doctor said that there was something that would help Mellie to hear. First, he suggested Mellie should try hearing aids….

> Mellie is a happy child. She has many friends. She can do all the things her friends can do. Mellie loves being with her friends. They sing and dance and listen to stories. She loves her 'new ears' — her cochlear implants!

Figure 2. Children's book in information pack.

As Melissa and I read this book together, some things concerned me. Why had the doctor emphatically told Mellie's parents that the cochlear implants would make Mellie hear? Melissa's implant had only slightly improved her access to sound, and we knew other children with similar, or more limited results, some of whom had never acquired spoken language. Surely, if this book was a part of the information pack for parents, it should at least hint at the possibility of variable outcomes. Additionally, Mellie was a baby when diagnosed, yet in the picture of her arriving at hospital for her implant surgery she is out of nappies and walking. How had Mellie been communicating in the extended lead up to the surgery? Why hadn't someone suggested to the parents that Mellie learn sign language? Had Mellie been without a language all this time?

My thoughts were interrupted by Melissa's question, 'Mum … were you and Dad sad when you found out that I was deaf?' And any sense that I might be overreacting about a fictional elephant departed. I wanted to answer her honestly, so I admitted that yes, like Mellie's parents, we had been sad at first. But, I explained, the reason for my sadness was not that she was in any way a disappointment, but only because I didn't understand what being deaf meant. She had only been a baby, I had been frightened that she wouldn't be able to live a good life. I had never met another person who was deaf before …

I assured her that I understood now that I needn't have felt sad. That, given a choice, I would never change a thing about her. But the question broke my heart

a little, and it reminded me of another reason why good quality information matters. If an organization can publish material that potentially makes a child who is DHH wonder if their very existence in the world may be a source of grief or a burden on their parents, then it matters greatly. If what my daughter took from this attractive little book, (part of a service providers' information pack) was an inkling that her worth in her parents', or indeed in anyone's eyes, might be intertwined with her ability to hear or speak, then there is a problem. The fact that the book, repellent to me as a parent further along the path, had appeared entirely benign when we had first read it with our children, back when we were in the throes of decision-making, raises questions about information provision that needs to be addressed.

Parents' feelings matter too, of course, for a number of reasons, not least because of the substantial body of literature linking confident and well-supported parents with better language outcomes in children (see following section). I know as well as anyone the worry which many new parents feel when their child's hearing loss is identified, and that the initial instinct can be to seek a solution to reverse the 'problem'. However, I wondered whether too much emphasis might be placed on these initial feelings after diagnosis and whether what we parents *want* to hear in those early days is perhaps at odds with what we need to understand in order to accept that our child is DHH, and always will be; and to make fully informed decisions in their best interest. These reflections and experiences posed many questions in my mind about the nature of information parents are provided with and led me to the point at which I commenced research to understand better issues of the information supplied in this and other related areas. The following section is an overview of some of these readings.

Information provision and decision-making

It has often been argued that that the provision of information is not a technical activity, but rather a contextualised social action (e.g. Young & Temple, 2014). A review of the literature about the provision of information regarding services for children who are DHH in many ways reinforces this perspective, highlighting the roles a range of contextual factors plays in the way information is delivered. Though stakeholders widely acknowledge the benefits of informed-choice, and there is no agreement about the importance of services adopting a family-centred approach to early intervention – to support POCDHH to gain 'the necessary knowledge, information and experiences to make fully informed decisions' (Moeller, Carr, Seaver, Stredler-Brown, & Holzinger, 2013, p. 434), it appears that the way information is provided is not always consistent with these recommendations.

Several complicating factors seem to exist in relation to the provision of quality information about early intervention services for children who are

DHH. These include the 'human elements' involved in the process of informed-choice such as the (often emotional) decision-making process POCDHH go through, as well as professionals' attitudes towards deafness, and its 'management', which can influence the way that potential options are communicated to parents.

Additionally, research in other fields (to be discussed below) has indicated the influence of broader contextual factors on information provision, which have been less thoroughly researched in the DHH field. Increasing market pressure, along with a shift to online modes of communication have significantly influenced the way information is designed and presented at times blurring the lines between information and promotional material. As a result of such internal/external and longstanding/emerging factors, the task of both distinguishing and garnering reliable and unbiased information can be particularly difficult for POCDHH.

The following sections take the form of a narrative literature review, investigating key concepts relating to the close relationship between information products and decision-making. These issues relate to both *what* and *how* information is produced within this context. The section will provide an overview of current understandings of the type of material that is (and is not) considered to facilitate informed choice as well as of the complexities of the decision-making process. The next sections will discuss how communicators' attitudes about deafness and its 'management' can influence the nature of information parents receive, and some of the ways in which similar issues relating to subjective presence in information have been approached in other social contexts. The paper ends with a final reflection on my own decision-making experience as a POCDHH.

A family-centred approach to informed choice for POCDHH

Notions of informed-choice and decision-making have been highly influential on the policy and practices in many healthcare areas (Baxter, Glendinning, & Clarke, 2008; Jørgensen, Brodersen, Hartling, Nielsen, & Gøtzsche, 2009). For paediatric services, (such as early intervention services), the conceptualization of informed-choice is predominantly situated within the parameters of a family-centred model in which the emphasis on individual responsibility and choice shifts to facilitating informed decision-making for the parent or primary care-givers of the child. Support for this family-centred approach is backed by findings linking confident, involved parents (i.e. with high levels of self-efficacy and involvement) with better outcomes for the child (e.g. Ching, 2014; Moeller et al., 2013; Sass-Lehrer, Porter, & Wu, 2015; Yoshinaga-Itano, 2014). Though definitions vary, fundamentally family-centred early intervention conceptualizes parents as being 'the most important agents of change for their children' (Decker & Vallotton, 2016, p. 38). Family-centred early intervention emphasizes the need

for professionals to empower parents in processes such as participation, self-responsibility, and co-determination (Hintermair, 2006). As such, family-centred care represents a shift away from a more traditional expert–client models of service delivery, repositioning professionals and parents as being in a partnership. A critical element of family-centred care, therefore, is the provision of information from 'a variety of sources that are comprehensive, meaningful, relevant, unbiased and evaluative to enable informed decision making' (Moeller et al., 2013, p. 434). In efforts to support the effective implementation of family-centred principles, including informed decision-making, many recommended best practice guidelines have been published. These include The Early Childhood Intervention Australia (ECIA) best practice guidelines (ECIA, 2015), the International Joint Committee on Infant Hearing (JCIH) guidelines (American Speech-Language-Hearing Association, 2007; Muse et al., 2013), and the Family-Centered Early Intervention (FCEI) Consensus Statement for Children who are Deaf and Hard of Hearing (Moeller et al., 2013).

