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“Part of our world”: Influences on caregiver decisions about communication choices for children with hearing loss

Kathryn Crowe,

HEARing CRC, Australia National Acoustic Laboratories, Australia Charles Sturt University, Australia

Loraine Fordham,

Charles Sturt University, Australia

Sharynne McLeod, and

Charles Sturt University, Australia

Teresa Y.C. Ching

HEARing CRC, Australia National Acoustic Laboratories, Australia

Abstract

Caregivers of young children with hearing loss make decisions about which communication mode/s and spoken language/s their children and family will use. Influences on decision-making about communication were examined for 177 caregivers of Australian children with hearing loss through a questionnaire. The majority of the 157 children used speech as part or all of their communication system ($n = 138$, 87.9%), and approximately one-third of the children ($n = 52$, 33.1%) currently or had previously used sign as part or all of their communication system. Twenty-two (14.0%) children and 35 (19.8%) caregivers used a spoken language other than English. Four themes emerged from the qualitative analysis of caregiver responses about the most important influences on their decision-making. Theme one identified caregivers' sources of information, including advice from professionals, family, and friends, as well as caregivers' own research and preferences. Theme two related to practicalities of communication within the family and the community, as well as the need for one language or communication mode to be acquired before another was introduced. Theme three described the influence of children's individual characteristics on caregivers' decision-making, including children's ability to access speech through audition, communication skills, additional disabilities, and children's own preferences about communication. Finally, in theme four caregivers expressed their hopes for their children's future lives, specifically fostering a sense of belonging, creating future opportunities and successes, and giving children the opportunity to choose their own method of communication. The findings can assist families and professionals to make informed decisions about children's communication.

Correspondence: Kathryn Crowe Charles Sturt University Panorama Avenue, Bathurst, NSW, 2795, AUSTRALIA Tel: +61-2-6338-4463 Fax: +61-2-63384417 kate.crowe@me.com.

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Emily Kingsley (1987) described the caregiver experience of having a newborn child being diagnosed with a disability in her allegory *Welcome to Holland*, in which a caregiver's highly anticipated holiday to Italy unexpectedly becomes immigration to Holland. Upon having a child diagnosed with a hearing loss, many caregivers may feel like they have immigrated to Holland. They are challenged by unfamiliar situations and unexpected decisions in the context of having a limited understanding of the impact hearing loss may have on their child and their family in the short- and long-term (Johnston et al., 2008; Young et al., 2008). Universal newborn hearing screening means that the presence of a hearing loss can now be detected very early in a child's life, and consequently caregivers are now required to make decisions for their children with hearing loss earlier than at any time in the past (Hardonk et al., 2010; Young, 2002). As the vast majority of children with hearing loss are born into families with no previous experience of hearing loss, the caregivers of young children with hearing loss often require a lot of information in order to make informed and effective decisions for their children (DesGeorges, 2003; Mitchell & Karchmer, 2004). Many decisions are initially made shortly after the diagnosis of hearing loss, at a time when caregivers have limited information about available options, and there is pressure for caregivers to make these decisions quickly (Decker et al., 2012). Decisions are made with the knowledge that they could have long-term implications for their children's linguistic, cognitive, social, emotional, and vocational futures, as well as for the immediate and long-term functioning of the caregivers and the family (Vaccari & Marschark, 1997; Young, 2002; Young & Tattersall, 2007).

Very early detection of hearing loss means that caregivers now need to consider how their children will communicate, long before either the impact of the hearing loss or the effect of amplification devices on children's spoken language development can be determined. Caregivers may approach this in different ways, either consciously engaging decision-making, or continuing with the families' current communication system without feeling that they have made a decision at all. Further, caregiver decision-making about communication does not represent a single decision made at one point in time (Young, 2002). Accounts of children's communication before and after cochlear implantation have demonstrated that caregivers may change the way they communicate with their children over time (Wheeler et al., 2009).

Caregivers of children with hearing loss may be faced with decisions concerning communication. The first issue is the mode/s of communication that will be used (i.e., speech and/or sign), which Marschark (2007) described as one of the most important issues faces by families of children with hearing loss. A second issue is faced by caregivers who are raising children in situations where more than one spoken language is used. These caregivers may also make decisions about which language, or languages, to use with their children. A small number of studies have investigated influences on caregiver decision-making about communication for their children with hearing loss, particularly in relation to decisions about communication mode. These influences will be discussed within the framework suggested by Young (2002) which considers caregiver decision-making along three dimensions: information, expectations, and identity.

Information

As caregivers may initially approach the task of decision-making regarding communication from the position of little prior knowledge about hearing loss, the gathering, interpretation, and application of information is a key component of decision-making (Young, 2002). The influence of information and advice, particularly from health and education professionals has been identified in a number of studies (Decker et al., 2012; Eleweke & Rodda, 2000). However, professional advice to caregivers has been reported to be conflicting, complicated, overwhelming, biased, based on opinion, and limited in the scope of information conveyed (Christiansen & Leigh, 2004; Decker, 2009; Steinberg et al., 2003; Young et al., 2005). Caregivers have reported accessing information from other sources, including family, friends, peers, and the internet (Decker et al., 2012; Porter & Edirippulige, 2007). Caregivers' experiences with Deaf¹ adults and Deaf organizations have also been noted to affect caregivers' perception of communication options (Christiansen & Leigh, 2004; Hyde et al., 2010). Little information is available concerning the influence of information on caregivers' decisions about multilingualism and language use. Two studies of oral multilingual children with hearing loss made mention of the fact that caregivers in their studies reported that they were advised by professionals to only speak English with their children (McConkey Robbins et al., 2004; Waltzman et al., 2003).

