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Parental Decision-Making and Deaf Children: A Systematic Literature Review

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Abstract

Parents or caregivers of children who are deaf or hard of hearing are required to make complex and rational decisions soon after the confirmation of hearing loss. Ways of facilitating decision-making have been a focus within the healthcare sector for two decades and shared decision-making is now widely viewed as the standard for good clinical care. A systematic literature review was undertaken to identify the extent to which the principles of shared decision-making and informed choice have been implemented for parents when they make decisions related to their children with permanent hearing loss. Five databases were searched for peer-reviewed papers describing the results of original research published from 2000 to 2017, yielding 37 relevant papers. Studies were reviewed using the three phases of decision-making—information exchange, deliberation, and implementation. Two decisions dominated these studies—implantable devices and communication modality. Most papers dealt with decision-making in the context of bilateral hearing loss, with only one study focusing on unilateral hearing loss. The review identified gaps where further research is needed to ensure the lessons learnt in the broader decision-making literature are implemented when parents make decisions regarding their child who is deaf or hard of hearing.

Decision-making is a fundamental part of everyday life. Some decisions require little thought or attention, while others need a more logical and considered approach to achieve a desired goal or outcome. How people make decisions is of interest to many fields of study, including philosophy, psychology, economics, marketing, and healthcare, with the research in these disciplines highlighting the potential for cognitive bias or systematic errors in thinking that are inherent in the decision-making process, and decision-making researchers seeking ways to minimize these subconscious biases and facilitate rational and logical decision-making (Bekker, 2009). It is necessary for parents or caregivers[1] of children who are deaf or hard-of hearing (D/HH) to make difficult but rational decisions following confirmation of their child's hearing loss. The present study reviewed the existing literature on decision-making by parents when their child has been diagnosed as D/HH and sought to map current practice around parental decision-making with recommended practice from the medical decision-making literature.

People make decisions to achieve a goal, and theories of decision-making provide insight into how individuals think in real-life situations to make these decisions. Two approaches are used to process decision-relevant information—heuristic and systematic processing. Heuristic processing requires little or no cognitive effort—it is autonomous and reflexive and leads to satisfactory decisions most of the time (Baron, 2008; Bekker, 2009; Kahneman, 2011). Systematic processing is conscious and deliberate and requires cognitive effort. When heuristic processing is insufficient, systematic processing continues until the individual feels they have sufficient information to make a decision. Both heuristic and systematic processing, however, are prone to errors in thinking or cognitive biases (Baron, 2008; Kahneman, 2011). These are systematic patterns of deviation from rational thinking which can lead to illogical interpretations, inaccurate judgments, distortion of perceptions, and as a result, poor decisions (Campbell, Croskerry, & Petrie, 2017). Every individual is influenced by these cognitive biases including experts in a field, such as economists, statisticians, and

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healthcare professionals, resulting in errors of judgment and decision-making (Chapman & Elstein, 2000; Kahneman, 2011; Avorn, 2018). Cognitive and technological strategies for debiasing or mitigating the effects of cognitive biases in decision-making have been investigated with some promising results (Soll, Milkman & Payne, 2015; Ludolph & Schultz, 2017).

Patient–doctor communication, and decision-making within the healthcare sector more generally, have seen significant changes over the past few decades (Edwards & Elwyn, 2009). The evidence-based medicine movement has driven these changes by reinforcing the need for critical appraisal of the information and advice provided to patients within the clinical setting, and the importance of considering the values and preferences of patients when decisions are made (Djulbegovic & Guyatt, 2017). The healthcare sector has examined the issue of cognitive biases in clinical decision-making, considered how this can affect patient care (Chapman & Elstein, 2000), and proposed ways to facilitate and optimize patient–clinician communication and decision-making such as through the use of patient decision aids (Edwards & Elwyn, 2009).

The international consensus statement on best practice for early intervention for deaf and hard-of-hearing (DHH) children (Moeller, Carr, Seaver, Stredler Brown, & Holzinger, 2013) underlines the role of professionals in promoting informed choice and decision-making. Informed choice has been defined as a decision "based on relevant knowledge, consistent with the decision-maker's values and behaviorally implemented" (Marteau, Dormandy, & Michie, 2001, p. 100). In other words, parents require information that promotes understanding about their options, the benefits, risks, and uncertainties of each option, and the short- and long-term consequences of choosing each option. They should consider their values, that is, how they feel about the possible benefits and risks inherent in each option and the trade-offs they are willing to make to achieve the goals they have for their child. How parents reach the point of making an informed choice is the result of the decision-making process, which occurs in three distinct stages: information exchange, deliberation, and deciding on the option to implement (Charles, Gafni, & Whelan, 1999). See Table 1.

The flow of information between professional and parents will vary according to the model of clinical decision-making employed, which can be broadly categorized along a decision-making continuum: the paternalistic model (clinician-driven) is on one end of the continuum and the informed decision-making model (parent-driven) at the other. Inbetween these two is the shared decision-making model where parents and professionals share the decision-making process (Charles et al., 1999). The informed decision-making model gained prominence towards the end of the 20th century and was the preferred model for parental decision-making adopted by newborn hearing screening programs at that time. In this model, the flow of information is from the professional to the parents, and then the parents continue with the deliberation and decision stages on their own. The premise behind this model was to "empower" parents and assist them to become autonomous decision-makers.