The importance of providing information to support informed-choice is also highlighted in other ways in the literature. Ethical considerations for the provision of information about services for children who are DHH are raised by Beattie (2010) and include notions of autonomy (respecting the individual), beneficence (doing good for others), non-maleficence (doing no harm), and justice (non-discrimination, fairness and equality). Similar ethical dimensions of information provision have received considerable attention in the broader healthcare context, with many studies noting the tension between information to promote understanding of critical issues and information to promote uptake in a particular activity. A central concern in much of this type of research focussed on health communication is that audiences may experience difficulty distinguishing one purpose from another in the material they encounter (e.g. Brown, Ramchandani, Gillow, & Tsaloumas, 2004; Hall, 2006; Hersch et al., 2011; Wise & James, 2012). However, the absence of any formal regulations or guidelines defining acceptable or unacceptable practices concerning the way services for children who are DHH provide information means that these matters are largely left to service providers' discretion.

As a point of comparison, it is notable that in other health-related fields in Australia, service providers are required to adhere to clear regulations surrounding the ethical dimensions of their work, in the form of the Guidelines for Advertising of Regulated Healthcare Services (Australian Health Practitioner Regulation Agency, 2014), as well as the Medical Board of Australia's Code of Conduct (Medical Board of Australia, 2014a) and Social Media Policy (Medical Board of Australia, 2014b). These guidelines refer to the importance of facilitating informed choice through reliable information and regulate how material is presented to potential consumers. Some examples of these regulations include the banning of 'the use of testimonials or purported testimonials', as well as information that is likely to create unrealistic expectations 'either directly, or by

implication, [or through the] use of emphasis, comparison, contrast or omission' (Australian Health Practitioner Regulation Agency, 2014, p. 4). The guidelines have been formulated in the interest of facilitating informed healthcare choices, particularly for those who 'may be vulnerable or not sufficiently well-informed to decide the suitability of certain types of services' (Australian Health Practitioner Regulation Agency, 2014 , p. 1).

Similar concerns have also been raised by researchers in other fields, who have been critical of commercially motivated tactics that either incite fear (Brookes & Harvey, 2015) or employ 'branding' strategies to push consumers in a particular direction through imbuing the brands with 'positive associations' or 'intangible ideals' (Ng, 2014, p. 103) to represent the brand as 'experience' or 'lifestyle' within the texts (Maier, 2011; Ng, 2014) rather than communicating concrete details about what it is the service/organization actually does.

The lack of guidance around the communicative practices of services targeting POCDHH is also essential to consider in light of the new more consumer-driven and competitive landscape brought about by the introduction of the Australian National Disability Insurance Scheme (NDIS), a changed funding model that requires organizations to more deliberately market their services than ever before to attract new clients. Such tension between the need to promote services while ensuring consumers are well-informed is particularly salient when considered in light of research concerning the relationship between the way information is presented, and the influence this can have on decision-making processes for audiences such as POCDHH.

Choosing – the decision-making process

Being cast in the role of 'expert on your child' can be daunting for POCDHH, the vast majority of whom are not deaf themselves, with very little pre-existing knowledge in this area (Hyde, Punch, & Komesaroff, 2010). Major decisions need to be made, often quickly, due to evidence linking better outcomes with early identification and access to hearing technology and early intervention services (Ching & Dillon, 2013; Pimperton & Kennedy, 2012; Yoshinaga-Itano, Sedey, Wiggin, & Chung, 2017). However, many studies indicate that, for a range of reasons, parents often find gathering 'all relevant information about the possible futures available to their children' to be a difficult, and stressful experience (Hyde et al., 2010). Additionally, the lack of accessible and evaluative evidence online about communication choices has been reported by POCDHH (Deaf Australia Inc, 2009; Porter & Edirippulige, 2007; Sorkin & Zwolan, 2008; Zaidman-Zait & Jamieson, 2004).

One complexity of information provision relates to the individual and varied nature of decision-making. This has been demonstrated through qualitative research into parents' preferences for information presentation in relation to particular information products designed for parents (Mitchell & Sloper, 2002;

Young, Jones, Starmer, & Sutherland, 2005). Although the types of information products discussed in these studies (e.g. booklets and brochures) have now largely been superseded by digital forms of information, the findings have some currency about understanding parents' decision-making processes. In these studies, opinions of parents differed, though some general preferences were indicated. Plain and simple language, clear visual design, attractive front covers, colour-coded chapters, and interesting designs were all felt to increase the readability of the material (Mitchell & Sloper, 2002; Young et al., 2005). Additionally, concerns that the design of information might play a role in 'attitude setting' were raised. An example of this is the way that layout decisions, such as the ordering of sections, were felt to influence how parents viewed various options. For example, the way medical or technical information about hearing aids and cochlear implants often came before information about communication options was raised as a concern by some parents who felt that this contributed to parents viewing their child's hearing loss predominantly as a medical problem. Additionally, the way language was used to establish tone or voice was felt to contribute to how much the resources acted as an emotional or a practical guide, though opinions over which was preferable varied; some preferring a casual, friendly tone, whilst others preferred a more detached voice, finding the informal manner patronizing (Young et al., 2005). Such research points to a need to consider both *what* and *how* information is presented. To anticipate that as long as parents are provided with numerous publications about early intervention they will be able to inform themselves appears to be a 'simplistic and dangerous' assumption (Mitchell & Sloper, 2002, p. 78).

Indeed, one criticism of the way that informed-choice is often represented within the literature is that it tends to be based on unrealistic expectations of rational decision-making on the part of choosers, when in actual fact the process is not so straightforward, with many viewing it as an ongoing fluid process (Matthijs et al., 2017; Moeller et al., 2013; Young et al., 2006).