Expectations

Young (2002) described caregivers' difficulties with decision-making for their children with hearing loss as being about more than just a lack of information. As hearing loss is outside the caregivers' experience and understanding they are not able to see how it affects "our identity, our values and priorities, how we present ourselves to the world, and how we make sense of what happens to us" (Young, 2002: 6). Therefore, caregivers' expectations are linked to how they develop an understanding of the meaning of deafness, and how this understanding impacts on their actions and choices for their children and families (Young, 2002). Some previous reports of influences on caregiver decision-making about their children's communication mode have reported that children's individual characteristics are important, particularly children's audiological profiles and early intervention experiences, frustration with communicating, the presence of additional disabilities, and children's communication preferences (Archbold et al., 2002; Gravel & O'Gara, 2003; Hardonk et al., 2011; Watson et al., 2008). Caregivers' understanding and expectations of the effects of these factors on their children's development and outcomes, as well as the impact of these on the family, may be important. Caregivers' expectations of what hearing loss may mean for themselves, their children, and their family may be affecting the languages and communication modes used in the family due to practicalities around communication. These may include the family's current communication method, the family's ability to learn a new method of communication, leaving communication options open, the children's future access to education, services and opportunities, and caregivers' attitudes, opinions, and education (Archbold et al., 2002; Gravel & O'Gara, 2003; Hardonk et al., 2011; Hyde & Punch, 2011; Kluwin & Gaustad, 1991; Li et al., 2003; Watson et al., 2008).

¹Here the term 'Deaf' (sociocultural perspective) is differentiated from 'deaf' (audiological perspective)

Identity

Young (2002: 7) conceptualizes identity in terms of each family's conception of "what the family is" and the family's "way of going about things". Specifically, this refers to a family's "cultural identity, preferred language, value systems, religious affiliations, class background, socioeconomic status, the community in which we choose to live coping styles, how we respond to crises, our varying abilities and capabilities to change and whether we are good at allowing new ideas and experiences to enter our worlds" Young (2002: 7). Related to this, previous research has identified caregiver participation in intervention, desire for normality, participation in Deaf and/or Hearing culture and participation in religion as impacting on caregiver decisions about communication (Gravel and O'Gara, 2003; Hardonk et al., 2011; Hyde & Punch, 2011; Meadow-Orlans et al., 2003; Watson et al., 2008). In addition to this, community attitudes towards speech and sign, and the languages spoken have also been noted as being of influence (Bird et al., 2012; Gravel & O'Gara, 2003; Hyde & Punch, 2011; Li et al., 2003).

Aim of this study

The limited existing literature describing caregiver decision-making about communication for their children with hearing loss is restricted in a number of ways. Firstly, studies have been based on small numbers of caregivers (Eleweke & Rodda, 2000). Secondly, studies have been focused on children with significant hearing losses, particularly children using cochlear implants (e.g., Wheeler et al., 2009). Finally, studies describing the decision-making of caregivers regarding language choice and multilingualism for their children with hearing loss are not available. The purpose of this study is to provide an exploratory analysis of the influences on caregiver choices about communication mode and language use for a population sample of children with hearing loss.

Method

Context of the Current Research

Caregivers surveyed in this study had children participating in the Longitudinal Outcomes of Children with Hearing Impairment (LOCHI) study. The LOCHI study examines the speech, language, academic, and functional outcomes of children with hearing loss, in a prospective, population-based cohort of children from Eastern Australia (Ching et al., in press). All children born between 2002 and 2007 in the Australian states of New South Wales, Queensland, and Victoria were invited to participate, if they were diagnosed with hearing loss, and if they accessed a pediatric hearing center prior to 3 years of age. These children, who are Australian citizens and residents, are eligible for government subsidized audiological services through Australian Hearing (Australian Hearing, 2005). Participants were recruited regardless of English language skills, language background, caregiver hearing status, socioeconomic status, geographic location, or the presence of additional disabilities.

Participants

Caregivers of 450 children participating in the LOCHI study were sent questionnaires requesting information concerning influences on their decision-making about communicating with their children. Questionnaires were returned by 177 caregivers and reported on 157 children, and are described in Crowe, McLeod, McKinnon, and Ching (2012c). Responses analysed in this paper were provided by 175 caregivers reporting on 155 children, 34.4% of the entire LOCHI cohort.

Child participants—Caregivers returned questionnaires reporting on 88 male (56.1%) and 69 female (43.9%) children aged between 3.5 years and 9.4 years (median=6.3; inter-quartile range 5.2 – 7.9). More children were hearing aid users ($n = 101$, 64.3%) than were cochlear implant users ($n = 56$, 35.7%). Eighty-nine (56.7%) children were first fitted with hearing aids before six months of age ($m = 10.4$ months, $SD = 11.8$). Caregivers were not asked to report on children's audiological characteristics; however, LOCHI study participants have a range of hearing losses (Crowe et al., 2012a).

Caregivers reported that 138 children currently used speech as part or all of their communication system (87.9%) and that the following spoken languages used by at least one child: Arabic, Cantonese, Chinese, English, French, German, Greek, Italian, Japanese, Maltese, Mandarin, Polish, Spanish, Tagalog, Telugu, and Urdu. The majority of children used English ($n = 130$, 82.2%) and used it fluently ($n = 99$, 63.1%). Twenty-two (14.0%) children were reported to use a spoken language other than English, with three (1.9%) children reported to be fluent users of this language. All of these 22 children were multilingual, using English and another spoken language. Caregivers reported that the majority of children were culturally Australian ($n = 140$, 89.1%) with 15 different cultural backgrounds reported in total. Fifty-two (33.1%) children currently or had previously used sign, and 29 (18.4%) children currently used sign as part or all of their communication system. Methods of sign reported by the caregivers were: Auslan, Auslan signs in English word order, Makaton/keyword signing, cued speech/articulation, Signed English, home sign, and fingerspelling. Nine (5.7%) children were reported to be fluent users of sign.

