Searching for Cochlear Implant Information on the Internet Maze: Implications for Parents and Professionals

Anat Zaidman-Zait
Janet R. Jamieson
University of British Columbia

The present study has three purposes: (a) to determine who disseminates information on cochlear implants on the Web; (b) to describe a representative sample of Web sites that disseminate information on cochlear implants, with a focus on the content topics and their relevance to parents of deaf children; and (c) to discuss the practical issues of Web-based information and its implications for professionals working with parents of deaf children. Using the terms “cochlear implants” and “children,” the first 10 sites generated by the four most popular search engines (Google, Yahoo, Microsoft’s MSN, and America Online) at two points in time were selected for analysis, resulting in a sample of 31 Web sites. The majority of Web sites represented medically oriented academic departments and government organizations, although a wide variety of other sources containing information about cochlear implants were also located. Qualitative analysis revealed that the content tended to fall into eight categories; however, the important issues of educational concerns, habilitation following surgery, and communication methods were either addressed minimally or neglected completely. Using analytical tools that had been developed to evaluate “user friendliness” in other domains, each Web site was assessed for its stability, service/design features and ease of use. In general, wide variability was noted across the Web sites for each of these factors. The strong recommendation is made that professionals understand and enhance their knowledge of both the advantages and limitations of incorporating the new technology into their work with parents.

Increasingly, individuals around the world are using the Internet and turning to the Web, an Internet system that allows the reader to access information by simply clicking on highlighted text, for health-related knowledge (Dryburgh, 2001; Pew Internet and American Life Project, 2002; Statistics Canada, 2002; US Department of Commerce, 2000). Several parent surveys indicated that parents consult the Web regularly concerning their children’s development and health (Ikemba et al., 2002; Zero to Three, 2000). For example, in a national survey by Zero to Three, 38% of parents reported that they used the Web regularly for child development information. Ikemba et al. found that 58% of families with Internet access in 2000 whose children required cardiac surgery used the Web to obtain information related to their child’s diagnosis.

It is clear, then, that information technology has increasingly become part of everyday life for many people and the Internet is an important source of obtaining health-related information. The Web is an important source of information for parents who are facing health issues or other special circumstances with regard to their children, including parents of deaf children who are candidates or recipients of cochlear implants (Christiansen & Leigh, 2002; Zaidman-Zait & Jamieson, 2004). Today, prior to and following parents’ interactions with professionals, parents may form a preference and gain knowledge from visiting related Web sites about cochlear implants (Susan Lane, personal communication, January, 2002). However, in
spite of the apparent large and growing number of parents seeking information about cochlear implants for their deaf children through the Web, there has been no attempt to ascertain the type or quality of information available to them through this medium. In addition, it is important to know who provides the information because this provides the consumer with a sense of the expertise and agenda of the site’s authors.

To Implant or Not to Implant: Information Needs of Parents of Young Deaf Children

Following the diagnosis of a child’s hearing loss, parents have a high need for obtaining multifarious information with regard to treatment, educational, and communication options available for their children. Cochlear implantation is one common and increasingly selected habilitation option for children who are deaf. Cochlear implantation was first approved for children in the United States in 1990, and by 2002 the United States Food and Drug Administration (FDA) had lowered the minimum age for implantation to 12 months (Spencer & Marschark, 2003). Currently, deaf children younger than 12 months are receiving cochlear implants as part of clinical trials. By 2002, more than 70,000 adults and children around the world were reported to be using cochlear implants (Spencer & Marschark).

Parents of deaf children who are candidates for or recipients of cochlear implants have been found to express a high need for wide range of information. In this connection, Nunez and Ceh (2001) evaluated the informational, professional, and community resource needs of families with young children who were either candidates or users of cochlear implants. The top 10 needs voiced by parents of cochlear implant candidates and recipients related to the categories of communication, educational resources and services, family and social support, and general information. Most and Zaidman-Zait (2003) investigated the needs of Israeli parents whose children were cochlear implant recipients, with a specific focus on their need for information and the most effective way of meeting these needs. A questionnaire was designed to assess parents’ informational and service needs as they related directly to cochlear implant surgical and habilitation procedures. Parents emphasized their need to receive relevant information pertaining to medical, educational, technical, and communication concerns (e.g., how cochlear implants work, candidacy criteria, and evaluation procedures) and their need for emotional support from professionals and from other parents of implanted children. Christiansen and Leigh (2002) conducted interviews with 43 parents whose children had received cochlear implants. All of the parents sought information from many sources, including other parents of children with cochlear implants, implanted children and adults, and health professionals such as pediatricians, audiologists, and speech/language pathologists. In addition, an important source of information for parents was the Web, as well as information distributed by the cochlear implant manufacturers. The results of these studies strongly and consistently suggest that parents did not impulsively make the decision to get an implant for their child; many parents appeared to go through a great deal of information gathering and soul searching before deciding.