Such a criticism is supported by research about informed decision-making within the broader context of healthcare options where it is suggested that decisions are made using two modes of thinking – those being the analytic mode, which is 'conscious, deliberative, reason-based, verbal and relatively slow', and experiential mode which is 'intuitive, automatic, associative and fast' (Hibbard & Peters, 2003, p. 417).

Regardless of the modes of thought involved, the strong 'affective component' involved in decision-making has been noted in relation to choices made by POCDHH (Hyde, Punch, & Komesaroff, 2010, p. 163). Parents have reported that their own beliefs, values and attitudes play an influential role in decisions they make for their children (Decker, Vallotton, & Johnson, 2012; Hyde et al., 2010). Parents in one study cited their own judgement, followed by the judgement of their partner or spouse, as having been the most influential factor in the decisions they made, though it is suggested that parents

'internalized' various sources of information they received and 'accepted it as their own beliefs' (Decker et al., 2012, p. 157). Additionally, even some parents who were highly motivated to make an informed-choice reported that it was 'an emotive moment' (Hyde et al., 2010, p. 163), or seeing a television commercial about a child with a cochlear implant (Komesaroff, 2007) that ultimately swayed the decisions they made for their child. Another contextual factor worth noting here the significant emotional strain parents may be under at this point of their lives, with some experiencing grief, stress or difficulties adjusting to their child's diagnosis (Sarant & Garrard, 2014; Sass-Lehrer, 2012).

The notion of the 'boundedly rational' (Schmidt, Bhatt, & Sunstein, 2017; Simon, 1959) decision-making process, in which choosers both think and feel their way through decisions, has implications for how information is designed and presented. Research about decision-making processes has looked at the strong impact of 'vivid presentations' (Sherer & Rogers, 1984) or 'arresting images' (Brookes & Harvey, 2015; Joffe, 2008), have been shown to influence the public's uptake of a particular promotional message. 'Priming' techniques such as the strategic use of visuals and text are also thought to influence the way audiences view an issue or a product (e.g. Powell, Boomgaarden, De Swert, & de Vreese, 2015). Additionally, incorporating health information in a narrative format appears to be more influential than if the same information appeared in a less personal form (Atkinson, 2009; Frank, 2010) and, furthermore, different types of narratives can elicit different reactions from choosers (Shaffer & Zikmund-Fisher, 2013). A theory of 'constructed preferences' (Simonson, 2008; Lichtenstein & Slovic, 2006) posits that choosers' healthcare preferences are inherently unstable, altering significantly according to the types of questions asked and the nature of the information presented.

In light of such research, it is asserted that 'to acknowledge that the way information is presented affects choice is to accept a new level of responsibility' (Hibbard & Peters, 2003, p. 428). Yet as discussed above, in the absence of clear guidelines or policy around the communicative practices used in by services for children who are DHH, parents frequently encounter material designed using strategies considered unacceptable in other spheres (Kecman, 2017). Some work in the field of services for children who are DHH has approached this problem through the design of resources to assist choosers in their decision-making process, for example through decision aids or grids (Humphries et al., 2014), or through efforts to educate POCDHH to become critical consumers of information. An example of this can be seen on Australian Hearing's website in a section entitled 'Which sites have trustworthy information about hearing loss?' (Australian Hearing Website, 2018).

While such approaches are potentially pragmatic, as a POCDHH myself, I feel it is important to address shortcomings in the information directly. Parents require comprehensive and reliable information from the outset, to provide them with, to the extent possible, an understanding about important issues, debates, risks,

benefits and an awareness of uncertainties associated with any given approach. Organizations should not assume that parents already possess comprehensive knowledge about all potential options, as this is often not the case (Spellun & Kushalnagar, 2018), and should be more mindful of the extent to which they may be 'constructing' parents' preferences. Parents do not know what they do not know. There is more that can be done by organizations and policymakers to ensure that the information POCDHH are provided with is comprehensive and reliable and is communicated in ways that support informed decision-making.

Constructions of deafness, professionals' attitudes and informed-choice

A well-explored area that is of great relevance to POCDHH's decision-making relates to the way deafness and potential intervention approaches are 'constructed' in information that parents encounter soon after diagnosis (Hyde et al., 2010; Matthijs et al., 2017; Matthijs et al., 2012; Mauldin, 2014). These attitudes can influence the choices parents make.

There are broadly speaking, two alternate constructs of deafness explored in the literature. On the one hand, there is the 'medicalised' construct of deafness sometimes termed 'hearing world' (Power, 2005) or 'impairment' or 'infirmity' models (Lane, 1990, 1995). On the other hand is the 'cultural–linguistic' or 'constructionist' construct (Lane, 1990, 1995; Matthijs et al., 2012).

It is generally the 'medical' perspective of deafness that POCDHH first encounter when their child is diagnosed. Through this lens, deafness is primarily viewed as an impairment or disability, and the role of intervention is 'treatment', consisting of intensive auditory and speech training to make speech possible (Matthijs et al., 2012). The over-arching focus is on 'the potential for normalizing deaf lives personally, socially and educationally' (Power, 2005, p. 453). From this perspective, the use of sign language is not generally promoted, as it is considered only relevant 'if needed', -something that is offered as a second choice if spoken language 'is not deemed to be achievable' (Matthijs et al., 2012, p. 388); for example if the child is not a suitable candidate for hearing technology such as cochlear implants or hearing aids.

The 'cultural–linguistic' perspective differs considerably from the medicalised model and also has potential implications for the types of choices parents make about early intervention approaches. This construct challenges the emphasis on 'Normalization' (Wolfensberger & Tullman, 1982) or 'Normalcy' (Bauman & Murray, 2014) interpreting it as an aversion to difference which some believe has become institutionalised in the beliefs, languages and practices of people without disabilities (Bauman & Murray, 2014). Proponents of this approach point to evidence that sign language or bilingualism benefits children psycho-socially, communicatively and culturally (Knoors & Marschark, 2012), as well as acting as a 'safety-net' to reduce the potential harm caused by language-

deprivation in early years (Humphries et al., 2012; Klaudia, 2013). It is also argued that this perspective can foster children's sense of identity, through allowing children to think of themselves as more than 'unfinished hearing people' but as part of a culture with its own language and community (Padden & Humphries cited in in Solomon, 2012, p. 56). In a cultural–linguistic approach to early intervention, speech therapy and the use of hearing technology are generally important components; however, they are not the sole focus, since this perspective brings with it a 'corresponding focus on visual possibilities rather than auditory deficits' (Matthijs et al., 2012, p. 388).