Forty (25.9%) children were reported to have a disability in addition to hearing loss, including vision impairment ($n = 13$, 8.4%), developmental delay ($n = 9$, 5.8%), cerebral palsy ($n = 7$, 4.5%), Autism Spectrum Disorder ($n = 4$, 2.6%), attention disorders ($n = 4$, 2.6%) learning disability or dyslexia ($n = 3$, 1.9%), and other disabilities ($n = 17$, 11.0%) (e.g., CHARGE syndrome, cystic fibrosis). Information was not available for three (1.9%) children.

The Index of Relative Socioeconomic Advantage and Disadvantage was used to report on children's socioeconomic status (IRSAD; Australian Bureau of Statistics, 2006). The IRSAD divides Australian socioeconomic status into ten deciles based on measurements of the relative financial, educational, and other resources of a geographic area. Areas with greater relative levels of advantage receive higher scores. The majority of children lived in areas with relatively less disadvantage (mean 7.6, median 8.0, mode 10).

Caregiver participants—The majority of caregiver respondents were female ($n = 148$, 83.6%) and were fluent users of English ($n = 163$, 92.1%), with eight (4.5%) reporting functional English skills, and one (0.6%) reporting that she did not use English. Thirty-five (19.8%) caregivers used a spoken language other than English with the majority reporting that they were fluent users of this language ($n = 23$, 57.5%). The languages reported were: Afrikaans, Arabic, Cantonese, Croatian, French, German, Greek, Indonesian, Italian, Japanese, Koine Greek, Lithuanian, Maltese, Mandarin, Nuer, Polish, Portuguese, Spanish, Sudanese Arabic, Tagalog, Telugu, Urdu, and Vietnamese. The majority of caregivers reported they were culturally Australian ($n = 144$, 81.4%), with 25 different cultural backgrounds reported in total. Seventy (39.5%) caregivers reported some proficiency in one or more of the following forms of signed communication: Auslan, Signed English, Cued Speech, Makaton, and fingerspelling. Caregivers often reported using more than one form of sign; however, only 18 caregivers reported that they were fluent users of a form of sign.

The highest level of education completed was a Bachelor's degree for the majority of caregivers ($n = 57$, 32.2%), followed by a postgraduate degree ($n = 28$, 15.8%). Other levels of completed education reported were: secondary education ($n = 25$, 14.1%), certificate ($n = 22$, 13.6%), advanced diploma/certificate ($n = 22$, 12.4%), and graduate diploma/certificate ($n = 15$, 8.5%). Six (3.4%) caregivers did not report educational information.

Questionnaire

Potential influences on caregivers' decision-making about communication mode and language use were identified via consultation with caregivers and professionals with experience with young children with hearing loss and through a literature review. Factors that were identified were used to create a 14-page, four-part, questionnaire. This questionnaire elicited data that was analysed qualitatively (this paper) and quantitatively (see Crowe et al., 2012c). Part A focused on caregivers' experiences of signed communication and hearing loss, and their attitudes to people with hearing loss. Part B examined caregivers' decision-making about use of speech and sign. Part C was only completed by the caregivers of children who had considered raising their child using more than one spoken language as it elicited responses regarding influences on decision-making about multilingualism and the use of English. Finally, Part D collected demographic information about child, caregiver, and family characteristics. Caregivers rated the importance of stated influences on their decision-making in Parts B and C and were invited to describe the most influential factors on their decision-making, through response to the question such as "overall, which factors were most influential in making your decision?" (Appendix A). Responses to open-ended questions from Parts B and C are examined in this paper, as well as one open response field in Part D where caregivers were able to make any additional comments.

Procedure

Two copies of the questionnaire (one for each primary caregiver) were posted to the residential addresses of 450 children participating in the LOCHI study in July 2011. Caregivers were invited to complete the questionnaire describing their decision-making regarding the use of signing, speech, and multilingualism for their child with hearing loss. As the children caregivers were reporting on were aged between three and nine years,

caregivers were often retrospectively reflecting on their decisions. No requests were received for the questionnaire to be provided in languages other than English. Ethical approval for data collection and use was obtained through institutional Human Research Ethics Committees. Ethical standards were met in the collection of these data. Spelling and grammatical errors in caregivers' responses reported in this paper have been corrected.

Data analysis

A thematic approach was taken to the analysis of caregiver questionnaire responses, in line with the procedures described by Braun and Clarke (2006). Caregiver responses were read for familiarization by the first author, and an initial set of codes were created. All caregiver responses were then reviewed in terms of the codes that they related to, and grouped into themes and sub-themes. The second and third authors reviewed themes and sub-themes. Themes and sub-themes were reviewed and revised to better describe caregivers' responses. Review of the themes and sub-themes continued until the meaning and definition of each theme was clear. In addition to this, an analysis of the reliability of the first author's coding was undertaken as suggested by Krathwohl (1998). A speech-language pathologist experienced in working with young children with hearing loss and their families independently coded responses for 30% of the questionnaires. Coding reliability was established at 79%. Discrepancies in coding were discussed until agreement was reached and records were amended appropriately.

Results

Questionnaire responses

Analysis of questionnaire responses yielded four main themes: sources of information, practicalities of communication, children as individuals, and children's future lives. Thirteen sub-themes were identified associated with these themes (see Table 1). Caregivers provided comments which were included in this analysis in the following areas: use of speech ($n = 156$, 88.1%), use of sign ($n = 150$, 84.7%), spoken language multilingualism ($n = 15$, 8.5%), use of spoken English ($n = 11$, 6.2%), and additional comments ($n = 48$, 27.1%).

