Parents of Deaf Children Seeking Hearing Loss-Related Information on the Internet: the Australian Experience

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Parents whose children are diagnosed in an infant screening program are required to make some difficult choices about the management of the hearing loss at a time when they are emotionally vulnerable. They are required to evaluate information and outcomes regarding issues such as technology for hearing impairment, communication options, education, and rehabilitation. The World Wide Web has become an important resource of health information for both health consumers and practitioners. The ability to obtain accurate health information online quickly, conveniently, and privately provides opportunity to make informed decisions. However, little is known about the level of the use of the Internet to acquire health information, particularly in the case of parents of deaf children seeking information. This study confirms that searches for health information on the Internet are conducted primarily by mothers. In the Australian context, there is minimal online information available to families beyond early intervention. Information on education issues, mental health, and deafness or the day-to-day management of a child or adolescent with a hearing loss are neglected topics on Web sites. This study also revealed that the majority of respondents had never visited Health*Insite* or Medline Plus, two gateway sites for reliable consumer health information, although the information on these sites is more generic in nature and unlikely to assist parents to make informed choices on complex issues such as communication options or education. However, the study suggested that half the parents have talked to their doctor or hearing professional about information they found on the Internet, which is an encouraging tendency.

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Parents whose children are diagnosed with a hearing loss in an infant screening program usually have little understanding of deafness in children or its management. They are required to weigh up information and possible outcomes regarding issues such as technology, communication options, education, and habilitation (DesGeorges, 2003; Kurtzer-White & Luterman, 2003) at a time when they are emotionally vulnerable. Information may be provided by professionals who hold strong ideological and methodological viewpoints that can be bewildering and unsettling for families. Although traditional avenues for information remain, families are turning to the Internet to access additional information on hearing loss and raising a deaf child.

The importance of information for families of a newly diagnosed baby has been well documented (DesGeorges, 2003; Luterman, Kurtzer-White, & Seewald, 1999; Meadow-Orlans, Mertens, Sass-Lehrer, & Scott-Olson, 1997). Information that is accurate and reliable enables parents to make informed choices and take an active role in their child's management (Bemrose, 2003; DesGeorges, 2003; Luterman et al., 1999; A. Young et al., 2005). The process of information gathering undertaken by parents can affect both parental coping and the decision-making process (Zaidman-Zait & Jamieson, 2004). Information empowers parents and provides them with self-esteem and confidence in their ability to raise a deaf child (Bemrose, 2003; A. Young, 2003).

Blackburn and Read (2005) believe that there is consistent evidence to suggest that parents of disabled

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Table 1 Comparison of demographic statistics for children under 21 years fitted with a hearing aid in Australia (31 March, 2006), population of each state (30 June, 2006), and geographic location of survey respondents

	Children under 21 years with hearing aid as on 31 March, 2006[a]		Geographic location of respondents		Population statistics by state as on 30 June, 2006[b]	
State	%	*n*	%	*n*	%	*n*
Australian capital territory	2.6	372	3	5	1.6	328,800
New South Wales	30.9	4,471	37	59	33.1	6,827,700
Northern Territory	3.2	468	<1	1	1	206,700
Queensland	20.4	2,952	15	23	19.7	4,053,400
South Australia	6.6	956	9	15	7.5	1,554,700
Tasmania	1.9	271	2	3	2.4	488,900
Victoria	25.1	3,629	25	39	24.7	5,091,700
Western Australia	9.3	1,351	8	13	10.0	2,050,900
Total	100	14,470	100	158	100	20,605,500

[a]Data supplied by Australian Hearing (M. Dewberry, personal communication, February 7, 2007). Figures include the approximately 1,400 children in Australia with cochlear implants who wear a hearing aid in the nonimplanted ear.