As the decision-making pendulum swung from the paternalistic model at one end to the informed decision-making model at the other, it became evident that patients in healthcare settings wanted information about their condition and possible treatment options, but they were uncomfortable with the decision-making being solely their responsibility (Charles, Gafni, & Whelan, 1997). Patients reported feeling abandoned by their clinicians (Elwyn et al., 2012). There was acknowledgement that both the clinician and the patient brought different understandings to the decision-making process and both should participate in it. Shared decision-making therefore sits on the continuum between paternalistic and informed decision-making models and is defined as: "an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences" (Elwyn et al., 2012). People will differ in their willingness and capacity to be involved in the decision-making process, and shared decision-making enables them to be involved to the extent that they wish (Edwards & Elwyn, 2009). Shared decision-making has been the focus of over 86 randomized trials (Elwyn et al., 2012), and is now viewed as the standard for good clinical care in many countries (Hoffman et al., 2014; Kon, 2010). Shared decision-making has been shown to improve patient knowledge, reduce decisional conflict, and improve satisfaction with the decision-making process (Elwyn et al., 2012; Légaré, Ratté, Gravel, & Graham, 2008; Montori, Kunneman, & Brito, 2017).

From the time any baby is born, its parents start to make decisions that could have a lifelong impact on the child. Parental child-rearing knowledge and experiences, and personal and cultural values and beliefs will affect these decisions. However, for over 90% of parents whose baby is identified with a permanent hearing loss, there is no family history, thus, no knowledge or experience of deafness (Mitchell & Karchmer, 2004). Their understanding and beliefs about childhood deafness are more likely to be based on cultural stereotypes or information from the media (Baron, 2008; Kahneman, 2011). This means that, at the time of diagnosis, most parents are required to make complex decisions regarding their child's future when they lack knowledge about childhood hearing loss and the choices available to them. Importantly, their decision-making could be influenced by their emotions and cognitive biases, as well as the potential cognitive biases of their clinician or practitioner.

The decisions that parents make might not be medical in nature but the need for parents to have the necessary information and knowledge to make an informed decision that is consistent with their values has been acknowledged (Moeller et al., 2013). The current study therefore focused on parental decision-making and investigated whether the processes for achieving an informed choice, as recommended within the medical decision-making literature, had been employed when parents whose children are D/HH make decisions on behalf of their child.

Present Study

This study sought to understand the extent to which the principles of shared decision-making and informed choice, recommended in the decision-making literature, have been implemented when parents make decisions related to the management of children with permanent bilateral or unilateral hearing loss. To our knowledge, a review on decision-making within this context has not been undertaken previously. A systematic quantitative literature review (Pickering & Byrne, 2014) was conducted to systematically analyze the literature and examine the number, proportion, and type of studies on decision-making and informed choice, (i.e., produce a structured quantitative summary), and identify any gaps in knowledge.

Method

The inclusion and exclusion criteria for articles were designed to capture research that examined aspects of parental decision-making with regards to D/HH children between 2000 and 2017.

Table 1 Phases of thinking and deciding and possible cognitive biases

Thinking and deciding[a]	Informed choice[b]	Shared decision-making process[c]	Informed decision-making[c]	Possible biases (i.e., errors in thinking) for parents and/or professionals
- Searching for possibilities to achieve the goal - Search for evidence—from memory or external source	Knowledge - Knowing about all options - Evidence-based information about pros and cons - Understanding of information	Information exchange - Two-way sharing of evidence-based information - Professionals: information about possible options, benefits, risks, and consequences of choice on psychological and social well-being - Parents: information about family lifestyle, preferences, beliefs, and knowledge about hearing loss	Information exchange - One-way flow of information—from clinician to parents - Professionals: best available evidence on options and the benefits and risks of each option	- Anchoring bias—priority given to first information received[d] - Choosing first acceptable option[d] - Rejection of the unfamiliar[d] - Choice made dependent on how the information is presented[a,d] - Availability cascade—tendency for group belief to gain more credibility the more it is discussed in public[e]
- Evaluating the weight of the evidence—the likelihood of the possibility achieving the goal. - Weight of evidence controlled by the thinker	Values - Choice is consistent with values - The desirability of the benefits and harms of each option	Deliberation - Professional and parents weigh up evidence to support or reject option - Environment where parents feel comfortable to ask questions, explore options and express opinions	Deliberation - Solely the task of the parents without further input from the clinician	- Overestimation of the benefits and underestimation of the risks of a preferred option[f] - Confirmation bias—the search for evidence to support the preference and ignoring evidence that is contrary to preference[f]
- Deciding on an action to achieve the goal, or - Developing a plan for future action	Behaviorally implemented - Choice or plan for future action are put into place	Implementation - Professionals and parents reach an agreement about the option, i.e., make a shared decision - Choice is implemented or plan put in place to implement the choice	Implementation - The parents alone make the decision they want to implement (i.e., without further involvement of the clinician)	- Omission bias: favoring harmful omissions (doing nothing) over equally harmful commissions (doing something)[a,d,f] - Opposite true when making decision about someone else; i.e., preference for action over inaction (commission bias)[g] - Status quo bias: preference for keeping things as they are when changing would be beneficial[a,d] - Sunk-cost bias: misconception that personal effort or investment into something that is not working justifies continuing same way[a,d,f]

Note. [a]Baron, 2008; [b]Marteau et al., 2001; [c]Charles et al., 1999; [d]Kahneman, 2011; [e]Cambell et al., 2017; [f]Chapman & Elstein, 2000; [g]Ritov & Baron, 1990.

The commencing date approximates the introduction of universal newborn hearing screening programs in Australia, United Kingdom, and the United States.