Theme one: Sources of information

Caregivers described various sources of information that influenced their decision-making regarding communication with their children. Caregivers reported that professionals were influential through both the provision of information and the communication policies of the intervention providers that they were in contact with (advice from professionals). Caregivers also described their own research, observations, experiences, and preferences as being important in some cases (caregiver's own research and preferences). Lastly, for some caregivers the opinions of family and friends were noted as impacting on their decision-making (advice from family and friends).

Advice from professionals—Medical professionals, including general practitioners, ear, nose and throat specialists, pediatricians, and surgeons, were reported to be influential by many caregivers. Allied health professionals were frequently named as being important in decision-making about communication mode and language: audiologists, speech-language

pathologists, psychologists, and social workers. Advice from educators was also reported to shape caregiver decision-making, including early intervention teachers, teachers of the deaf, and special education teachers. In addition to the influence of individual professionals, many caregivers stated that advice from, or the policy of, organizations they received services from were important. The organizations mentioned included early intervention centers, cochlear implant teams, and audiological service providers.

The majority of responses simply named the professional that had been of influence. However, some caregivers' responses were more detailed, and stated that professionals presented them with information in a way that allowed them to make their own decision. For example, one mother said "teacher of the deaf, provided unbiased information, not saying we should/should not [use sign]". However, other caregivers stated that their decision was strongly guided by a professional who told them what to do, such as this mother who explained her decision not to use sign was "because the teacher told us not to". One caregiver described the manner in which she was provided with advice concerning managing the family's multilingual environment for her child, "the early intervention teacher (speech pathologist) as she advised on what was the best way to introduce English (as daughter spoke only Polish for the first two years of her life) then balancing the two languages". Caregivers reported that professionals advised them that speech would be the best mode of communication to use with their children. However, two caregivers expressed they were not satisfied with the way they were advised by professionals. One caregiver stated "we were advised by the audiologist, but I'm not sure they alone can make these decisions or suggestions!", The other caregiver wrote "some teachers think they know what's best for our hearing impaired children when they have no idea".

Many caregivers reported that the communication mode they chose was influenced by the policy of their early intervention service provider. The majority of these caregivers described the policy of the service provider they accessed was to use oral communication exclusively. One typical statement was "early intervention was totally against signing". Only one caregiver indicated that the early intervention service she attended had a policy for the use of sign. Further, one caregiver indicated that their choice of communication mode was secondary to their choice of an early intervention agency when she wrote "we were most impressed with the agency's interest in [child] herself not just her deafness. We more chose the institution rather than the mode of communication".

Caregivers' own research and preferences—Caregivers' own research and observations were reported to have influenced decision-making about communication in a number of responses. Many caregivers indicated that their decisions were based on their own opinions and preferences. Concerning communication mode, the majority showed a preference for speech, as expressed by this mother, "I chose without any other factors that I wanted my child to use speech". In describing multilingualism and language use, the majority of caregivers showed a preference for the use of English, for example "because the majority of Maltese in Australia in this generation speak only English".

Experiences with adults with hearing loss were reported to have impacted on decisions about the use of both speech and sign. For example, one mother reported her decision to use

speech was affected by interaction with a deaf mother, “we wanted her to learn to speak because after speaking with a deaf mother she told us how hard life was being deaf”. Another mother described the opposite, with her interactions with the Deaf community influencing her decision to use sign with her child, “Deaf adults in the Deaf community – seeing how positive they were. Not disabled like they are seen in medical profession”.

Observation of other children with hearing loss was influential for some caregivers. For example, one mother wrote the following to describe influences on her decision about communication mode, “the fact that we had seen kids who were more hearing impaired than her who had a normal education and were fully integrated into the hearing world”. Another mother described knowledge of other multilingual children with hearing loss as being important, “heard about other children who use two languages and their speech level”. While another caregiver commented that despite seeking information for themselves, the final decision about communication mode was the child’s, not hers:

We spoke with several deaf adults who all commented on how they wished their parents had kept them in contact with other deaf children particularly during their teen years Their struggle helped us to decide/understand that it was not about what we wanted, but what would allow him to be included in life supported by people who understood his disability.

Advice from family and friends—Caregivers indicated that family and friends influenced their decisions about communication mode and language use. One mother stated that her spouse’s opinion was important in deciding which communication mode to use when she wrote “husband not keen for us to sign”. Another caregiver made reference to her husband’s beliefs regarding the use of a language other than English with their child “my husband’s and my intuition and our backgrounds. How we had a certain responsibility to pass on the Polish language”.

Theme two: Practicalities of communication

A second clear theme emerged in regard to how caregivers’ choices were related to their practical concerns about communication. These included the use of different communication modes and languages within the family and the community (accessibility of communication), the optimal timing for the children and families to acquire speech and/or sign (timing of acquisition), and the perceived absence of a practical alternative to the communication mode or language (necessity of our situation).

Accessibility of communication—Caregivers frequently made reference to the communication mode and languages used by other people in their children’s environment when describing influences on their decisions. Choosing the communication mode already used by the caregivers and family was mentioned on many occasions, for example, “basically we all speak in the family and the kids had to as well. It was not even a decision”. Other caregivers stated that the use of speech by the broader community impacted on their choice to use speech rather than sign, such as “enabling my child with the ability to communicate with everyone he comes into contact with” and “so few people know sign language now”. Some caregivers also mentioned that their choice to use sign was influenced

by the presence of other family members who used sign to communicate, “we use Makaton as his twin is learning this and this is how we communicate as a family”.

Caregivers raising their children in multilingual environments cited the languages used by other family members as being important in their decision-making. For one caregiver this influenced the choice to use English only, “concentrated solely on English to enable our family, friends and community to be able to communicate with child and he be able to understand and respond and participate fully in conversation etc”. For another caregiver, the family’s lack of English skills was influential, “that our extended family, mainly grandparents have limited English – [I] wanted my daughter to communicate with them”. In another case, the caregiver expressed that the languages used with her child reflected the languages used in the household, “I don’t think I really considered – should we teach him English only? We use both languages at home and he picked them up”.