[b]Data from the Australian Bureau of Statistics—2006.

children experience difficulty accessing timely and crucial information. And in a study investigating parenting of deaf children, A. Young (2003) found that the difficulties parents faced accessing information they required had "impacted significantly on [their] experience of parenting." It is, therefore, probably not surprising that parents are turning to the Internet to find information quickly and conveniently.

Hearing Loss in Australian Children

The funding and provision of services for children with a hearing loss in Australia varies between the states. Children diagnosed with a permanent hearing loss receive all audiological services through Australian Hearing which is funded by the Australian Government. Australian Hearing provides free audiological assessments, hearing aids and other assistive technologies to all children aged between birth and 21 years with minimal exceptions. In 2006, Australian Hearing provided services to 14,470 aided children under 21 years of age (see Table 1). These figures include the approximately 1,400 children in Australia with cochlear implants, who wear a hearing aid in the nonimplanted ear (M. Dewberry, personal communication, February 7, 2007). Data from Australian Hearing are considered to be the most reliable source for the prevalence of hearing loss in Australian children (CRC Hear and Victorian Deaf Society, Canberra, 2006). Statistics are not available on deaf children in Australia with an additional disability. There are also no accurate figures on the size of the Australian Deaf Community with estimates ranging from 6,500 to 15,000 individuals, whereas the number of children within the Deaf community is undetermined (Johnston, 2004).

Screening for hearing is the responsibility of the state governments. Early intervention services and school education are provided by either the Department of Education in each state, the Catholic Education Department in each state or privately and publicly funded service providers. Cochlear implantation may be funded by either the Australian Government or private health funds.

Health Information on the Internet

The World Wide Web has become an important source of health information for both health consumers and practitioners (Ahmad, Hudak, Bercovitz, Hollenberg, & Levinson, 2006; Cline & Haynes, 2001). The ability to obtain accurate health information online quickly, conveniently, and privately provides opportunity to make informed decisions. A number of factors are known to influence a consumer's use of the Internet in Australia, such as age, household income, access speed and education level (Curtin, 2001; "Save@Home," 2007), but little is known about the level of the use of the Internet to acquire health information, particularly parents of deaf children seeking information.

Although health consumers have become enthusiastic adopters of Internet technology, the varying quality of health information on the Internet accessed by consumers remains an area of concern (Shepperd, Charnock, & Gann, 1999). The Internet is not the only place where consumers find unreliable or outdated information (Noll, Spitz, & Pierro, 2001), but the ease of access and the democratic nature of the Internet make it particularly problematic. A number of guidelines and checklists have been published to assist consumers to assess the quality of health information on the Internet such as the Health on the Net Foundation (http://www.hon.ch/HONcode/Conduct.html), DISCERN (http://www.discern.org.uk) and the Health Information Quality Assessment Tool (http://hitiweb.mitretek.org/iq/). The common criteria for evaluating health information on the Internet include the currency of the information along with methods for assessing the reliability, validity, and accuracy of the information (Shepperd et al., 1999).

However, the validity of the various rating systems remains uncertain, and the need for accreditation of health Web sites divides opinion (Gagliardi & Jadad, 2002). Although consumers have access to peer-reviewed journals along with gateway sites offered by health-care providers and government agencies, which include health information that meets certain quality criteria (Shepperd et al., 1999), the reality is consumers continue to use generic Internet search engines to find the information they require (Fox, 2006). The 8th HON Survey of Health and Medical Internet Users showed that 46% of patients and 28% of health professionals preferred general search engines. This same survey found that consumers failed to verify seals of approval, such as the HONCode, or may simply be unaware of their existence ("Excerpt of the 8th HON's Survey," 2002). In addition, parents are less likely to check the source of information than nonparents (Allen & Rainie, 2002). Furthermore, it remains unclear whether consumer use of rating instruments has any impact on their health outcomes (Gagliardi & Jadad, 2002).