Inclusion Criteria

Studies had to fulfill the following criteria for inclusion in the review: (a) target hearing parents or caregivers of children who had a bilateral or unilateral permanent hearing loss and who made decisions on behalf of their child aged from birth to 12 years of age; (b) include a proxy decision made on behalf of the child as a result of the child's hearing loss; (c) examine any component of the decision-making process, (i.e., information exchange, deliberation or implementation), either explicitly or implicitly using quantitative, qualitative, or a mixed methods approach; and (d) be peer-reviewed papers describing the results of original research published from 2000 to 2017. Studies whose foci were decisions around genetic selection, reproductive choices, and genetic testing were excluded.

Search Strategy

Five electronic databases were searched—PubMed, PsycINFO, CINAHL, EMBASE, and World of Science. The reference lists of papers included in the review were also examined for any additional studies. Three variables were combined for each search—terms for parent or caregiver, decision-making or choice behavior, and D/HH or hearing loss (see Appendix).

Procedure

The titles and abstracts identified in the searches were assessed for inclusion, and full-text articles were retrieved for papers if they were potentially relevant. This was undertaken by the first author. The Mixed Methods Appraisal Tool (MMAT)—Version 2011 was used to appraise the methodological quality of the studies (Pluye et al., 2011). The MMAT has been used in many disciplines for "mixed studies reviews," where methodology is varied across the studies (Pluye & Hong, 2014). Each paper is rated against various quality criteria (usually 4) depending on whether it is qualitative, quantitative, or a mixed methods design. The study either meets the criterion (rating = "yes") or does not meet the criterion (rating = "no" or "can't tell"). Only studies that met the inclusion criteria were assessed for quality. The lead author initially rated all included studies and then allocated a random selection of papers to the other authors to rate independently. Initial inter-rater reliability was 88%, and where differences occurred these were resolved through discussion. Studies were not excluded on the basis of their quality.

Evidence Synthesis

The systematic review was undertaken using QSR International's NVivo 11 Software. This provides a useful method of collecting, categorizing, and analyzing the papers. An electronic version of each article was imported into NVivo for data extraction. Attributes of each paper (such as study design, focal decision, aspect of decision-making) were coded to provide a comprehensive quantitative summary of the papers. The results section of each paper was then broadly coded into the three phases of the decision-making process, (i.e., information exchange, deliberation, and implementation), for further analysis. The same process was used irrespective of the study design.

Results

A total of 541 titles was identified in the search in March 2017. When 198 duplicates were removed, the remaining 343 titles and abstracts were tested for potential match to the inclusion criteria. As a result of this screening, 39 full-text papers were reviewed for inclusion. Six of these were excluded as they did not examine a component of informed choice, leaving 33 papers identified as meeting the inclusion criteria for this review (see Figure 1). Following this process, a second search of the literature was conducted in December 2017 to ensure any paper published since March 2017 would be included. An additional five studies were identified for full-text review. Of these, four met the

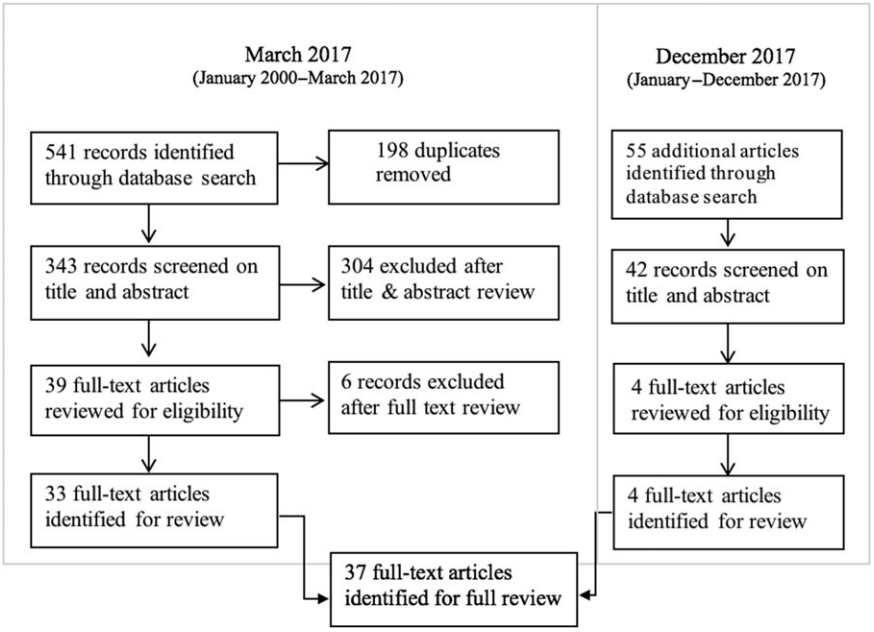

Figure 1 Two stage search and retrieval process.

inclusion criteria and were subsequently included in this review. As a result, there were 37 papers that reported the results of 35 separate studies. Details on these studies are given in Table 2. The quantitative and qualitative results of one single study were reported in two separate papers (Crowe, Fordham, McLeod, & Ching, 2014; Crowe, McLeod, McKinnon, & Ching, 2014). Another study used the same group of parents to investigate two focal decisions, using different methodologies for the different decisions (Li, Bain, & Steinberg, 2003; Li, Bain, & Steinberg, 2004).

The studies were distributed over the period examined with peaks in 2003 (N = 4), 2013 (N = 4), 2014 (N = 4), and 2017 (N = 4). Studies were undertaken on every continent, but principally in English-speaking countries—Australia (N = 2), Canada (N = 5), United Kingdom (N = 8), and the United States (N = 10). All papers were published in English. Most papers were published in journals focused on deafness (N = 16), otolaryngology (N = 7), and audiology (N = 8). Thirty of the 35 studies (86%) were retrospective, with parents being asked to think back on the decision-making experience regarding their focal decision. For 12 studies, parental decision-making was not the primary focus of the study. Seventeen studies (48.6 %) were undertaken in a single setting—usually, a hospital or cochlear implant facility. Finally, four of the studies originated from a single cochlear implant program in the United Kingdom (Archbold, Sach, O'Neill, Lutman, & Gregory, 2006; Mulla, Wright, & Archbold, 2013; Sach & Whynes, 2005; Wheeler, Archbold, Hardie, & Watson, 2009).