The process of obtaining information may be an important factor influencing both parental coping and family involvement in the child’s habilitation. Information seeking, defined by Feher-Prout (1996) as a “problem focused” coping strategy, is also part of the coping process that parents experience following the diagnosis, and in the case of parents of children with hearing loss, the information-seeking process is very challenging. The vast majority of parents of deaf children are themselves hearing, with little or no prior experience with childhood hearing loss (McKellin, 1995; Meadow & Sass-Lehrer, 1995). Parents are confronted with complex and unfamiliar medical, educational, and audiological terminology, along with widely conflicting opinions regarding medical treatment, sensory devices, mode of communication, and educational placement. Furthermore, while seeking information, parents are coping with powerful emotional reactions to their child’s diagnosis. Spencer (2001) found that parents’ styles of acquiring information about cochlear implants were associated with their children’s post-implant performance. Parents who actively searched for information and carefully considered myriad factors tended to be most satisfied with their decision, and the children’s language outcomes were better than those in
families that took a less analytic approach. The process of gathering information on which to base the decision of whether to choose a cochlear implant for their child is of paramount importance: It not only affects the decision-making process, but may also strongly influence parental coping.

Efforts to Evaluate Information Dissemination on the Web

Scholars from different disciplines, particularly those in health care, business, and library science, have been alarmed by the new medium, its offerings, and its lack of accountability and have made efforts to evaluate information dissemination on the Web. These multidisciplinary efforts have primarily, though not exclusively, focused on the categories, properties, and usability of the Web sites.

Wyman (1997) identified most evaluation methods as focusing on different properties of the Web site, including: (a) evaluating the information content and accuracy (information-based evaluation); (b) conducting user-based evaluation, by assessing how users obtain the information and how they evaluate its content and usability; (c) exploring issues such as ease of use and usability (design-based assessment); and (d) assessing the Web system itself (system-based assessment) by examining, for example, retrieval procedures, error reports, links, and applications operating from the Web site. More recently, Martland (2001), using a library science perspective, developed an objective, valid, and reliable evaluation tool for information on child development. She established categories representative of the common criteria used in the evaluation of Web sites, including content (level of documentation provided for the information presented), authority (rated on the credentials of both the sponsoring organization and the individual authors of the information presented), stability of site (presence or absence of a creation/copyright date, evidence of maintenance), and ease of use (rated on the accessibility of material on the site, ease of navigation, consistent page layout, working links and acceptable loading time).

E-commerce efforts to evaluate Web sites have resulted in the “7C framework” that examines Web site design from a customer interface perspective (Rayport & Jaworski, 2003). The seven design elements of the consumer interface include the site’s layout and design, which captures the aesthetic and functional look and feel of a Web site (context); the site content; the interaction that occurs between site users (community); the communication that unfolds between the site and its users; the extent of the formal linkages between the site and other sites (connection); a site’s ability to tailor itself to different users (customization); and a site’s capabilities to enable commercial transactions (commerce). Thus, although specific topics of Web sites will vary from one discipline to another or even within disciplines, it is evident that issues of accuracy, usability, and maintenance figure centrally in all evaluation efforts.