The quality of online information available to parents about child health issues has been investigated in a few studies with variable results (Chen, Minkes, & Langer, 2000; Corpron & Lelli, 2001; Cotterill, 2001; Oermann & Lowery, 2003). These studies highlight not only the difficulty of locating reliable information pertaining to specific childhood illnesses (Cotterill, 2001) but also a large variability in the accuracy of information which might allow parents to make informed choices about treatment (Chen et al., 2000; Corpron & Lelli, 2001).

Parents and the Internet

In 2002, the Pew Internet and American Life Project found that 67% of the parents surveyed reported using the Internet to search for health information (Allen & Rainie, 2002). Mothers are more likely to search for health information than fathers (Allen & Rainie, 2002). Studies on parents of disabled children seeking information on the Internet are very limited. A study by Baum (2004) of Internet Parent Support Groups (IPSGs) for primary caregivers of a child with special health-care needs found that one of the important reasons for participating in an IPSG was for improved access to current information and resources. In their study, which investigated the experiences of parents of disabled children and their use of the Internet, Blackburn and Read (2005) found that a substantial percentage of parents (72%) used the Internet to obtain information about parenting their disabled child. They found that although the Internet is a viable option for parents to access the information and services they need, it is not an option for all families and should not become the primary source of information. Families who cannot or do not wish to use the Internet should not be excluded from accessing the information they require. A range of information delivery is necessary to accommodate the needs and circumstances of families.

The Internet and Families With a Deaf Child

There is limited information available on parents of deaf children and their use of the Internet. In a large study of parents of deaf children carried out in the United Kingdom as part of the National Deaf Children's Society Toolkit Development project, the authors found that parents rated the importance of the Internet differently depending on whether they were deaf or hearing. One third of deaf parents of deaf children rated the Internet as important, whereas less than a quarter of hearing parents felt the same

(A. Young, Greally, & Nugent, 2003). Only one study was found looking at the Internet and information needs of parents of deaf children. This study evaluates the information parents are likely to find on the Internet when investigating cochlear implantation for their child (Zaidman-Zait & Jamieson, 2004). The authors found that the information on cochlear implants and how they work was readily available. But the information on some topics seen as very important to parents of deaf children, such as education, habilitation, and communication choices, was limited or absent altogether.

Aim

The aim of this study was to examine the patterns of Internet use by parents of deaf children seeking hearing-loss-related information within the Australian context. The purpose was to more fully understand the demographic details of parents of deaf children who turn to the Internet, whether any particular variables play a significant role in their Internet use, and the type of information parents are searching for on the Internet. A better understanding of these issues would broaden the current knowledge base and assist in future development of Web sites that better meet the needs of Australian families with deaf children.

Method

The Survey

The study consisted of an online questionnaire (Supplementary Material), hosted by Questionpro (http://www.questionpro.com) that provides commercially available online software for surveys. Each survey had a unique URL. Data were maintained behind a firewall and could only be accessed by the owner of the survey using a password and user ID. Parents of a child with a permanent hearing loss, aged from birth to 21 years, and living in Australia were the targeted study respondents. The questionnaire was pretested on five parents of deaf children from a local parent support group using a hard-copy format and refined using their comments and suggestions. The survey was online for a 2-month period, closing on August 31, 2005.

The questionnaire consisted of an introduction and five sections and took approximately 10 min to complete. Participation in the survey was voluntary, and withdrawal from the survey at any point was possible. Respondents were anonymous. Checking "Continue" at the end of the introduction was considered consent to participate in the study. The questionnaire consisted of single answers and multiple-choice or open-text questions. Radio buttons were used when only one answer was sought, and check boxes provided for multiple responses. There was no word limit on open-text questions.

Section I sought to establish where parents currently received information about their child's hearing loss and related topics. Section II looked at how parents use the Internet to search for information and the broad topics of information which are sought. Section III dealt with the demographic details and hearing status of the children and Section IV, the demographic details of the parents. Section V reviewed whether parents visited the major Australian deafness-related Web sites and how often. The final question was an open-text question which asked parents what information they would like to see included on Australian Web sites about hearing loss and related topics.