The JCIH guidelines (see above) state that, 'families should be made aware of all communication options and available hearing technologies (presented in an unbiased manner)' (American Speech-Language-Hearing Association, 2007, p. 899), on the basis, that this will support informed choices. Despite this, a number of studies have indicated that, whilst the benefits of oral communication approaches such as auditory-verbal therapy are often made clear in information provided to POCDHH, any associated potential risks, harms or uncertainties are not as clearly communicated (Matthijs et al., 2017; Spellun & Kushalnagar, 2018). For example, parents may not be made aware of the higher instances of psycho-social and or educational difficulties experienced by DHH children with cochlear implants (Dammeyer, 2009, 2012; Stevenson, Kreppner, Pimperton, Worsfold, & Kennedy, 2015). Another issue appears to be that the decision about communication mode is often presented, unnecessarily, as an 'either–or dilemma' to parents (Humphries et al., 2012; Knoors & Marschark, 2012). The research about the dominance of the medical perspective has been noted as one area where there is a discrepancy between 'actual and desired family-centered care' (Ingber & Dromi, 2010) and between 'formal' and 'lived' ideologies of service providers for children who are DHH (Matthijs et al., 2012). The findings of the studies discussed suggest that although organizations may believe themselves to be family-centred, and to be facilitating informed decision-making, that they may be mistaken. Greater reflexivity and discussion about how information can genuinely support informed decision-making is required.

Approaches to monitoring information provision in contemporary contexts

Issues around the quality of health information are, of course, not new; however, the increased number of consumers preferring to seek health information online has intensified interest in this area. (Stvilia, Mon, & Yi, 2009). While online health information has the potential to enhance informed decision-making and empower choosers, the reverse is also true (Kobes, Harris, Regehr, Tekian, & Ingledew, 2018; Winker, et al., 2000).

Some approaches to this problem have been the development of tools to provide consumers with a means to evaluate the quality of various sources of information. For example, researchers in 'information epidemiology' or

'infodemiology' (Bernstam et al., 2008) are concerned with exploring and developing approaches to monitor reliability, accuracy and accessibility of online information, through the development of tools and criteria to assist consumers to assess the quality of various sources of information (Charnock & Shepperd, 2004; Kim, Eng, Deering, & Maxfield, 1999; Kobes et al., 2018). However, a number of limitations have been noted in these standardized approaches; they do not appear to be reliable in contexts with greater levels of uncertainties about the efficacy of 'treatments' (Bernstam et al., 2008; Bernstam, Sagaram, Walji, Johnson, & Meric-Bernstam, 2005),as is the case with early intervention approaches (Knoors & Marschark, 2012; Luckner & Cooke, 2010). Another limitation is that they do not cope well with the ever-increasing range of genres now employed on websites (Stvilia et al., 2009).

Indeed, the emergence of 'hybridized' discourses where previously distinct media forms such as information, advertisements, entertainment, editorials, or news become creatively mixed and blended into new forms such as 'docu-drama', 'infotainment', 'infomercial' (Fairclough, 1995; Feng & Wignell, 2011; Lim, Nekmat, & Nahar, 2011; Rahm, 2006) is another concern for informed-choice in contemporary contexts. This type of 'interdiscursivity' (Fairclough, 1992) – that is, the blending of various genres and purposes, means that texts often draw on many different styles of discourse within a single text (for example, scientific or educational discourse), and employ 'voices' from all walks of life (for example, the voices of experts, celebrities, children) to reinforce the credibility and desirability of a particular activity or organization from different angles (Feng & Wignell, 2011).

In some instances, this hybridization is considered to be a deliberately misleading form of representation, or 'genre-misrepresentation' (Hall, 2006) a strategy through which commercial or ideological motives are obscured with publications 'masquerading' as something more objective (Young et al., 2006); for example medical leaflets (Hall, 2006; Wise & James, 2012), posters and billboards (Brookes & Harvey, 2015; O'Halloran, 2008), and websites (Braun, 2009; Carreon, Watson Todd, & Knox, 2013; Harvey, 2013; Moran & Lee, 2013). Issues of trustworthiness are raised in such research, where these types of publications have been characterized as 'dressed in a cloak of empowerment' (Hall, 2006), appearing to provide unvarnished facts (Harvey, 2013), whilst at the same time concealing a hidden agenda behind a 'narrative of choice' (Moran & Lee, 2013). Particularly confusing in terms of informed-choice, it is argued, is the tendency for some organizations to employ 'branding' strategies to expressly align themselves with values such as empowerment, choice, and flexibility (Braun, 2009; Moran & Lee, 2013; Ng, 2014) within their publications, whilst at the same time employing a range of persuasive communication strategies to push choosers in a particular direction. There is concern that this 'rhetoric of choice' (Braun, 2009) may lead choosers to falsely believe that they are being supported to make informed decisions.

Such questions of 'buried ideology' (Machin & Mayr, 2012) are at the centre of Critical Discourse Analysis (CDA), in which information providers are viewed as 'discourse technologists' (Fairclough, 1995; Wise & James, 2012), constructing material designed to modify consumers' behaviour. In some health-related fields, CDA has explored the ways that organizations may deliberately pathologize, or medicalize a non-medical issue (for example male hair loss or certain cosmetic issues for women) to persuade consumers that a purchasable product or service is required for them to be 'normal' (Braun, 2009; Harvey, 2013; Moran & Lee, 2013). Questions around the moral legitimacy of 'medicalisation' within health campaigns have been raised (Conrad, 2005; Moynihan & Henry, 2006) particularly where fear is being harnessed for commercial reasons (Brookes & Harvey, 2015; Hastings, Stead, & Webb, 2004).