The Value—and Dangers—of the Web to Parents of Young Deaf Children

The Web permits parents and professionals easy access to thousands of pages of information on an as-needed basis, 24 hr per day, every day of the year. What gives the Web one of its democratic advantages at the same time creates one of its major problems: the issue of quality of information. There is a complete lack of quality control, which may contribute to low reliability and hence leads to the question of the accuracy of the information published in “the Wild West of the information age” (Smith, 1999, p. 31). However, with respect to accuracy, it should be noted that because health information on the Internet covers a broad and complex array of topics, it is unrealistic to expect an accuracy evaluation for each site. Thus, accuracy indicators are intended to assist the consumer in “finding a means to establish accuracy without actually checking the facts” (Martland, 2001, pp. 29–30) and in determining who is an authority on the topic. To complicate matters further, there are fewer clear “markers” than in traditional publishing to allow naive readers (e.g., parents) to discriminate between genuine insight and deliberate invention (Wyatt, 1997), to easily recognize a document as reliable, or even to determine whether it is intended for professionals rather than for consumers. This may prove especially problematic for parents, who are trying to distinguish fact from opinion in a highly polarized area. Parents
may also be overwhelmed by information overload, that is, having too many things to do at once on the Web site (McGrath & Hollingshead, 1994) or learning more than they want to know (Gutzman, 2001). Overload of information can be a problem in cases when a large number of ideas need to be organized and evaluated (Gallupe & Cooper, 1993), and may be the case when parents are seeking information with regard to their child’s hearing loss, which is not organized on the Web in a leading way to help them gradually absorb it. Finally, parents need to be assured that the information they are obtaining about cochlear implants is current, but in the medium of the Web, sites may still be online but not have been touched in years (Martland, 2001).

There were three purposes to the present study: (a) to determine who disseminates information on cochlear implants on the Web; (b) to describe a representative sample of Web sites that disseminate information on cochlear implants, with a focus on the content topics and their relevance to parents of deaf children; and (c) to discuss the practical issues of Web-based information and its implications for professionals working with parents of deaf children. In the current study, no attempt was made to investigate accuracy of information because, as previously stated, there is no “gold standard” document for all information concerning cochlear implantation in children, and much research concerning child outcomes is ongoing. Through this initial attempt to study Web sites that focus on cochlear implants, it is hoped that practitioners will be better able to understand and communicate the possibilities, limitations, and implications of using the Web as part of their partnership with parents.

Method

The first step was to search for information on cochlear implants on the Web in a manner that might be used by parents of deaf children and to locate a sample of Web sites that have the highest probability for parents to come across. Information retrieval on the Web is mostly conducted through the use of search engines (Pallen, 1995), which are designed to help people locate information. Keywords are entered and a list of relevant Web sites is displayed. The order in which the sites are displayed depends on a number of factors, including the search engine characteristics, popularity of the Web site, the Web site size, and the placement fee paid to the owner of the search engine.

In order to locate a representative sample of Web sites, the most popular search engines based on recent surveys were chosen: Google, Yahoo, Microsoft’s MSN, and America Online (AOL; Gwendolyn, 2002; Sherman, 2002). It is important to note that Google’s system for determining Web page popularity differs from that used by the other search engines, which is typically a straightforward count of “hits” on the site. In contrast, Google uses PageRank™, which uses links as a kind of vote to vouch for the authority of a given Web site. Hence, using Google to search for information on cochlear implants will increase the probability that the Web sites in the present sample are the ones that parents will meet when they search the Web in general or follow links from other Web sites.

Two keyword terms, “cochlear implants” alone and in conjunction with “children,” were entered. Users tend in practice to restrict their exploration to the top-ranked Web sites; they are usually not interested in accessing the entire set of relevant documents, which may sometimes number in the thousands, and usually will not explore more than the first 10 (Baeza-Yates & Ribeiro-Neto, 1999; Oard, 1997). For this reason, only the first 10 sites generated by each search engine were reviewed.

The Web is a dynamic environment that may change over time. Hence, two inquiries in the selected search engines were conducted at two different time points, first in October, 2002 (Time 1), and again in January, 2003 (Time 2). The initial search (October, 2002) resulted in 28 Web sites across the four search engines. Web sites that were inactive or contained information unrelated to cochlear implants were excluded (e.g., Cochlear Fluids Research Laboratory). The final sample at Time 1 included 24 Web sites. The same method was used in Time 2 and added 7 new Web sites to the Time 1 sample, resulting in a final combined sample of 31 Web sites.