Survey Distribution

An initial letter was sent to a total of 229 organizations and service providers who offer services to deaf children and their families across Australia. These included Australian Hearing, all early intervention services, all schools with hearing units, and all non-government agencies and organizations who offer services to deaf children. This letter consisted of a brief overview of the research and a request to distribute the URL of the survey to parents using their service. Details about the survey were placed on five Web sites.

Reminder letters were sent 1 month after the initial letters to 47 organizations and service providers where no correspondence or phone contact had indicated whether they had distributed the information to parents. Reminder letters were not sent to the schools with hearing support units because of cost.

Survey Methodology

The anonymous nature of online surveys makes it impossible to verify whether the respondents meet the inclusion criteria. Although Internet surveys have been shown to be comparable to traditional surveys in

terms of validity and reliability of the data (Eysenbach & Wyatt, 2002), they do have the potential for a number of biases (Umbach, 2004) including selection bias and nonresponse bias. The exclusive use of an online survey tool, therefore, makes it difficult to assess how representative the study population was of the entire population of parents of deaf children in Australia. Table 1 shows that the respondents were distributed throughout the states and indicates that the percentage of respondents from each state was approximately similar to the percentage of deaf and hard-of-hearing children in that state.

Quantitative data were analyzed using frequency distributions and cross-tabulations to assess the relationships between different variables. The Pearson chi-square test was used to identify any trends among variables. Qualitative data obtained in open-text questions were categorized into broad areas which were then systematically refined.

Results

Information about the survey appeared on five Web sites, and 229 organizations and service providers were informed of the study. Three hundred and six people accessed the survey online. A total of 207 individuals started the survey, that is, they checked "Continue" at the end of the introduction, and 166 completed it, although not all questions were completed on each survey. Thirty-one surveys that were started were entirely blank.

Demographic Details

The demographic details of the respondents are outlined in Table 2. Eighty-nine percent of the respondents were mothers of a deaf child, and two thirds were aged between 34 and 49 years of age. The vast majority were very comfortable speaking (94%) and reading (96%) English. Respondents were from across the country with 77% living in the three most populous states, New South Wales, Victoria, and Queensland (see Table 1). Over half (56%) were located in the city. The hearing status of the parents was not established in the survey.

Details of their deaf children were sought and are outlined in Table 3. Most families (82%) had only one deaf child, and the majority of children (90%) had a permanent bilateral hearing loss. In all, 44 of the children with a bilateral loss and 11 with a unilateral loss were reported to be in the profound range. Sixty-six percent of the children were aged under 10 years and 34% between 10 and 21 years of age. Two thirds of the children (65%) use oral communication only with a similar number (68%) wearing hearing aids. A quarter of the children (26%) have a cochlear implant. Sixteen percent of the children had an additional medical condition or disability.

Table 2 Demographic details of respondents

	%	*n*
Relationship to child		
Father	10	15
Mother	89	140
Guardian	1	2
Age (years)		
18–34	29	45
34–49	67	106
50–64	4	6
Employment status		
Employed (full time/part time/ self-employed	58	91
Unemployed/homemaker/student	42	64
Highest level of education		
High school	36	56
Vocational training	15	24
University degree	49	77
How comfortable are you SPEAKING English?		
Very comfortable	94	149
Somewhat comfortable	6	9
How comfortable are you READING English?		
Very comfortable	96	152
Somewhat comfortable	3	5
Geographic area		
City (i.e., metropolitan areas)	56	87
Regional (i.e., large rural centers)	31	49

Parents and the Internet

The majority of respondents was very comfortable using the Internet and accessed the Internet from home (see Table 4). Almost half the respondents had