Study Design

There were 14 quantitative descriptive, 20 qualitative, and 3 mixed methods studies. Quantitative studies used a variety of survey methods including self-administered (N = 10) or researcher-administered (N = 2) questionnaires and online surveys (N = 2). Qualitative methods included face-to-face interviews (N = 15) and telephone interviews (N = 2). Analysis of the qualitative studies varied as different interpretive approaches were used, including modified grounded theory (Borum, 2012; Okubo, Takahashi, & Kai, 2008; Vieira, Bevilacqua, Ferreira, & Dupae, 2014), discourse analysis (Bruin & Nevøy, 2014), interpretative description (Fitzpatrick, Jacques, & Neuss, 2011), naturalistic inquiry (Jackson, Traub, & Turnbull, 2008), thematic analysis (Chang, 2017; Hardonk et al., 2010), and content analysis (Kluwin & Stewart, 2000). The mixed methods studies involved an initial questionnaire followed by interviews with a subset of respondents.

Study Quality

Three papers met all four MMAT criteria for methodologic quality of the study. Half of the studies only met one or two of the four MMAT criteria for methodology, when meeting three or four quality criteria is desirable. Table 2 reports the individual ratings of each paper, and Table 3 reports the summative data on quality ratings.

Participants

Respondents in the quantitative studies ranged from 19 (Steinberg et al., 2000) to 247 parents (Hyde, Punch, & Komesaroff, 2010). Qualitative studies ranged from case-study interviews with the parents of a single child (Kotjan, Purves, & Small, 2013) to interviews with 216 parents (Sach & Whynes, 2005). Only one study examined parental decision-making for a child with a unilateral hearing loss, involving 23 caregivers of children with unilateral aural atresia (Graham, Haworth, Chorney, Bance, & Hong, 2015). One further study included parents of children who had either a bilateral or unilateral hearing loss, but the results regarding decision-making were not separately reported (Mulla et al., 2013). All other studies involved parents whose children had a bilateral hearing loss. Two assessed parent decision-making when the child had been diagnosed with auditory neuropathy spectrum disorder (Stroebel & Swanepoel, 2014; Uus, Young, & Day, 2015). Two examined decisions with particular populations of parents in the United States, namely Hispanic (Steinberg, Bain, Li, Delgado, & Ruperto, 2003) and African American families (Borum, 2012). One study investigated decision-making following maternal suspicion of hearing loss in low-income families attending a facility in Southern India (Merugumala, Pothula, & Cooper, 2017). Four studies specified that the children had been diagnosed through newborn hearing screening (Bruin & Nevøy, 2014; Hardonk et al., 2010; Matthijs et al., 2017; Uus et al., 2015). Last, while most studies provided some details about the child/children concerned, 17 (46%) only reported on the participants' relationship to the child, and five (16%) on the relationship to the child and hearing status of the participant, despite the views and experiences of parents themselves being the foci of the studies.

Focal Decisions

Two decisions dominated the literature with regards to parental decision-making—decisions related to cochlear implantation (CI) (N = 20) and decisions related to communication modality (N = 8); see Table 2. Two studies considered parental decision-making regarding a bone-anchored device for their child (Graham et al., 2015; Mulla et al., 2013); three papers evaluated decisions regarding communication modality and oral bilingualism (Crowe, Fordham, et al., 2014; Crowe, McLeod, et al., 2014; Guiberson, 2013); and one investigated parent choice of cochlear implant brand (Clamp, Rotchell, Maddocks, & Robinson, 2013). One study, over a series of interviews, looked at the changing values of parents and the realities of implementing a decision (Matthijs et al., 2017). Finally, six studies compared parents who had implemented an option (e.g., CI) with those who chose not to implement the same option, and the reasons for their decision (Chang, 2017; Graham et al., 2015; Hardonk et al., 2010; Kluwin & Stewart, 2000; Okubo et al., 2008; Ramsden, Papaioannou, Gordon, James, & Papsin, 2009).

Information Exchange

Provision of information

Information provision was considered in 24 (65%) of the papers, including sources of information, type of information, and the adequacy of the information provided to make a decision. The principal sources of information for CI were reported to be ear, nose, and throat surgeons and audiologists (Alkhamra, 2015; Crowe, Fordham et al., 2014; Decker, Vallotton, & Johnson, 2012; Hardonk et al., 2010; Hyde et al., 2010; Johnston, Durieux-Smith, Fitzpatrick, O'Connor, Benzies, & Angus, 2008; Li et al., 2003; Most & Zaidman-Zait, 2003). The sources of information about communication modality and bilingualism were varied, with teachers of the Deaf, speech pathologists, and deaf adults reported as playing the more significant roles (Crowe, Fordham, et al., 2014; Decker et al., 2012; Eleweke & Rodda, 2000; Guiberson, 2013).