Many caregivers reported that a lack of fluency in a communication mode or in a spoken language impacted on their decision. This was framed in three ways. Firstly, lack of fluency was described in terms of the caregiver or the family having limited fluency in sign, for example, “our lack of signing skills in the family”, or in their language other than English, for example, “English is my first language and one of if not the main language”. Secondly, lack of fluency was described through concerns or constraints on caregivers’ abilities to develop proficiency in sign. For example, one mother described concern over the rate at which she could acquire fluency in sign, “my concern about learning sign fast enough to keep up with rate of language acquisition by my daughter”. Another mother described that she had limited time in which to learn and use sign, “large family and a busy mummy with very young children. It would have been difficult to learn [sign] and teach a new skill”. Finally, one caregiver described the choice for her daughter to be a monolingual user of English as being influenced by a lack of personal resources, “attending many appointments for hearing and having a toddler as well as a baby left little energy to encourage bilingualism with her”.

Caregivers also indicated that using sign with their children was preferred, or necessary, in some situations. A number of caregivers related this choice to being able to communicate using sign in situations where their children were unable to wear amplification devices, for example, “just wanted basic signing for water sports etc”.

Timing of acquisition—Caregivers described beliefs that acquisition of sign and speech, or English and other spoken languages, should occur in a specific order. Caregivers frequently reported that they consciously chose to focus on the development of speech first, before considering developing skills in sign. In some cases speech was used first and sign was introduced later. A number of caregivers indicated that they felt, or had been told, that the acquisition of sign would hinder or prevent the acquisition of speech. One father stated, “the theory that sign would distract him from learning to speak normally”. However, other caregivers stated that they wanted their children to use speech first, and to have the opportunity to learn to sign in the future. For example, one caregiver responded, “we use English all the time. However, we have started Auslan lessons as a family so if she ever needed it, it was a skill she could use”.

Some caregivers indicated that they were glad that they had introduced sign to their children when they were young, as this gave their children immediate access to language. For example, one mother said, “signing was a way of learning while waiting for speech to develop”. However, a few caregivers expressed regret at not having used more sign with their children when they were younger, such as this mother “when my son was five I introduced sign more strongly, but now I wish I had done that earlier”.

Three caregivers commented on their decisions about multilingualism and the use of English in terms of the acquisition order of the languages being important. In all cases acquisition of English was the first priority. For example,

We had [our son] and had always said we would teach our children both languages but by the time we had diagnosed his hearing loss, it became important to learn English and allow his natural exposure to Spanish to be there if he wanted to pick it up.

Necessity of our situation—A number of caregivers stated that their choice of communication mode was a matter of choosing to do what was necessary. Many described that their choice of communication mode was the only option that was available, or practical, for their situation. This was exemplified in this mother’s response, “I don’t really see it as a decision I made but rather a necessity to a situation”. There were also many caregivers who indicated that using sign was simply not necessary for their children, which will be discussed in the following theme (children as individuals). One caregiver also described her choice to use English with her son in terms of it being a necessity, “we realize that he needs English mostly and if he picks up Spanish then this is a bonus”.

Theme three: Children as individuals

The theme children as individuals exemplified how children’s individual skills and characteristics influenced the decisions of many caregivers. The impact of children’s ability to access speech through audition was referred to in three different ways by caregivers: the impact of the severity of the hearing loss, the impact of hearing aids and cochlear implants, and uncertainty as to whether children would be able to access speech through audition (children’s access to speech). Children’s current communication ability was also important for many caregivers (children’s communication skills), as was whether children experienced any disabilities in addition to hearing loss (children’s additional needs). For some caregivers, children’s own preferences for a particular communication mode was also influential (children’s own preference).

Children’s access to speech—The severity of children’s hearing loss was referred to as being influential in decision-making about communication mode and language use in many caregivers’ responses. Access to speech through audition was stated to have influenced many caregivers’ decisions to use speech with their children. For example, one mother responded “my child’s level of hearing loss meant that unaided he could hear speech but missed certain letters”. Many caregivers made reference to the severity of their children’s hearing loss as influencing their decision not to use sign. For example, “Her level of hearing loss is moderate so there was no reason to believe she couldn’t use speech”. Furthermore,

caregivers also reported that children's level of hearing was important in making decisions about multilingualism and language use.

Children's amplification (e.g., hearing aids, cochlear implants) was reported to be important in decision-making about communication mode for many caregivers. Some caregivers made explicit reference to children's access to, and use of, amplification devices as being influential in the decision to use speech. For example one caregiver described her child's experience with using hearing aids, "he achieves very good speech with the hearing aids and functions quite well generally without any sign". A number of caregivers mentioned the accessibility of appropriate amplification for their children, as specified by this mother "ease of obtaining cochlear implants". Other caregivers referred to their children's hearing loss being identified early, or their children having received access to amplification devices early, as being influential in their decision-making. For example, one father responded "we were very keen to introduce hearing aids early to our child as it was explained to us that this would assist his speech significantly".

Finally, a few caregivers indicated in their responses that their decision about the use of sign with their children was influenced by uncertainty about whether their child would be able to access speech through audition. One caregiver cited a deterioration of her son's hearing loss as a reason for introducing sign into their communication. Another described a 'wait and see' approach to the use of sign while she waited for an accurate prediction of her child's audiological potential: "the fact that we wanted to wait and see how his speech developed naturally, once his hearing loss stabilized".

Children's current communication skills—Many caregivers reported that their children's current communication skills were important in decision-making about future communication mode and language use. The majority referred to children having good skills in their current communication mode and many caregivers also expressed that this was why they did not use sign with their child. A typical response was "our child was able to attain good speech and good communication skills without any other means i.e., sign, cued speech etc.". Some caregivers stated that their children were already speaking when their hearing loss was diagnosed, while others referred to their children's progress with intervention as being influential in continuing the use of speech. For example, one mother responded "I was encouraged to use Auslan by the early intervention group but because my child used speech it became unnecessary". The mother of a child who was multilingual said simply that she was influenced by knowing "that my son communicates in both languages".