Table 3 Demographic details and hearing status of children

	%	*n*
No. of deaf children in family		
One	82	133
Two	16	26
Three	2	3
Age		
Under 12 months	6	12
12–24 months	11	20
2–5 years	26	50
5–10 years	23	43
10–15 years	20	39
15–18 years	9	17
18–21 years	5	10
Type of hearing loss		
Bilateral	90	167
Unilateral	10	18
Method of communication		
Oral	65	123
Manual	7	14
Both	28	53
Child wears hearing aid		
Yes	68	129
No	25	48
Sometimes	7	14
Child has a cochlear implant		
Yes	26	48
No	74	137
Child has another medical condition or disability		
Yes	16	30
No	84	159

participated in an online support group or e-mail list for people interested in hearing loss. Fewer (30%) had signed up for electronic newsletters dealing with hearing loss.

The most popular way of searching for information is through the use of a generic search engine (87%). Parents also visit Web sites which they feel specialize in hearing loss (44%) or those recommended by other parents of deaf children (31%). Online information recommended by professionals (16%), family members, and friends (11%) and "Choices" (5%), a publication for parents provided by Australian Hearing, also influences the Web sites visited by the respondents. Around 90% of the respondents have never visited the Australian Government health information gateway—Health*Insite*—or Medline Plus, both designed to provide consumers with reliable health information.

There is a wide variation in the frequency with which parents access the Internet for information about deafness from daily access (12%) to less than every few months (17%). Thirty-one percent access the Internet several times a month to search for information about deafness.

Two thirds of the respondents (64%) visit two to five Web sites to find the information they require, and more than half (56%) report that they find the information they are seeking most of the time. Thirty percent only sometimes find the information they require.

Over half the respondents (52%) had spoken to their doctor or hearing professional about the information they had found on the Internet. Of these respondents, over two thirds felt the professional was either somewhat (40%) or very interested (18%) in the information the parents had found. Additional information on this topic was not sought from the respondents.

Cross-tabulations and chi-square analysis indicate that the pattern of Internet use for information seeking is unrelated to the age of the parent, the age of their child, where they live, or their employment status. Their use of the Internet is also unrelated to the type of hearing loss of their child (i.e., bilateral or unilateral), if their child has a cochlear implant or an additional disability or medical condition, or the method of communication used by the child.

Education level, however, does influence the level of Internet use (see Table 5). Parents with a university education are more frequent users of the Internet for information seeking, χ^2 (4, N = 154) = 20.24, $p < .05$, and are also more likely to participate in online support groups, χ^2 (1, N = 151) = 9.17, $p < .05$ (see Table 6). A small percentage of parents (5.5%) with high school as their highest level of education indicated that the information on the Internet had a major influence on their decision making, compared to 24.4% with an undergraduate degree and 33.3% with postgraduate qualifications. Cross-tabulations and chi-square analysis indicate that university-educated parents are more likely to find information on the Internet which has a major influence on decisions they

Table 4 Internet use of respondents

	%	*n*
How comfortable are you using the Internet?		
Very comfortable	67	109
Somewhat comfortable	23	38
From where do you most often access the Internet?		
Home	89	146
Work	9	14
How often do you use the Internet to find information about deafness and related topics?		
Every day	12	20
Several times a week	17	27
Several times a month	31	50
Every few months	21	34
Less often	17	28
About how many different Web sites do you usually visit or browse when looking for information about hearing loss?		
1	4	6
2–3	35	57
4–5	29	46
6–10	17	27
11–20	4	6
>20	3	5
How often are you able to find the information you are looking for?		
Always	5	8
Most of the time	56	91
Only sometimes	30	48
How do you find or search for hearing-related Web sites?		
Search engine	87	135
Web sites specializing in hearing loss	44	68
Web sites in "Choices"	5	8
Web sites recommended by doctor or hearing professional	16	25
Web sites recommended by a friend or family member	11	18
Web sites recommended by other parents of deaf children	31	49
In general, does the information you find on the Internet influence the decisions you make about your deaf/hearing-impaired child?		
Major influence	18	29
Minor influence	58	94
Other	24	38
Have you talked to a doctor or other hearing professional about information you have found on the Internet?		
Yes	52	82
No	43	69
If you talked to the doctor or other hearing professional, how interested were they in hearing about the information you found on the Internet?		
Very interested	18	21
Somewhat interested	40	47
Not too interested	11	13
Have you ever participated in an online support group or e-mail list for people interested in hearing loss?		
Yes	49	78
No	51	80
Have you ever signed up for an electronic newsletter that e-mails the latest news about hearing?		
Yes	30	47
No	70	112