A number of studies mentioned the need for parents to receive unbiased information, but what this represented was not clarified (Alkhamra, 2015; Crowe, Fordham, et al., 2014; Eleweke & Rodda, 2000; Fitzpatrick et al., 2011; Guiberson, 2013; Johnston

Table 2 Characteristics of included studies

Study and country	Samples	Decision-making topic	Aspect of decision-making reported	Study method and rating (MMAT)
Alkhamra (2015) Jordan	60 parents	Cochlear implantation (CI)	Information, values	Quantitative descriptive[a]
Archbold et al. (2006) UK	101 parents; 104 children	Cochlear implantation	Information, values, DM process	Quantitative descriptive[a]
Borum (2012) USA	14 parents; 14 children	Communication choice	Values	Qualitative[c]
Bruin and Nevøy (2014) Norway	27 parents; 28 children	Communication choice after CI	Values, DM process	Qualitative[a]
Chang (2017) USA	33 parents; 34 children	Cochlear implantation	Information, values, DM process	Qualitative[b]
Clamp et al. (2013) UK	64 parents	Cochlear implantation	Information, values	Quantitative descriptive[b]
Crowe et al. (2014a) Australia	177 parents; 157 children	Communication choice and oral bilingualism	Information, values, DM process	Quantitative descriptive[b]
Crowe et al. (2014b) Australia	177 parents; 157 children	Communication choice and oral bilingualism	Information, values	Qualitative[b]
Decker et al. (2012) USA	36 parents; 35 children	Communication choice	Information, values	Quantitative descriptive[d]
Eleweke and Rodda (2000) UK	2 families (i.e., 4 parents)	Communication choice	Information, values, implementation	Qualitative[d]
Fitzpatrick et al. (2011) Canada	14 parents; 15 children	Bilateral cochlear implantation	Information, values	Qualitative[b]
Graham et al. (2015) Canada	23 parents; 23 children	Bone anchored hearing device	Decisional conflict, implementation	Quantitative descriptive[b]
Guiberson (2013) Spain	71 parents; 71 children	Oral bilingualism	Information, values	Quantitative descriptive[d]
Hardonk et al. (2010) Belgium	12 parents; 13 children	Cochlear implantation	Information, values, DM process	Qualitative[b]
Hyde et al. (2010) Australia	247 parents; 247 children	Cochlear implantation	Information, implementation	Mixed methods[b]
Incesulu et al. (2003) Turkey	27 parents; 28 children	Cochlear implantation	Information, values	Quantitative descriptive[c]
Jackson et al. (2008) USA	9 parents; 8 children	Various	Information, values, DM process	Qualitative[b]
Johnston et al. (2008) Canada	7 families (8 parents); 8 children	Cochlear implantation	Information, values	Qualitative[b]
Kluwin & Stewart (2000) USA	35 parents	Cochlear implantation	Information, values	Qualitative[c]
Kotjan et al. (2013) Canada	1 family (2 parents); 1 child	CI with cochlear nerve deficiency	Information, values	Qualitative[c]
Li et al. (2003) USA	83 parents	Communication choice	Values	Quantitative descriptive[d]
Li et al. (2004) USA	83 parents (survey); 50 (interviews)	Cochlear implantation	Values	Mixed methods[d]
Matthijs et al. (2017) Belgium	5 parents; 3 children	Communication choice	DM process	Qualitative [b]
Merugumala et al. (2017) India	17 parents	Seeking diagnosis/treatment	Values, implementation	Qualitative[c]
Most & Zaidman-Zait (2003) Israel	35 parents; 35 children	Cochlear implantation	Information, information exchange	Quantitative descriptive[c]
Mulla et al. (2013) UK	10 families; 10 children	Bone anchored hearing device	Information, DM process	Qualitative[d]
Nelson et al. (2017) USA	81 parents; 81 children	Cochlear implantation	Values	Quantitative descriptive[b]
Okubo et al. (2008) Japan	21 interviews; 26 parents; 23 children	Cochlear implantation	Information, values, deliberation	Qualitative[b]
Penaranda et al. (2011) Colombia	13 couples (26 parents); 13 children	Cochlear implantation	Values	Qualitative[d]
Ramsden et al. (2009) Canada	46 children	Bilateral cochlear implantation	Values	Quantitative descriptive[b]
Sach & Whynes (2005) UK	216 parents	Cochlear implantation	Values	Qualitative[b]
Steinberg et al. (2000) USA	20 families; 20 children	Cochlear implantation	Values	Quantitative descriptive[d]
Steinberg et al. (2003) USA	29 parents; 29 children	Multiple—Hispanic families	Information, values, DM process	Mixed methods[b]
Stroebel & Swanepoel (2014) South Africa	30 parents; 30 children	Multiple—ANSD	Information	Quantitative non-randomized[c]
Uus et al. (2015) UK	25 parents; 21 children	Multiple—ANSD	Information, DM process	Qualitative[c]
Vieira et al. (2014) Brazil	9 families; 9 children	Cochlear implantation	Values, DM process	Qualitative[d]
Wheeler et al. (2009) UK	12 parents; 12 children	Communication choice	Values, DM process	Qualitative[c]

Note. ANSD = auditory neuropathy spectrum disorder, DM = decision making.
[a]Met all 4 MMAT criteria.
[b]Met 3 MMAT criteria.
[c]Met 2 MMAT criteria.
[d]Met 1 MMAT criterion.