A number of caregivers remarked on their children having difficulty communicating through a single mode or language. Some caregivers described that the use of both speech and sign as a means of addressing their children's immediate communication needs, as summarized by this mother "he needs both sign and speech to communicate effectively at this stage". Other caregivers made reference to their children having difficulty with communication as influencing their choices about communication mode. For example, "although we started using speech heavily with him, our push for it has tapered off. He has not developed any speech despite our efforts and our focus now is sign language". Another mother described her decision to use only English with her son being due to his limited communicative

development, “due to limited English, introducing another language would have made the child even more frustrated and delayed in comprehension”.

Children’s additional needs—Whether children had a disability in addition to hearing loss also appeared to influence the decision-making process of a number of caregivers, affecting decision about both communication mode and language use. The nature of the children’s additional disabilities was seen to preclude the use of sign in some cases, as described by this mother: “The fact that he has cerebral palsy which affects his whole body: gross and fine motor skills. We didn’t know if he’d be able to sign”. In other cases, use of both sign and speech was considered precisely because of the children’s additional disabilities. One mother explained her decision as “my child has other disabilities that hinder his speech, so both speech and Makaton are used. But I would like him to speak”. One caregiver also described that changes in the nature of her child’s health had affected the communication choices she made. This child used sign for the first 42 months of her life while she had a tracheostomy tube and was unable to speak, but speech became the goal once the tracheostomy tube was removed.

Children’s own preferences—There were some responses in which caregivers described children themselves making decisions about communication mode. In some cases caregivers reported that their children had shown a preference for using speech. One mother noted “we initially used Signed English and speech. When she got bilateral cochlear implants her signing virtually stopped and she learnt to talk/listen. She made it very clear to us that she had a voice and wanted it heard”. However, in other cases children were reported by their caregivers to have shown a preference for sign. In one case this was noted through the caregiver’s observation of the child’s behavior: “he was very visual and seemed to respond more to what he saw than what he heard”.

Theme four: Children’s future lives

A fourth theme was identified, whereby caregivers’ decisions were influenced by a desire to create the best possible opportunities for their children’s future lives. Caregivers mentioned desires for their children to experience a sense of belonging (fostering belonging). This was described in terms of membership within the ‘hearing world’ and/or the ‘Deaf world’ when communication mode was discussed, and between Australian culture and other cultures when language use and multilingualism were discussed. Many caregivers also mentioned wanting their children to have the best possible opportunities in the future, particularly in terms of accessing education and employment (future opportunities and success). Finally, some caregivers indicated that their children would make their own decisions about how they wanted to communicate when they were older (children can choose).

Fostering belonging—Belonging to, and engaging with, different cultural groups was mentioned by many caregivers as influencing decisions about communication mode and language use. Many caregivers’ descriptions of the factors influencing their choice of communication mode included references to belonging to, and participating in the hearing world/community and/or the Deaf world/community. The importance of participation in the hearing world, which some caregivers described as “our hearing world”, was evident in

many responses such as this one: “we wanted our child to be part of our ‘hearing world’ ”. In some cases use of speech and engagement with the hearing world appeared to be linked to caregivers hoping that their children would have an ‘easier’ life. One mother described this as, “we wanted [child] to have an easier life which we associated with her being able to participate fully in the hearing and speaking world”. Additionally, a number of caregivers stated that their decision-making was based on wanting their children to be normal, or to be treated normally. Some caregivers also indicated that they wanted their children to be like other people. For example, one mother stated “I don’t want people to treat my child differently from other children”.

Fitting in with different cultural groups was also important for caregivers making decisions about multilingualism and language use. Caregivers cited this as a reason for using, or not using, a language other than English with their children. For example, one caregiver described engagement with mainstream Australian culture as being important in terms of “fitting in with Australian culture”, whilst for another it was transmission of her cultural heritage “Maltese is her ancestry as well as Australian and I thought it would be nice for her to learn it”.

On the other hand, a number of caregivers made reference to wanting their children to engage with the Deaf world and the Deaf community. One caregiver expressed that her decision-making about the use of sign with her son was influenced by wanting him to experience equality, with the Deaf community representing “a place to go where he is equal to everyone and not struggling to communicate as he may be in the hearing world”. One Deaf caregiver described how the need for her child to develop a strong sense of identity was central to her decision about communication mode. She stated that her daughter’s “identity and feeling of belonging to the Deaf community ... is very important”. The timing of this decision was also important as this caregiver continued by stating “we were considering cochlear implantation in the first 6 months, so all we cared about was her identity and how we can ensure she is who she is”.

In some responses caregivers gave their perspectives on biculturalism and having access to both hearing and Deaf worlds. For example, one caregiver described the need for her child to feel comfortable as both a signing and a speaking person: “We are a signing family and we are all deaf it is very important for him to have access to both languages and feel he does have an identity, and be proud of who he is and who his family is”.

Future opportunities and success—Many caregivers indicated that their decision about communication mode and language use related to creating an environment in which their children could access opportunities and have the best possibility for success in the future. Caregivers identified access to education, employment, literacy, future choice, social relationships, and achieving their potential as being key issues in this regard. Caregivers associated speech and use of English with providing their children with the ability to access these opportunities. For example, one mother stated her decision about using speech with her child was influenced by “our wish for our child to be able to maximize his opportunities in life, which we felt would be achieved most easily if he could speak”. This was also important for caregivers making decisions about multilingualism and language use. For

example one caregiver stated “he would have access to mainstream school if he could communicate appropriately in English. Better education and employment prospects”. Another caregiver commented that she wanted her child with a hearing loss to have the same opportunities in life as his hearing sibling: “we wanted to bring our son up exactly the same way as his big brother, attend the same pre-school, school and have the same opportunities as other ‘hearing’ kids. We felt the only way this could happen was to teach him to communicate with speech”.