Though the debate over the dominance of the medical construction of deafness discussed in the previous section is far more nuanced and complicated than some of the examples given above, there are stakeholders who are affronted by what they perceive to be relentlessly negative representations of deafness (Bath, 2012; Deaf Australia Inc, 2009) as primarily a 'condition to be cured' (Hyde et al., 2010) and CDA has been revealing in past research that such attitudes do permeate the advice some professionals give to some parents (Matthijs et al., 2012). Similarly, concerns about the highly positive representations of services and products (e.g. cochlear implants) in the public discourse have been raised in recent years (Oschner, Spohrer, & Stock, 2015; Mauldin, 2014). However, a criticism of the existing research of informed-choice and children who are DHH has been its tendency to dwell on specific issues, thus becoming 'too narrow in scope or factional in its outlook' to contribute to constructive discussions about informed-choice (Young et al., 2006, p. 324). For this reason, a CDA approach which often seeks relegate information to a particular discourse or ideology (c.f. Matthijs et al., 2017) may also be somewhat limiting; and perhaps less divisive methods for improving the quality and reliability of information are required.

Reflections on our decision-making to date

To return to Melissa's story, I will summarise the choices we made for her. Melissa has a cochlear implant in one ear, a hearing aid in her other, and quite likes them both, though she doesn't seem to notice when her cochlear implant stops working and often forgets to wear it. She speaks well. In the soundproof room where her speech and listening are tested, she obtains excellent scores; however, in noisy environments, such as her mainstream classroom, it is nearly impossible for her to understand what people are saying. She has a full-time Auslan interpreter at school, approved by the NW Department of Education on the basis that this accommodation gives her equal access to the curriculum. Rather than spending all her effort trying to hear, or lip-read, she can focus on

learning new concepts. She has made good progress and loves school. Her class-mates learn a little bit of Auslan every day.

None of this is the norm for children who are DHHin Australia since the over-whelming majority of children who are DHH graduate from an exclusively oral early intervention programme (particularly in some states where auditory-verbal therapy is the only available service for families). Some may see the need for an interpreter as an indicator of failure; I see it as a 'success story' different to most. At the end of last year, Melissa won the class medal for 'Out-standing Student' on presentation day. To my embarrassment, I wept in public again, though this time the tears were nothing to do with her being normal (as had once seemed the ultimate goal), but more because she was not, and because there was nothing wrong with that.

The intention of including this update on Melissa's progress is not to validate my own choices, or to suggest these choices were best, or right. There is no one-size-fits-all approach (Leigh & Marschark, 2016; Young & Temple, 2014). Our family is fiercely proud of Melissa, and who she is; we much appreciate the work of the many early intervention professionals who have been part of our life. But the fact that she can speak, and can 'pass' (McDonald, 2010) in the hearing world is not the sum of her, and the fact that she is deaf has expanded all of our horizons and has given her access to another culture and language.

There are potential risks, benefits and uncertainties associated with all options and the evidence on the efficacy of any given approach to early intervention remains inconclusive. To produce material that suggests otherwise is to do parents and their children a great disservice.

Disclosure statement

Notes on contributor

Emily Kecman is a secondary school teacher, a PhD candidate and a mother to three children - one of whom is deaf. Her research involves investigating the way that issues affecting families of deaf children are written about and represented within academic and promotional material produced in the contemporary context.

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References

Adams, T. E., Holman Jones, S., & Ellis, C. (2015). *Autoethnography: Understanding qualitative research*. New York: Oxford University Press.

American Speech-Language-HearingAssociation. (2007). *Year 2007 position statement: Principles and guidelines for early hearing detection and intervention programs*. Retrieved from https://www.infanthearing.org/resources/2007_JCIH.pdf

Atkinson, P. (2009). Illness narratives revisited: The failure of narrative reductionism. *Sociological Research Online*, *14*(5), 1–10.

Australian Health Practitioner Regulation Agency. (2014). *Guidelines for advertising regulated health services*. Retrieved from https://www.ahpra.gov.au/Publications/Advertising-resources/Legislation-guidelines/Advertising-guidelines.aspx

Australian Hearing. (2005). *Choices*. Retrieved from https://trove.nla.gov.au/work/20547025?q&versionId=46505258

Australian Hearing. (2018). *Australian hearing website*. Retrieved from https://www.hearing.com.au/About-hearing/Hearing-in-babies-children/Resources/Which-sites-have-trustworthy-information-about-hearing

Bath, P. (2012). *Perspectives from the deaf community: Representations of deaf identity in the Toronto Star Newspaper (2005–2010)*. Ottawa: Université d'Ottawa/University of Ottawa. doi:10.20381/ruor-6035

Bauman, H.-D. L., & Murray, J. J. (2014). *Deaf gain: Raising the stakes for human diversity*. Minneapolis: University of Minnesota Press.

Baxter, K., Glendinning, C., & Clarke, S. (2008). Making informed choices in social care: The importance of accessible information. *Health & Social Care in the Community*, *16*(2), 197–207. doi:10.1111/j.1365-2524.2007.00742.x

Beattie, R. G. (2010). The ethics of newborn hearing screening. In C. Driscoll & B. McPherson (Eds.), *Newborn screening systems: The complete perspective* (pp. 31–48). San Diego, CA: Plural Pub.

Bernstam, E. V., Sagaram, S., Walji, M., Johnson, C. W., & Meric-Bernstam, F. (2005). Usability of quality measures for online health information: Can commonly used technical quality criteria be reliably assessed? *International Journal of Medical Informatics*, *74*(7–8), 675–683. doi:10.1016/j.ijmedinf.2005.02.002

Bernstam, E. V., Walji, M. F., Sagaram, S., Sagaram, D., Johnson, C. W., & Meric-Bernstam, F. (2008). Commonly cited website quality criteria are not effective at identifying inaccurate online information about breast cancer. *Cancer*, *112*(6), 1206–1213. doi:10.1002/cncr.23308

Braun, V. (2009). 'The women are doing it for themselves'. The rhetoric of choice and agency around female genital cosmetic surgery. *Australian Feminist Studies*, *24*(60), 233–249. doi:10.1080/08164640902852449

Brookes, G., & Harvey, K. (2015). Peddling a semiotics of fear: A critical examination of scare tactics and commercial strategies in public health promotion. *Social Semiotics*, *25*(1), 57–80. doi:10.1080/10350330.2014.988920

Brown, H., Ramchandani, M., Gillow, J., & Tsaloumas, M. (2004). Are patient information leaflets contributing to informed consent for cataract surgery? *Journal of Medical Ethics*, *30*(2), 218–220. doi:10.1136/jme.2003.003723

Carreon, J. R., Watson Todd, R., & Knox, J. S. (2013). Medical tourism communication of a Thai private hospital website. *Journal of Applied Linguistics and Professional Practice*, *8*(2), 71. doi:10.1558/japl.v8i2.165

Chang, H. (2016). Autoethnography in health research: Growing pains? *Qualitative Health Research*, *26*(4), 443–51. doi:10.1177/1049732315627432

Charnock, D., & Shepperd, S. (2004). Learning to DISCERN online: Applying an appraisal tool to health websites in a workshop setting. *Health Education Research*, *19*(4), 440–446. doi:10.1093/her/cyg046

Ching, T. Y. C. (2014, June 6). *Outcomes of children with hearing loss: Implications for management*. Paper presented at HEAL, Como.