Table 3 Percentages of studies and MMAT ratings

Rating	All		Quantitative		Qualitative		Mixed	
	N	%	N	%	N	%	N	%
Met 0 of 4 MMAT criteria	—	—	—	—	—	—	—	—
Met 1 of 4 MMAT criteria	9	24.3	4	28.6	4	20	1	33
Met 2 of 4 MMAT criteria	9	24.3	4	28.6	5	25	—	—
Met 3 of 4 MMAT criteria	16	43.2	4	28.6	10	50	2	67
Met all 4 MMAT criteria	3	8.1	2	14.3	1	5	—	—
Total	37	99	14	100.1	20	100	3	100

et al., 2008; Steinberg et al., 2003). One study described how parents recognized bias on websites for different communication approaches and the challenges this posed for their information seeking (Chang, 2017). In a number of studies, parents indicated that seeking information from other parents was an important component of their decision-making, particularly when deciding on an implantable device (Chang, 2017; Fitzpatrick et al., 2011; Hyde et al., 2010; Incesulu, Vural, & Erkam, 2003; Johnston et al., 2008; Kluwin & Stewart, 2000; Most & Zaidman-Zait, 2003; Johnston et al., 2008; Mulla et al., 2013; Penaranda, Suarez, Nino, Aparicio, Garcia, & Baron, 2011). Conversely, others reported that information from other parents making similar decisions was not important or helpful in their decision-making (Decker et al., 2012; Guiberson, 2013; Hardonk et al., 2010). Five papers discussed the influences of deaf adults in the decisions parents made, particularly regarding communication choice and CI (Crowe, Fordham, et al., 2014; Hyde et al., 2010; Li et al., 2004; Matthijs et al., 2017; Obuko et al., 2008).

Knowledge

Three studies indicated that parents had difficulty in understanding the information provided to them and that this affected their ability to make an informed decision (Hardonk et al., 2010; Mulla et al., 2013; Steinberg et al., 2003). At the time of diagnosis, parents' knowledge about cochlear implants was largely informed by the media, according to three of the studies (Alkhamra, 2015; Hyde et al., 2010; Kluwin & Stewart, 2000). Parents were not always clear about their available options (Steinberg et al., 2003; Johnston et al., 2008; Mulla et al., 2013; Merugumala et al., 2017) or they felt that their only option was CI (Sach & Whynes, 2005; Hyde et al., 2010).

Several papers indicated that families felt they had sufficient information to make the focal decision (Fitzpatrick et al., 2011; Incesulu et al., 2003; Johnston et al., 2008; Penaranda et al., 2011); however, others indicated that the parents felt they needed, or sourced, additional information (Alkhamra, 2015; Chang, 2017; Crowe, Fordham, et al., 2014; Decker et al., 2012; Fitzpatrick et al., 2011; Guiberson, 2013; Hardonk et al., 2010; Kluwin & Stewart, 2000; Hardonk et al., 2010; Kotjan et al., 2013; Steinberg et al., 2003). Other studies indicated that information was not balanced, or that there was conflicting advice on the best approach from professionals, which complicated their decision-making (Bruin & Nevøy, 2014; Eleweke & Rodda, 2000; Jackson et al., 2008; Kotjan et al., 2013; Matthijs et al., 2017; Mulla et al., 2013; Nelson, Herde, Munoz, White, & Page, 2017; Stroebel & Swanepoel, 2014; Uus et al., 2015; Wheeler et al., 2009).

Benefits and risks

Only one paper examined the perceived benefits and risks of CI in-depth and how these affected parental decision-making (Okubo et al., 2008). The most frequently cited risk discussed with parents was surgical risk for implantable devices. Whether other potential risks of choosing an option were discussed was unclear from these papers. Hyde et al. (2010) indicated that parents often were not made aware of other risks, such as adverse social, psychological, and language outcomes. In addition, parents acknowledged that they were not sure they would have been receptive to learning about potential risks or negative outcomes at the time they were making their decision (Hyde et al., 2010; Kotjan et al., 2013).

Deliberation

Parental values were explored in terms of beliefs and preferences in a number of the studies, particularly with regard to possible outcomes or expectations of making the focal decision. Six papers explicitly examined parental values and the role they played in their decision-making (Decker et al., 2012; Guiberson, 2013; Li et al., 2003, 2004; Okubo et al., 2008; Steinberg et al., 2000). The predominant value of parents cited in studies about communication modality and CI was for the child to develop oral language. One study investigated how social influences and networks affected parents' values and decisions about whether to implant or not (Chang, 2017). Three papers indicated how some parents made decisions contrary to professional recommendations because their preferences and lived experience were not understood or explored (Bruin & Nevøy, 2014; Hardonk et al., 2010; Matthijs et al., 2017). One paper mentioned the impact of religious beliefs (Steinberg et al., 2003), and the cultural contexts influencing parental decision-making were also reported (Borum, 2012; Merugumala et al., 2017; Steinberg et al., 2003). Two studies discussed the challenges of decision-making when the parents of the child held conflicting values (Jackson et al., 2008; Vieira et al., 2014). Parent attitudes regarding future opportunities for their child, particularly in terms of education and employment, were also discussed (Alkhamra, 2015; Archbold et al., 2006; Borum, 2012; Crowe, Fordham, et al., 2014; Crowe, McLeod, et al., 2014; Guiberson, 2013; Hyde et al., 2010; Li et al., 2003; Nelson et al., 2017; Sach & Whynes, 2005).

Pressure on decision-making

Some studies reported that parents felt pressured by professionals to make a decision (Bruin & Nevøy, 2014; Chang, 2017; Hyde et al., 2010; Jackson et al., 2008; Uus et al., 2015). In one paper that interviewed both parents and professionals, the parents did not feel pressured, but the professionals were concerned that this might be the case (Johnston et al., 2008). Several papers indicated that parents expressed concerns about making lifelong decisions on behalf of their child (Crowe, Fordham, et al., 2014; Incesulu et al., 2003; Johnston et al., 2008; Li et al., 2004; Okubo et al., 2008; Vieira et al., 2014).