Children can choose—Some caregivers referred to wanting their children to be able to choose how they communicated in the future for themselves. In some cases, the opportunity to make this decision was framed around giving children access to both speech and sign. One mother commented “we wanted him to have both forms of communication and when he was older to make a decision he could decide what he wanted. We wanted him to have the tools to make an informed decision”. In other cases caregivers chose to use speech, and left the possibility for their children to use sign in the future open. For example one father stated “want her to choose, at least if she wants to communicate with speech she can, if not, then that is okay (when she is older)”. Other caregivers also indicated that they would support the use of sign in the future, if this was preferred by their children: “she has the option of learning sign if ever she wants to”.

Discussion

Analysis of caregivers’ responses generated four themes that were key to decision-making about communication mode and language use for their children with hearing loss. These were the information they had received from a variety of sources, the practicalities of communicating with their children (and their children’s communication with others), their children’s individual situations, and the future lives that they hoped for their children.

The most frequently mentioned influence on decision-making was information. Information came from a variety of sources including professionals, family and friends, as well as caregivers own experiences and interactions. While caregivers reported gaining information from different sources, it was not possible to identify whether they were able to make an informed decision, based on having “access to comprehensive, unbiased and evidence-based information, about the full range of options” (Early Support, 2006: 3). In some cases, caregivers reported that their decisions were based on information that may not have facilitated informed choice, for example following directions from professionals and following the policy of the early intervention provider. While informed choices by caregivers is considered to allow for the best outcomes for the child and family, the capacity of individual caregivers to engage in the decision-making process has been questioned (Young et al., 2006). However, some caregivers also reported active engagement with information by independently researching options and drawing their own conclusions on what was best for their child and their family, another important aspect of informed choice (Early Support, 2006).

The practicalities of communication were also frequently described by caregivers as being important in decision-making, particularly in regard to expectations of how the child would

be able to communicate within the family and the community. The difficulties adults may experience in acquiring proficiency in a sign language or new communication mode, especially when the purpose of this learning is specifically to communicate with their children with hearing loss, have been reported (Kemp, 1998; Marschark, 2007; McKee & McKee, 1992; Peterson, 2001). This is particularly challenging for fathers and extended family such as grandparents (Hyde & Punch, 2011). Another practicality that caregivers frequently referred to was the need for languages and communication modes to be acquired in a specific order. In the case of communication mode there was more often a preference for the use of speech before sign, with the view that use of sign early in children's development impeded the acquisition of speech. This view that is not unanimously supported by research evidence (Hassanzadeh, 2012; Marschark, 2007). However, recent thinking is turning toward early acquisition of speech in preference to sign as being a practical, viable, and positive option for the majority of children with hearing loss in the twenty-first century (Knoors & Marschark, 2012) and children with hearing loss are increasingly being educated in mainstream spoken language environments (Moores, 2004).

In the case of multilingualism, there was a preference for learning English first, with acquisition of other spoken languages reported more often as desirable rather than essential. There is very little research examining multilingual language acquisition in children with hearing loss; however, professionals providing this advice to caregivers have been mentioned previously (McConkey Robbins et al., 2004; Waltzman et al., 2003). In a systematic review of studies examining the speech and language outcomes of children using spoken languages other than English published between 2000 and 2011, only eight studies were identified which described multilingual spoken language development for children with hearing loss (Crowe & McLeod, 2013). All children from multilingual home environments showed skills in the dominant language of the community, with some studies showing their language development was equivalent to their monolingual peers, and others finding their language development was not as advanced as for their monolingual peers (Crowe & McLeod, 2013).

Children's individual abilities and needs were highlighted as being important by caregivers. Particular emphasis was given to children's abilities to access spoken language through audition. This was expressed either through caregivers' descriptions of the impact of the severity of children's hearing losses or the successful use of amplification devices to access speech through audition. The importance of children's audiological characteristics in decision-making about communication mode is not surprising and has been described elsewhere, for instance, in Marschark (2007). Some caregivers of children with disabilities in addition to hearing loss reported that the nature of their children's additional needs was important in their decision-making. While the types of additional needs that children with hearing loss experience may effect their speech and spoken language outcomes (Cupples et al., 2012), little is known about caregiver decision-making about communication for these children.

Consideration of children's futures was of importance to caregivers who were making decisions about communication mode and language use. Caregivers frequently described the concept of "belonging". Many caregivers reported the importance of belonging to, and

engaging with, the majority culture and community (hearing culture/community and Australian culture/community), of which the caregivers were also usually members. This is in line with the assertion by Young (2002) of the role of the families' existing identity in decisions about communication. However, some caregivers expressed a desire for their children to have the opportunity to experience belonging within the Deaf community, or within the community with which they shared a cultural heritage. The transmission and maintenance of a shared cultural heritage between caregiver and child has been noted to be of importance in decisions about communication in research of Hispanic (Steinberg et al., 2003) and African American (Borum, 2012) caregivers of children with hearing loss. For these caregivers, giving their children a range of communication options was of importance with the understanding that a shared language is of importance for community membership (Baker-Shenk & Cokely, 1991). The prospect of a specific method of communication allowing children to access opportunities, particularly educational and vocational opportunities, was of importance. Caregivers' associations between the use of speech and access to mainstream education options that have been noted previously (e.g., Hardonk et al., 2011) were also found in the present study. Finally, one aspect of caregiver decision-making identified in this study that has not been noted in previous research was the desire of some caregivers to let their children make their own decisions about how they would communicate. In some cases this took the form of caregivers being open-minded about the prospect that their children may like to sign in the future, while in other cases caregivers actively encouraged children to use speech and sign so that they would be able to make an informed choice for themselves. Consideration of children's own opinions, preferences, and desires in relation to developing effective communication is important (McLeod, 2011), and has been described in both the United Nations Convention on the Rights of the Child (III 14 C) and the International Convention on the Rights of Persons with Disabilities (Article 24, 3b and 3c) (UN General Assembly, 2005, 2007).