Ching, T. Y., & Dillon, H. (2013). Major findings of the LOCHI study on children at 3 years of age and implications for audiological management. *International Journal of Audiology*, *52*(Supp 2), S65–S68. doi:10.3109/14992027.2013.866339

Conrad, P. (2005). The shifting engines of medicalization. *Journal of Health and Social Behavior*, *46*(1), 3–14. doi:10.1177/002214650504600102

Cook, P. (2014). 'To actually be sociological': Autoethnography as an assessment and learning tool. *Journal of Sociology*, *50*(3), 269–282.

Dammeyer, J. (2009). Psychosocial development in a danish population of children With cochlear implants and deaf and hard-of-hearing children. *Journal of Deaf Studies and Deaf Education*, *15*(1), 50–8. doi:10.1093/deafed/enp024

Dammeyer, J. (2012). A longitudinal study of pragmatic language development in three children with cochlear implants. *Deafness & Education International*, *14*(4), 217–232. doi:10.1179/1464315412Z.00000000024

Deaf Australia Inc. (2009). *Policy on early intervention for deaf andhard of hearing children*. Retrieved from http://deafaustralia.org.au/wpcontent/uploads/Educationearlyintervention policy-310420091.pdf

Decker, K. B., & Vallotton, C. D. (2016). Early Intervention for children with hearing loss: Information parents receive about supporting children's language. *Journal of Early Intervention*, *38*(3), 151–169.

Decker, K. B., Vallotton, C. D., & Johnson, H. A. (2012). Parents' communication decision for children with hearing loss: Sources of information and influence. *American Annals of the Deaf*, *157*(4), 326–339. doi:10.1353/aad.2012.1631

Early Childhood Intervention Australia. (2015). *ECIA national guidelines on best practice in early intervention*. Retrieved from https://www.ecia.org.au/Resources/National-Guidelines-for-Best-Practice-in-ECI

Fairclough, N. (1992). *Discourse and social change* (Vol. 10). Cambridge: Polity press.

Fairclough, N. (1995). Technologisation of discourse. In C. R. Caldas-Coulthard & M. Coulthard (Eds.), *Texts and practices: Readings in critical discourse analysis* (pp. 71–83). New York and London: Routledge.

Feng, D., & Wignell, P. (2011). Intertextual voices and engagement in TV advertisements. *Visual Communication*, *10*(4), 565–588. doi:10.1177/1470357211415788

Frank, A. W. (2010). *Letting stories breathe: A socio-narratology*. Chicago, IL: University of Chicago Press.

Hall, D. R. (2006). Medical leaflets, empowerment and disempowerment. In *Advances in medical discourse analysis: Oral and written contexts* (pp. 271–288). Frankfurt am Main-Berlin-Bern-Bruxelles-New York-Oxford-Wien: Peter Lang.

Harvey, K. (2013). Medicalisation, pharmaceutical promotion and the internet: A critical multimodal discourse analysis of hair loss websites. *Social Semiotics*, *23*(5), 691–714. doi:10.1080/10350330.2013.777596

Hastings, G., Stead, M., & Webb, J. (2004). Fear appeals in social marketing: Strategic and ethical reasons for concern. *Psychology & Marketing*, *21*(11), 961–986. doi:10.1002/mar.20043

Hersch, J., Jansen, J., Irwig, L., Barratt, A., Thornton, H., Howard, K., & McCaffery, K. (2011). How do we achieve informed choice for women considering breast screening? *Preventive Medicine*, *53*(3), 144–146. doi:10.1016/j.ypmed.2011.06.013

Hibbard, J. H., & Peters, E. (2003). Supporting informed consumer health care decisions: Data presentation approaches that facilitate the use of information in choice. *Annual Review of Public Health*, *24*(1), 413–433. doi:10.1146/annurev.publhealth.24.100901.141005

Hintermair, M. (2006). Parental resources, parental stress, and socioemotional development of deaf and hard of hearing children. *The Journal of Deaf Studies and Deaf Education*, *11*(4), 493–513.

Humphries, T., Kushalnagar, P., Mathur, G., Napoli, D. J., Padden, C., Rathmann, C., & Smith, S. R. (2012). Language acquisition for deaf children: Reducing the harms of zero tolerance to the use of alternative approaches. *Harm Reduction Journal*, *9*(1), 16. doi:10.1186/1477-7517-9-16

Humphries, T., Kushalnagar, P., Mathur, G., Napoli, D. J., Padden, C., & Rathmann, C. (2014). Ensuring language acquisition for deaf children: What linguists can do? *Language*, *90*(2), e31–e52.

Hyde, M., Punch, R., & Komesaroff, L. (2010). Coming to a decision about cochlear implantation: Parents making choices for their deaf children. *Journal of Deaf Studies and Deaf Education*, *15*(2), 162–178. doi:10.1093/deafed/enq004

Ingber, S., & Dromi, E. (2010). Actual versus desired family-centered practice in early intervention for children with hearing loss. *Journal of Deaf Studies and Deaf Education*, *15*(1), 59–71. doi:10.1093/deafed/enp025

Joffe, H. (2008). The power of visual material: Persuasion, emotion and identification. *Diogenes*, *55*(1), 84–93. doi:10.1177/0392192107087919

Joint Committee on Infant Hearing. (2007). Year 2007 position statement: Principles and guidelines for early hearing detection and intervention programs. *Pediatrics*, *120*(4), 898–921.