make about the management of their child's hearing loss χ^2 (3, N = 153) = 10.2, $p < .05$ (see Table 7).

What Information Are Parents Searching for on the Internet?

At the time of the survey, the two most common topics searched for on the Internet by parents were parent support groups (55%) and educational options (54%; see Table 8). This was consistent irrespective of the age of the child. Parents are looking for information on a wide range of topics including hearing loss per se (40%), hearing aids (35%), cochlear implants (28%), communication options (30%), and alternative treatments and management (6%).

What Would Parents Like to Find on the Internet?

Eighty-two parents responded to the final open-text question which asked parents what information they would like to see included on Australian Web sites about deafness and related topics. Major themes

Table 5 Cross-tabulation for level of education and frequency of Internet use

	Frequency of Internet access					
Education level	Every day	Several times a week	Several times a month	Every few months	Other	Total
High school/vocational training	10	9	18	17	25	79
University degree	9	17	29	16	4	75
Total	19	26	47	33	29	154

Note. Degrees of freedom = 4; chi-square = 20.24; $p \leq .001$.

spanned the life of the child from early intervention to school education and the future.

Common to many areas is the need for unbiased information, which is evidence based, in order for parents to make informed choices ("… some unbiased accounts of what can be achieved with the different methods," Parent 1). Parents want to find objective information about their options regarding early intervention, education, communication, and technology ("Unbiased information about communication options backed by research findings and information about educational options," Parent 2; "Detailed service provider information, ie what do they do, how do they measure the effectiveness of what they do," Parent 3). They want information about current research and developments ("current research topics in progress and results," Parent 4) and assistive technologies ("… such as our recent search for recoding teletext for T.V.," Parent 5).

Parents enjoy the stories of other families and Deaf adults ("inspiring stories about successful deaf adults," Parent 6). Some ask for success stories, whereas others would like to know the ups and downs of having a deaf child ("I'd like to know about kids that find it tough as well as ones who do well," Parent 7).

A number of parents felt that information on the Internet was aimed at children with a profound hearing loss, whereas children with a lesser degree of hearing loss, including unilateral loss, are not well catered for ("A lot of information seems to relate to people with profound loss and its [*sic*] difficult for parents to work out where their child fits in if their child has a lesser loss," Parent 8). Genetics, auditory neuropathy, and large vestibular aqueduct syndrome are other topics which parents mentioned. One parent described the information available on Connexin 26 as "too scientific (not parent friendly)."

Table 6 Cross-tabulation for level of education and participation in online support group

	Participation in online support group		
Education level	Yes	No	Total
High school/vocational training	31	47	78
University degree	47	26	73
Total	78	73	151

Note. Degrees of freedom = 1; chi-square = 9.17; $p \leq .01$.

Parent support was another strong theme ("Support for parents through each stage of child's life, ie 0–2, 2–5, 5–10 etc.," Parent 9). Information about parent support groups, including groups for families of older deaf children, as well as information for continuing education for parents such as Auslan classes and parent workshops and seminars ("… a calendar of events," Parent 10) were raised.

A number of parents with older children would like information about what happens after school—career advice, employment options, and hearing support at universities and TAFE (Technical and Further Education), "Education options for deaf children after high school and what assistance they are able to access," Parent 11.