Implementation

Most of the papers were retrospective, so the parents had already implemented their decision. In terms of CI, the studies overwhelmingly indicated that parents who chose to implant their child believed they had made the right decision (Fitzpatrick et al., 2011; Incesulu et al., 2003; Johnston et al., 2008; Kluwin & Stewart, 2000; Nelson et al., 2017; Sach & Whynes, 2005; Stroebel & Swanepoel, 2014; Vieira et al., 2014). Some studies indicated that parents felt they had little option other than the decision they made because of funding, the availability of services, or the communication modality preference of the service providers (Bruin & Nevøy, 2014; Crowe, McLeod, et al., 2014; Eleweke & Rodda, 2000; Mulla et al., 2013; Sach & Whynes, 2005; Steinberg et al., 2003; Uus et al., 2015; Wheeler et al., 2009).

Funding

In most of the countries where these studies were undertaken, the cost of devices for children with hearing loss is covered by a national program or health system so cost was not usually a consideration in parental decision-making. The one study looking at very low-income families found that cost was a major barrier for families seeking intervention for their child (Merugumala et al., 2017).

Shared decision-making and informed choice

None of the studies explicitly explored the use of shared decision-making as part of the consultation process between clinicians and parents although it was mentioned in four papers (Clamp et al., 2013; Johnston et al., 2008; Li et al., 2003; Steinberg et al., 2003). One study did discuss the barriers to shared decision-making when parents were unable to access information that met their cultural and linguistic needs (Steinberg et al., 2003). The concept of informed choice or informed decision was mentioned in a number of studies but there was minimal discussion about what an informed choice was and how it might be achieved (Alkhamra, 2015; Chang, 2017; Crowe, Fordham, et al., 2014; Crowe, McLeod, et al., 2014; Eleweke & Rodda, 2000; Hardonk et al., 2010; Hyde et al., 2010; Matthijs et al., 2017; Mulla et al., 2013; Okubo et al., 2008; Peñaranda et al., 2011; Steinberg et al., 2003).

Discussion

The principles of informed choice and shared decision-making have been the focus of much investigation over the past two decades in many areas of healthcare. The difficulties of making informed decisions for parents whose children are D/HH when confronted with strongly-held views and contested best options have also been documented (Young et al., 2006). The medical decision-making literature has recommended ways to optimize decision-making and bring evidence into the consultation and, in doing so, minimize the possibility of cognitive bias in clinicians and patients. This systematic quantitative literature review (Pickering & Byrne, 2014) explored the available knowledge in the peer-reviewed literature to clarify whether recommendations in the medical decision-making literature form the basis for discussions with parents making decisions regarding their child who is D/HH. The analysis included 37 relevant papers that examined different aspects of parental decision-making.

The literature was overwhelmingly directed towards hearing parents whose children had a bilateral hearing loss. Only one study investigated decisions regarding unilateral hearing loss. The information needs and values of these parents is likely to differ from the values of hearing parents whose children have a bilateral hearing loss and want their child to develop spoken language and be part of the "hearing world." The values and desired outcomes of the parents whose children have a unilateral hearing loss require more investigation if their decision-making needs are to be appropriately understood.

There was little evidence from the reviewed studies that the process of shared decision-making has been integrated into everyday practice: shared decision-making was mentioned briefly in the discussion sections of two papers only (Clamp et al., 2013; Steinberg et al., 2003). This underreporting could indicate the routine use of shared decision-making and that reporting the process was considered unnecessary. More likely, however, and as reported in other studies (Jackson, Cheater, & Reid, 2008; Hoffman et al., 2014), the process of shared decision-making is not widely used and, therefore, not included for discussion. The majority of focal decisions in this review concerned implantable devices and are thus medical in nature. Shared decision-making has been investigated in numerous randomized trials across a variety of medical conditions, and has been shown to encourage more patient involvement, greater knowledge about the options, and confidence in the decisions made (Elwyn et al., 2012). Proponents of shared decision-making have argued the ethical imperative for individual clinicians and practitioners to incorporate shared decision-making into their consultations with patients (Elwyn et al., 2012; Hoffman et al., 2014). A similar approach might be beneficial for parents, particularly in the early years after the identification of their child's hearing loss when they are still learning about hearing loss and developing their own understanding and value systems about what it means to be D/HH.

Despite parents being the participants in every study, only half of the studies reported the demographic details of the parents. The decisions parents make will undoubtedly be influenced by factors related to the child's hearing loss, but any decision will affect the whole family. The consequences of choosing an option, and the effect this could have on the child, parents, and siblings, are likely also to influence the decisions parents make (Chang, 2017). Jackson et al. (2008), in their systematic review of the decision needs of parents making health decisions for their child, highlighted that parents make decisions for reasons other than simply health considerations. Other influences such as education level, socioeconomic status, cultural background, geographic location, and other issues in the family's life might affect both the capacity of the parents to make informed choices as well as the decisions they make. Having more detailed information about the parents would be helpful when considering the representativeness of the sample and generalizability of the findings.

The need for parents to receive unbiased or bias-free information to make an informed choice was a common thread throughout the studies in the review. As previously discussed, cognitive bias in decision-making is reflexive and subconscious, and neither clinicians nor parents are immune to these biases. The notion of bias has different connotations when providing information to parents about options for their child who is D/HH. Bias in this context centers primarily on communication choices and requires that information should not be biased towards a particular communication modality (Young et al., 2006). It is, however, possible to provide information about all available options in a way that biases parental thinking and decision-making. As Holm and Davies (2009) have stated, "…it is important to remember that it is sometimes possible to deceive people, while telling them the truth if the truth is framed in a misleading way. Even though misleading is not lying, it is a distinct ethical wrong" (Holm & Davies, 2009, p.61). The Cochrane Collaboration review into the efficacy of

patient decision aids (Abhyankar et al., 2013) provided comprehensive guidance on (a) the provision of information (i.e., critically appraised information that is balanced and value-neutral regarding all options) as well as (b) ways of presenting information to limit the biases inherent in thinking and deciding (i.e., information that is balanced and value-neutral in both content and presentation). The guidelines for the provision of information in patient decision aids provide a basis for the development and presentation of information for parents in a way that promotes knowledge and minimizes cognitive biases.