Jørgensen, K., Brodersen, J., Hartling, O., Nielsen, M., & Gøtzsche, P. (2009). Informed choice requires information about both benefits and harms. *Journal of Medical Ethics*, *35*(4), 268–269. doi:10.1136/jme.2008.027961

Kecman, E. (2017). *Exploring 'attitude' in information for parents of deaf and hard-of-hearing (D/HH) children in NSW. An Appraisal Analysis of two early intervention websites* (Unpublished Master of Research Thesis). Macquarie University, Sydney, Australia.

Kim, P., Eng, T. R., Deering, M. J., & Maxfield, A. (1999). Published criteria for evaluating health related web sites: Review. *Bmj*, *318*(7184), 647–649. doi:10.1136/bmj.318.7184.64

Klaudia, K. (2013, December). The benefits of sign language for deaf children with and without cochlear implant(s). *European Scientific Journal*, *4*, 341–349.

Knoors, H., & Marschark, M. (2012). Language planning for the 21st century: Revisiting bilingual language policy for deaf children. *Journal of Deaf Studies and Deaf Education*, *17*(3), 291–305. doi:10.1093/deafed/ens018ens

Kobes, K., Harris, I. B., Regehr, G., Tekian, A., & Ingledew, P. A. (2018). Malignant websites? Analyzing the quality of prostate cancer education web resources. *Canadian Urological Association Journal*, *12*(10). doi:10.5489/cuaj.5084

Komesaroff, L. (2007). *Surgical consent: Bioethics and cochlear implantation*. Seattle, WA: University of Washington Press.

Lane, H. (1990). Cultural and infirmity models of deaf Americans. *Journal of the Academy of Rehabilitative Audiology*, *23*, 11–26.

Lane, H. (1995). Constructions of deafness. *Disability & Society*, *10*(2), 171–190.

Leigh, G., & Marschark, M. (2016). Recognizing diversity in deaf education: From Paris to Athens with a diversion to Milan. In *Diversity in deaf education*, 1–20. New York, NY: Oxford University Press.

Lichtenstein, S., & Slovic, P. (Eds.). (2006). *The construction of preference*. New York: Cambridge University Press.

Lim, S. S., Nekmat, E., & Nahar, S. N. (2011). The implications of multimodality for media literacy. In K. O'Halloran & B. A. Smith (Eds.), *Multimodal studies – exploring issues and domains* (pp. 169–183). London: Routledge.

Luckner, J. L., & Cooke, C. (2010). A summary of the vocabulary research with students who are deaf or hard of hearing. *American Annals of the Deaf*, *155*(1), 38–67.

Machin, D., & Mayr, A. (2012). *How to do critical discourse analysis: A multimodal introduction*. London: Sage.

Maier, C. D. (2011). Knowledge communication in green corporate marketing: A multimodal discourse analysis of an ecomagination video. In K. O'Halloran & B. Smith (Eds.), *Multimodal representation and knowledge* (pp. 153–169). New York: Routledge.

Matthijs, L., Hardonk, S., Sermijn, J., Van Puyvelde, M., Leigh, G., Van Herreweghe, M., & Loots, G. (2017). Mothers of deaf children in the 21st century. Dynamic positioning between the medical and cultural–linguistic discourses. *Journal of Deaf Studies and Deaf Education*, *22*(4), 365–377. doi:10.1093/deafed/enx021

Matthijs, L., Loots, G., Mouvet, K., Van Herreweghe, M., Hardonk, S., Van Hove, G., … Leigh, G. (2012). First information parents receive after UNHS detection of their baby's hearing loss. *Journal of Deaf Studies and Deaf Education*, *17*(4), 387–401. doi:10.1093/deafed/ens020

Mauldin, L. (2014). Precarious plasticity: Neuropolitics, cochlear implants, and the redefinition of deafness. *Science, Technology, & Human Values*, *39*(1), 130-153. doi:10.1177/0162243913512538

McDonald, D. M. (2010). (1) Critical essay: Hearsay: how stories of deafness and deaf people are told (2) Creative work: The art of being deaf. doi:10.14264/uql.2015.956

Medical Board of Australia. (2014a). *Good medical practice a code of conduct for doctors in Australia*. Retrieved from www.medicalboard.gov.au/Codes-Guidelines-Policies/Code-of-conduct.aspx

Medical Board of Australia. (2014b). *National board policy for registered health practioners Social Media Policy*. Retrieved from http://www.medicalboard.gov.au/Codes-Guidelines-Policies/Social-media-policy.aspx

Mitchell, W., & Sloper, P. (2002). Information that informs rather than alienates families with disabled children: Developing a model of good practice. *Health & Social Care in the Community*, *10*(2), 74–81.

Moeller, M. P., Carr, G., Seaver, L., Stredler-Brown, A., & Holzinger, D. (2013). Best practices in family-centered early intervention for children who are deaf or hard of hearing: An international consensus statement. *Journal of Deaf Studies and Deaf Education*, *18*(4), 429–445. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/24030911, doi:10.1093/deafed/ent034

Moran, C., & Lee, C. (2013). Selling genital cosmetic surgery to healthy women: A multimodal discourse analysis of Australian surgical websites. *Critical Discourse Studies*, *10*(4), 373–391. doi:10.1080/17405904.2013.813772

Moynihan, R., & Henry, D. (2006). The fight against disease mongering: Generating knowledge for action. *Plos Medicine*, *3*(4), e191. doi:10.1371/journal.pmed.0030191

Muse, C., Harrison, J., Yoshinaga-Itano, C., Grimes, A., Brookhouser, P. E., Epstein, S. … Martin, P. (2013). Supplement to the JCIH 2007 position statement: Principles and guidelines for early intervention after confirmation that a child is deaf or hard of hearing. *Pediatrics*, *131*(4), e1324–e1349.

Ng, C. J. W. (2014). 'We offer unparalleled flexibility': Purveying conceptual values in higher educational corporate branding. *Discourse & Communication*, 391–410. doi:10.1177/1750481314537576

O'Halloran, K. L. (2008). Systemic functional-multimodal discourse analysis (SF-MDA): Constructing ideational meaning using language and visual imagery. *Visual Communication*, *7*(4), 443–475. doi:10.1177/1470357208096210

Oschner, B., Spohrer, M., & Stock, R. (2015). Human, non-human, and beyond: Cochlear implants in socio-technological environments. *NanoEthics*, *9*(3), 237–250.