Mental health issues ("managing socialisation issues," Parent 12; "resilience in children," Parent 13; "puberty with a deaf child," Parent 14) and information for families with a child with a unilateral hearing loss ("More on unilateral loss, possible outcomes …," Parent 15) were other areas of need.

Discussion

This study investigated the experiences and viewpoints of parents of deaf children in Australia and their use of the Internet when seeking information related to hearing loss.

Table 7 Cross-tabulation for level of education and influence of online information on decision making

	Influence on decision making				
Education level	Major	Minor	None	Do not know	Total
High school/vocational training	7	48	16	7	78
University degree	20	42	7	6	75
Total	27	90	23	13	153

Note. Degrees of freedom = 3; chi-square = 10.2; $p \leq .025$.

This study confirms primarily mothers search for health information on the Internet (Allen & Rainie, 2002). They are searching for information from the early years until the child leaves school and beyond. Their use of the Internet for information gathering was unrelated to the age of the parent, the age of their child, where they live, or their employment status. Their use of the Internet is also unrelated to the type of hearing loss of their child, that is, bilateral or unilateral; if their child has a cochlear implant, an additional disability, or medical condition; or the method of communication used by the child.

There has been little written about the ongoing information needs of families of deaf children. Harrison and Roush (2001) found that the information needs of families change over time, being different at diagnosis, a few months after diagnosis, and at transition phases in their child's life such as entering school (Harrison & Roush, 2001; McKellin, 1995). The need for professional advice and written information tends to rise around transition stages. A similar percentage of parents whose children were approaching school-leaving age rated the importance of written information as highly as parents with children in the preschool years (A. Young et al., 2003). This current study confirms that parents continue to search for information throughout the life of their child. Parents of high school children report seeking online information regarding, inter alia, postschool options for study and employment and mental health issues.

Table 8 Information parents search for on the Internet

	%	*n*
Parent support groups	55	85
Educational options	54	84
Hearing loss	40	62
Organizations and societies	39	60
Hearing aids	35	55
Communication options	30	46
Cochlear implants	28	43
Early intervention	17	27
Mental health	8	13
Alternative treatment/management	6	10

In the Australian context, there is minimal online information available to families beyond early intervention. Information on education issues, mental health and deafness, or the day-to-day management of a child or adolescent with a hearing loss are neglected topics on Web sites. Zaidman-Zait and Jamieson (2004) in their review of Web sites on cochlear implantation express a similar concern regarding the important information required by families to make informed choices, such as education and communication options, which is not included on Web sites. The limited online resources available to parents with a child with a milder hearing loss or unilateral loss were also highlighted by parents in the survey.

In Australia, people with a university education are more than two and a half times more likely to have Internet access at home (Curtin, 2001). Almost half the parents in this study have a university degree and are more frequent users of the Internet for information seeking and are also more likely to participate in online support groups. They report that the information they find on the Internet has a major influence on decisions they make about the management of their child's hearing loss.

This survey did not investigate where these parents found information, which had a major influence on their decision making, and this warrants further investigation. Ninety percent of respondents had never visited Health*Insite* or Medline Plus, two gateway sites for reliable consumer health information, although the information on these sites is more generic in nature and unlikely to assist parents to make informed choices on complex issues such as communication options or education. The authors argue that parents with higher levels of education are more likely to access scholarly journals on the Internet which assist them to make informed choices. In light of the fact that parents in the survey were asking for evidence-based information about communication, education

and outcomes, the proposition for public accessibility to scholarly journals may have considerable appeal for parents (Willinsky, 2003; Zaidman-Zait & Jamieson, 2004). Alternatively, the summary of evidence-based information found in the "Abstract" of scholarly journals may provide the solution to bridging the information gap between parents and professionals (Jadad, 1999).