Publishing houses and online shopping Web sites were excluded from analysis of the second research question (regarding content), leaving 26 of the final sample of 31 Web sites for analysis. Two of the Web
### Table 1  Sources of Cochlear Implant Information Dissemination on the Internet (N = 31)

<table>
<thead>
<tr>
<th>Name</th>
<th>URL</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Department of Otolaryngology/Head and Neck Surgery at Columbia University</td>
<td><a href="http://www.entcolumbia.org/cochkid.htm">http://www.entcolumbia.org/cochkid.htm</a></td>
<td>Academic department</td>
</tr>
<tr>
<td>Department of Otolaryngology, School of Medicine at Washington University</td>
<td><a href="http://wuphysicians.wustl.edu/dept.asp?pageID=24&amp;ID=8">http://wuphysicians.wustl.edu/dept.asp?pageID=24&amp;ID=8</a></td>
<td>Academic department</td>
</tr>
<tr>
<td>Department of Electrical Engineering at the University of Texas at Dallas</td>
<td><a href="http://www.utdallas.edu/~loizou/cimplants/tutorial/">http://www.utdallas.edu/~loizou/cimplants/tutorial/</a></td>
<td>Academic department</td>
</tr>
<tr>
<td>School of Medicine at New York University Cochlear Implants in Children: Ethics and Choices</td>
<td><a href="http://www.med.nyu.edu/cochlear/cochlear.html">http://www.med.nyu.edu/cochlear/cochlear.html</a></td>
<td>Academic department</td>
</tr>
<tr>
<td>Beyond Discovery</td>
<td><a href="http://www.beyonddiscovery.org/">http://www.beyonddiscovery.org/</a></td>
<td>Academic organization*</td>
</tr>
<tr>
<td>The Society for Neuroscience</td>
<td><a href="http://web.sfn.org/content/Publications/BrainBriefings/hearing.html">http://web.sfn.org/content/Publications/BrainBriefings/hearing.html</a></td>
<td>Academic organization</td>
</tr>
<tr>
<td>Nemours</td>
<td><a href="http://www.nemours.org/no/fl/nccjax/svcs/otolaryngology_cochlear.html">http://www.nemours.org/no/fl/nccjax/svcs/otolaryngology_cochlear.html</a></td>
<td>Health care provider</td>
</tr>
<tr>
<td>The Voice Center</td>
<td><a href="http://www.voice-center.com/cochlear_implants.html">http://www.voice-center.com/cochlear_implants.html</a></td>
<td>Health care provider</td>
</tr>
<tr>
<td>Atlanta Ear Clinic</td>
<td><a href="http://www.atlantaearclinic.com/cochlear_home.htm">http://www.atlantaearclinic.com/cochlear_home.htm</a></td>
<td>Health care provider</td>
</tr>
<tr>
<td>National Cochlear Implant Users Association</td>
<td><a href="http://www.nciua.demon.co.uk/kids.htm">http://www.nciua.demon.co.uk/kids.htm</a></td>
<td>Consumer organization</td>
</tr>
<tr>
<td>Cochlear Implant Association, Inc. (CIAI)</td>
<td><a href="http://www.cici.org/">http://www.cici.org/</a></td>
<td>Consumer organization</td>
</tr>
<tr>
<td>Hear This Organization</td>
<td><a href="http://www.heartthisorg.com/index.htm">http://www.heartthisorg.com/index.htm</a></td>
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</tr>
<tr>
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<tr>
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<td>Government affiliate (newsletter)</td>
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<td>ADVANCE for Audiologists</td>
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<td>Professional organisatio</td>
</tr>
<tr>
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<td>Professional organisation</td>
</tr>
<tr>
<td>Omer Zak</td>
<td><a href="http://www.zak.co.il/deaf-info/old/ci-faq.html">http://www.zak.co.il/deaf-info/old/ci-faq.html</a></td>
<td>Private web site</td>
</tr>
<tr>
<td>Ear Surgery Information Center</td>
<td><a href="http://www.earsurgery.org/cochlear.html">http://www.earsurgery.org/cochlear.html</a></td>
<td>Unclassified</td>
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<td>East Melbourne Hearing Research Group</td>
<td><a href="http://www.medoto.unimelb.edu.au/info/history2.htm">http://www.medoto.unimelb.edu.au/info/history2.htm</a></td>
<td>Other</td>
</tr>
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<td>Gallaudet University Press</td>
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<td>On-line shop</td>
</tr>
</tbody>
</table>

*Note: All web sites were retrieved in January, 2003.*

*Academic organizations are non-profit groups of scholars engaged in scientific research dedicated to different research areas.*
sites in the sample consisted primarily of PDF files. Because these files did not contain any information about who administered their dissemination, only their content was examined. A hard copy of each of the 26 Web sites was printed and the authors separately read the materials. The topic classifications were arrived at through a bottom-up procedure. First, an exhaustive list of all issues and topics noted by the authors were recorded. Next, the list was grouped into thematically similar categories that were arrived at following extensive discussion and eventual consensus between the two researchers. By means of this bottom-up analytical process, eight main topics were found to be covered in the Web sites.