Pimperton, H., & Kennedy, C. R. (2012). The impact of early identification of permanent childhood hearing impairment on speech and language outcomes. *Archives of Disease in Childhood*, *97*(7), 648–53. doi:10.1136/archdischild-2011-301501

Porter, A., & Edirippulige, S. (2007). Parents of deaf children seeking hearing loss-related information on the internet: The Australian experience. *Journal of Deaf Studies and Deaf Education*, *12*(4), 518–529. doi.org/10.1093/deafed/eni042

Powell, T. E., Boomgaarden, H. G., De Swert, K., & de Vreese, C. H. (2015). A clearer picture: The contribution of visuals and text to framing effects. *Journal of Communication*, *65*(6), 997–1017.

Power, D. (2005). Models of deafness: Cochlear implants in the Australian daily press. *Journal of Deaf Studies and Deaf Education*, *10*(4), 451–459. doi:10.1093/deafed/eni042

Rahm, H. (2006). Getting attention in the media: Interdiscursivity and ideology in advertisements. In I. Lassen, J. Strunck, & T. Vestergaard (Eds.), *Mediating ideology in text and image* (pp. 193–210). Amsterdam: John Benjamins.

Sarant, J., & Garrard, P. (2014). Parenting stress in parents of children with cochlear implants: Relationships among parent stress, child language, and unilateral versus bilateral implants. *Journal of Deaf Studies and Deaf Education*, *19*(1), 85–106. doi:10.1093/deafed/ent032

Sass-Lehrer, M. (2012). Early intervention for children birth to 3: Families, communities, and communication. In L. A. Schmeltz (Ed.), *A resource guide for early hearing detection and intervention*, 10-1–10-16. Retrieved from https://www.infanthearing.org/ehdi-ebook/2016_ebook/17%20Chapter17EarlyIntervention2016.pdf

Sass-Lehrer, M., Porter, A., & Wu, C. L. (2015). Families: Partnerships in practice. In M. Sass-Lehrer (Ed.), *Early intervention for deaf and hard-of-hearing infants, toddlers, and their families: Interdisciplinary perspectives* (pp. 78–91). New York: Oxford University Press.

Schmidt, A., Bhatt, A. & Sunstein, C. R. (2017). *Boundedly rational patients? Health and patient mistakes in a behavioral framework*. Harvard Public Law Working Paper No. 17-29, SSRN. Retrieved from https://ssrn.com/abstract=2953250, doi.org/10.2139/ssrn.2953250

Shaffer, V. A., & Zikmund-Fisher, B. J. (2013). All stories are not alike apurpose-, content-, and valence-based taxonomy of patient narratives in decision aids. *Medical Decision Making*, *33*(1), 4–13. doi:10.1177/0272989X12463266

Sherer, M., & Rogers, R. W. (1984). The role of vivid information in fear appeals and attitude change. *Journal of Research in Personality*, *18*(3), 321–334.

Simon, H. A. (1959). Theories of decision-making in economics and behavioral science. *The American Economic Review*, *49*(3), 253–283.

Simonson, I. (2008). Will I like a "medium" pillow? Another look at constructed and inherent preferences. *Journal of Consumer Psychology*, *18*(3), 155–169.

Solomon, A. (2012). *Far from the tree: Parents, children and the search for identity*. New York: Scribner.

Sorkin, D. L., & Zwolan, T. A. (2008). Parental perspectives regarding early intervention and its role in cochlear implantation in children. *Otology & Neurotology*, *29*(2), 137–141.

Spellun, A., & Kushalnagar, P. (2018). Sign language for deaf infants: A key intervention for a developmental emergency. *Clinical Pediatrics*. doi:10.1177/0009922818778041

Stevenson, J., Kreppner, J., Pimperton, H., Worsfold, S., & Kennedy, C. (2015). Emotional and behavioural difficulties in children and adolescents with hearing impairment: A systematic review and meta-analysis. *European Child & Adolescent Psychiatry*, *24*(5), 477–496. doi:10.1007/s00787-015-0697-1

Stvilia, B., Mon, L., & Yi, Y. J. (2009). A model for online consumer health information quality. *Journal of the American Society for Information Science and Technology*, *60*(9), 1781–1791. doi:10.1002/asi.21115

Winker, M. A., Flanagin, A., Chi-Lum, B., White, J., Andrews, K., Kennett, R. L., … Musacchio, R. A. (2000). Guidelines for medical and health information sites on the internet: Principles governing AMA web sites. *JAMA*, *283*(12), 1600–1606. doi:10.1001/jama.283.12.1600

Wise, D., & James, M. B. (2012). The HPV school vaccination program: A discourse analysis of information provided to parents about the product and the program. *Public Communication Review*, *2*(1), 4–15. doi.org/10.5130/pcr.v2i1.2179

Wolfensberger, W., & Tullman, S. (1982). A brief outline of the principle of normalization. *Rehabilitation Psychology*, *27*(3), 131–145.

Yoshinaga-Itano, C. (2014). Principles and guidelines for early intervention after confirmation that a child is deaf or hard of hearing. *Journal of Deaf Studies and Deaf Education*, *19*(2), 143–175. doi:10.1093/deafed/ent043[AQ51]

Yoshinaga-Itano, C., Sedey, A. L., Wiggin, M., & Chung, W. (2017). Early hearing detection and vocabulary of children with hearing loss. *Pediatrics*, *140*, e20162964.

Young, A., Carr, G., Hunt, R., McCracken, W., Skipp, A., & Tattersall, H. (2006). Informed choice and deaf children: Underpinning concepts and enduring challenges. *Journal of Deaf Studies and Deaf Education*, *11*(3), 322–336. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/16717258, doi:10.1093/deafed/enj041

Young, A., Jones, D., Starmer, C., & Sutherland, H. (2005). Issues and dilemmas in the production of standard information for parents of young deaf children—parents' views. *Deafness & Education International*, *7*(2), 63–76. doi:10.1093/deafed/enj041

Young, A., & Temple, B. (2014). *Approaches to social research: The case of deaf studies*. Perspectives on Deafness. New York, NY: Oxford University Press.

Zaidman-Zait, A., & Jamieson, J. R. (2004). Searching for cochlear implant information on the internet maze: Implications for parents and professionals. *Journal of Deaf Studies and Deaf Education*, *9*(4), 413–426.