Adults of all reading levels prefer easy-to-read information (D'Alessandro & Dosa, 2001), and it could be argued that abstracts and scholarly journals are not written at a level considered appropriate for the majority of consumers and may further bewilder parents. However, criticism of readability tests suggests that prior experience and motivation of the reader are not taken into consideration. Consumers with chronic diseases and disabilities are able to read more complex information as they become familiar with the disability, its terminology, and jargon (McCray, 2005; Shepperd et al., 1999). Furthermore, 80% of patients who access Web sites for health professionals do so to obtain more complex information ("Excerpt of the 8th HON's Survey," 2002). Parents of deaf children are on a very steep learning curve at the time of diagnosis. However, many reach a complex level of understanding about hearing loss over time and would benefit from having access to the same evidence-based information as the professionals guiding and supporting them when deciding on issues of raising their deaf child.

It has been suggested that parents do need to be directed to quality information and the role of health professionals in this can be significant (Mitchell & Sloper, 2002; Zaidman-Zait & Jamieson, 2004). In this survey, half the parents have talked to their doctor or hearing professional about information they found on the Internet. It is encouraging to find that over 80% of these professionals were interested in what the parents had found. The Internet has escalated the trend of patients wishing to be active participants in their health care and well-being (Eng et al., 1998; Peterson, 2000; K. M. Young, 2000), resulting in the control of health information moving away from the expert to the consumer (Yellowlees & Brooks, 1999). Professionals need to support and guide parents through their information-seeking and decision-making process (A. Young et al., 2005) and hence move away from being the gatekeepers of knowledge to advisors and partners in the process (Yellowless & Brooks, 1999).

Respondents to this survey were almost exclusively comfortable speaking and reading English, and only one parent of Aboriginal or Torres Strait Islander descent completed the survey. A study of ethnic minority families with a child with a severe disability in the United Kingdom in 1999 found these families and children to have greater reported unmet needs, including information and support, than their European counterparts (Chamba, Ahmad, Hirst, Lawton, & Beresford, 1999). One would suspect the picture would be similar in Australia. We have little idea about the Internet use of ethnic minorities in Australia, and there is minimal community language content on Australian Web sites (Curtin, 2001). This survey has shed no light on families of deaf children from culturally diverse backgrounds and their use of the Internet. This apparent inequality of access to information raises the issue of the so-called "digital divide"—the growing gap in the ability of segments of the community to access information and communication technologies. In recent years, the focus of this inequality has moved away from technology as an end to technology as a means to an end. The key to breaching this divide lies in providing meaningful access to the new technologies in order to minimize the gaps in opportunity and performance experienced by disadvantaged groups (Warschauer, 2003). Governments, nongovernment organizations, and the community sector need to pay serious attention to the question of creating new and meaningful online content for underserved and disadvantaged groups (Baum, 2004; Blackburn, Read, & Hughes, 2005; Warschauer, 2003).

Fifty-five percent of the respondents have participated in an online support group specializing in hearing loss issues. Their experiences in this regard were not investigated in this survey, although the authors have conducted a pilot study of parents of deaf children participating in online support groups which is yet to be published. Health-related groups are one of the fastest growing areas for online support (Gary & Remolino, 2000) and have become another source of information for parents in a number of health-care areas (Baum, 2004; Leonard et al., 2004;

Shank, Laible, Murphy-Berman, & Wright, 1999). Zaidman-Zait and Jamieson (2004) have discussed the community-building potential of online groups, particularly for rural families, and the most appropriate and effective use of online support groups for parents warrants further investigation.

Conclusion

Young adults becoming parents today have probably been using computers, the Internet, chat rooms, and e-mail for a large percentage of their lives. They are used to accessing information instantly—when they want it. It is likely that the demand for online information will increase over time. Service providers and Web site developers will need to understand this changing dynamic and adapt their information provision accordingly and ensure online information is meaningful, relevant, and accessible for parents to assist them in making informed decisions about raising their deaf child.

Supplementary Material

Supplementary material is available at http://jdsde.oxfordjournals.org./

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