The decision-making literature has shown that cognitive biases insinuate themselves into all stages of the decision-making process. Cognitive biases in general practice, oncology, and obstetrics and gynecologist have been studied most (Blumenthal-Barby & Krieger, 2015). Despite bias being an ongoing area of concern within the deafness sector, we are unaware of any studies that have examined cognitive biases in a similar way. Each person the parents visit, including clinicians, early interventionists, teachers of the Deaf, other parents, and deaf adults, can unwittingly provide information or experiences in a way that has the potential to bias parental decision-making. Campbell et al. (2017) have suggested that simply telling people to be aware of their biases is unlikely to be effective as they are largely subconscious. An added complication is that it is also easier for individuals to detect bias in others than in oneself (Kahneman, 2011). Recognizing and mitigating cognitive bias requires broad awareness of the issue and active practice in both the workplace and everyday life (Campbell et al., 2017). A systematic review on debiasing health-related judgments and decision-making found an increase in research regarding the efficacy of debiasing strategies over the past decade. Technological strategies, such as visual aids and decision support tools, show particular promise (Ludolph &Schultz, 2017). Shared decision-making encourages the use of technological strategies during the information exchange and deliberation stages as a means of debiasing the decision-making process.

Simply providing information to parents is unlikely to result in an informed choice. Informed choice requires balanced and value-neutral information that parents understand, and a deliberation process that assists them to consider their options in a meaningful way before making a decision. If parents have sufficient knowledge and understanding about their options, and they choose an option that aligns with their values, only then will they have made an informed decision. Decision-making is not an exact science. Good outcomes can be the result of good fortune, rather than good decision-making, and a good decision can result in undesirable outcomes (Baron, 2008). Parents make decisions under uncertainty and decisions might need to be revisited. This does not mean they made a bad decision, but that they made the best decision they could at that time with the restrictions they had, and the information available to them. The primary unknown when they make their initial decisions is their child. As the child develops, their knowledge about the strengths and weaknesses of the child will grow, and new decisions might be needed. The process of information exchange, deliberation and implementation must start again.

There were some limitations to this review. First, decision-making was not the main focus of some studies, and papers that reported tangentially on parent decision-making might not have been included as this information was not reported in the title or abstract. Although broad search terms for decision-making were used, some relevant papers might have been excluded. Second, the first author undertook the search and review of papers to be included. This was done at two points in time to reduce the possibility of missing papers, but this might also introduce a bias into the papers selected. Third, a systematic quantitative literature review, as undertaken in this study, searches only original research reported in the peer-reviewed literature, which meant the exclusion of some potentially informative gray literature, book chapters, and expert opinion from the review (Mahood, Van Eerd, & Irvin, 2014). Finally, the authors found that the quality rating criteria provided by the MMAT system did not provide sufficient guidelines for effectively rating the quality of papers. The authors discussed the criteria beforehand, and while the inter-rater reliability was high, other reviewers might have rated the papers differently. The ratings, however, do reflect the wide variation in the methodological quality of papers included in the review.

Conclusion

This systematic quantitative review provides a research map regarding the extent to which practices that promote effective decision-making in the clinical setting are being used when parents are making decisions regarding their child who is D/HH. The review has highlighted where the research has focussed and identified gaps where further study is required to evaluate the efficacy of parental decision-making for their child who is D/HH to a similar extent as within the healthcare sector. Three broad areas for further study are highlighted in this review, namely populations, cognitive bias and shared decision-making. Firstly, the decision support needs of different populations of parents (such as parents with very low-income or poor literacy levels) as well as parents whose children have different types of hearing losses, particularly unilateral hearing loss and children with additional needs, need further investigation. Secondly, a more in-depth look at cognitive biases of clinicians, other professionals and parents would highlight the types of biases within these populations and assist in the development of debiasing strategies and techniques to mitigate their effect and promote rational decision-making. The potential for other parents and deaf adults to bias parental decision-making has not received any attention. They provide important emotional support, information, and an indication of the possibilities for people with hearing loss. However, stories and testimonials can bias parental decision-making, and the literature recommends they be used with caution, particularly in situations where decisions are preference-sensitive (Ubel, Jepson, & Baron, 2001; Winterbottom & Bekker, 2009; Winterbottom, Bekker, Conner, & Mooney, 2008). This is an area that requires more rigorous research. And finally, shared decision-making needs investigation. Shared decision-making has been shown to produce improved quality of care, improved satisfaction with the decision-making process, and improved self-confidence in patients (Elwyn et al., 2012; Légaré et al., 2008; Montori et al., 2017). Because of the value of this approach to parents and practitioners alike, additional studies where the focus is specifically on shared decision-making are required to confirm the extent of use of shared decision-making and the efficacy of this approach with parents of Deaf and hard-of-hearing children; “best practice” demands it.

Supplementary Data

Supplementary data is available at *Journal of Deaf Studies and Deaf Education* online.

Note

1. The term "parents" is used throughout and indicates persons with primary responsibility for the child.

Conflicts of Interest

No conflicts of interest were reported.

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