Limitations

The present study accessed a large number of caregivers of children of different ages, which created two limitations for the present study. Firstly, caregivers' recollections of their decision-making may have been influenced by the fact that their children had experienced success or challenges with the communication mode or languages that they initially chose for their children. Secondly, as caregivers' reports of influences on their decision-making were collected retrospectively, influences could not be correlated with ages or stages in their children's development. The generalizability of the findings of the present study may also be limited in some regards. The socioeconomic status of respondents was skewed towards those who experienced relatively lower levels of disadvantage, meaning that compared to the Australian population respondents were from areas of greater social, economic, and infrastructure advantages. In addition, there were proportionally fewer multilingual caregivers in this sample than would be expected in the general Australian population (Crowe et al., 2012b). Lastly, Australia provides a context in which universal newborn hearing screening is widely available and early fitting of hearing aids, early cochlear implantation, and audiological and intervention services are readily available and affordable (Australian Hearing, 2005, 2011; Leigh, 2008, 2010), so the findings of the current study may be different in other countries.

Clinical Implications

The findings of this study have important implications for understanding the decision-making of caregivers about communication mode and language use for their children with hearing loss. Firstly, professionals guiding caregivers through this decision-making process need to be aware of what is important from a caregiver perspective, rather than limiting their view to the impact of audiological characteristics. Professionals also need to be aware that while caregivers bring their own information, expectations, and identity considerations to the decision-making process, that some of these may not be correct. As informed choice relies on caregivers having access to accurate information, professionals have an important role in providing caregivers with objective, evidence-based information that dispels erroneous assumptions, such as that the use of sign prevents the acquisition of speech. Further, understanding the issues that caregivers consider to be important in decision-making allows professionals to support and empower caregivers as they travel through the communication journey together.

Future Research

Further research is required to explore issues of caregiver decision-making in greater depth, particularly in relation to decisions about multilingualism for children with hearing loss. Depth is required both in terms of examining the impact of different influences at different ages and stages of children's development for different languages and cultures, and also when looking at caregivers' choices both prospectively and retrospectively. Given the large number of references caregivers made to professionals playing an influential role in their decision-making, it is also important to examine the influences on the information and advice that professionals provide to caregivers.

Conclusion

Caregivers' decision-making about the communication mode and language/s used by their children with hearing loss was influenced by the information they accessed, practicalities of communicating within the family and the community, children's individual characteristics, and creating the best possible future opportunities for their children. These findings have implications for professionals supporting caregivers in making informed choices about communicating with their children with hearing loss.

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Appendix

Questions used to elicit caregiver responses

Influences on choices about the use of speech

- Which of the following situations is true for your child?
 - ☐ I use speech with my child and/or others use speech with my child
 - ☐ I have considered using speech with my child but decided not to. Why not? _____
 - ☐ I have never considered using speech with my child. Why not? _____
- Overall, which factors were *most* influential in making your decision?

Most influential: _____

Next most influential: _____
- Additional comments: _____

Influences on choices about the use of sign

- Which of the following situations is true for your child?
 - ☐ I use sign with my child and/or others use sign with my child
 - ☐ I have considered using sign with my child but decided not to. Why not? _____
 - ☐ I have never considered using sign with my child. Why not? _____
- Overall, which factors were *most* influential in making your decision?

Most influential: _____

Next most influential: _____
- Additional comments: _____

Influences on choices about multilingualism

- Please indicate which of the following are true for you and your family:
 - ☐ I have tried to raise my child as multilingual but he/she only understands/uses one language
 - ☐ I have considered that my child could be multilingual but decided that he/she would be monolingual. Why not? _____
 - ☐ I have never considered that my child could/should be multilingual. Why not? _____
- Overall, which factors were *most* influential in making your decision?

Most influential: _____

Next most influential: _____
- Additional comments: _____

Influences on choices about the use of English

- Overall, which factors were *most* influential in making your decision?

Most influential: _____

Next most influential: _____
- Additional comments: _____

Additional comments

- Do you have any additional comments? _____

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Table 1

Influences on caregivers' decision-making about their children's communication mode and language use.

Themes	Sub-themes	Explanatory/exemplar caregiver quotes	Number of responses mentioning this sub-theme
Sources of information	Advice from professionals	"Teacher said not to sign because she is capable of speech"	123
	Caregivers' own research and preferences	"It was the way I was raised as I only have partial hearing loss same for my kids"	78
	Advice from family and friends	"Our own feelings as parents and that of our immediate family"	18
Practicalities of communication	Accessibility of communication	"The ability to communicate with everyone he comes into contact with"	118
	Timing of acquisition	"We focused only on English first, but will be adding a second language slowly"	45
	Necessity of our situation	"There does not seem to be a need for sign"	15
Children as individuals	Children's access to speech	"Unaided he could hear speech but missed certain letters"	98
	Children's current communication skills	"He needs both sign and speech to communicate effectively at this stage"	73
	Children's additional needs	"My child has other disabilities that hinder his speech"	14
	Children's own preferences	"She made it very clear to us that she had a voice and wanted it heard"	8
Children's future lives	Fostering belonging	"Maltese is her ancestry as well as Australian"	71
	Future opportunities and success	"To be able to maximize his opportunities in life"	28
	Children can choose	"She has the option of learning sign if ever she wants to"	13