Results

The final sample of Web sites was analyzed in terms of disseminators, content, properties, and usability. The implications of professionals using Web-based information in their work with parents of deaf children will be included in the Discussion.

Who Disseminates Information about Cochlear Implants on the Web?

Web sites about cochlear implants have been created by individuals, groups, and organizations. As shown in Table 1, sources included academic departments, publishers or online bookshops, government organizations, health care providers, cochlear implant manufacturers, professional organizations, and consumer advocacy groups. The majority of Web sites containing information about cochlear implants were established by academic departments (6 of the 31 sites, or 19.4%), usually medical schools, and government organizations or affiliates (4, or 12.9%). (Although publishers or online book shops accounted for 5, or 16.1%, of the Web sites, they disseminated information such as availability and purchasing of books, rather than information specifically related to cochlear implants.)

The sites were also described in terms of the online environment and type of format in which the information is provided. It was found that the sites were embedded in a variety of online environments and formats including Web sites that were completely devoted to the issue of cochlear implants, articles that were posted on the Web, pages in a general Web site, clinic centers that offered surgical services, and online book marketing related to cochlear implants. These categories demonstrate a range of types of Web sites, from Web sites designed specifically to disseminate information on cochlear implants to Web sites that contained only one page of information.

What Content Is Included in the Web Sites?

The second research question of the study was to describe the content coverage, that is, the kind of information provided to the public in the sampled Web sites. As mentioned previously, eight main categories were identified.

1. Cochlear implants and how they work. The most frequently presented topic, described to some extent by 20 of the 26 Web sites (76.9%), dealt with the question of what a cochlear implant is and how it works. There was great variance in the amount and depth of the information provided on this topic, ranging from a general description of the way a cochlear implant works to providing extensive technical details. In order to capture this variability, a 0–3 point scale was created to specify the quantity of information provided in each Web site. The scale levels are Level 0 = no information included; Level 1 = 0–30 lines included, covering very basic information (what a cochlear implant is, no explanation of how it works, usually no pictures); Level 2 = 31–85 lines, usually including figures or pictures; Level 3 = extensive information including technical details about the device and how it works, and sometimes the information is spread out in different section of the Web site. Of the 20 Web sites that disseminated information on this topic, 10 (40%) gave very basic information, 7 (35%) disseminated more detailed information, and the rest gave extensive explanations. Some Web sites gave very helpful visual information, even movies, about the working process of the cochlear implant.

2. Candidacy criteria. The second most frequently occurring topic concerned eligibility for candidacy
among children, with 15 of the 26 Web sites (57.7%) providing this information. However, the information was not consistent across Web sites, with various numbers and types of criteria mentioned in different sites. The criteria were categorized into main groups, including age, audiological characteristics, medical and surgical considerations, psychological background, oral skills, home/educational environment, and family commitment to habilitation. Within the Web sites that contained any of this information, the number of categories mentioned ranged from 1 to 5 ($M = 3.66$, $SD = 1.49$).

In addition, because age was the most frequently mentioned criterion for candidacy (noted in 11, or 42.3%, of the Web sites), it was closely examined. Within the sites that mentioned age, six (54.5%) specified 24 months of age as the criterion, whereas only three Web sites (27.3%) mentioned 12 months of age. It seems that information available on the former group of Web sites is neither current nor precise according to American FDA regulations. In 2002, the FDA recommended 12 months as the minimum age for implantation (Spencer & Marschark, 2003).

It should be mentioned that posted publications (i.e., articles) are not expected to be updated, and, thus, it is important to be mindful that the information may be irrelevant in light of more current developments or changes. In the current Web site sample, four (36.4%) of the Web sites that did not indicate 12 months as the age criterion were publication-type.

There were other important points of variability among the Web sites concerning candidacy. For example, two Web sites mentioned that candidacy is determined on a case-by-case basis. In terms of the audiological criteria, some sites emphasized that candidacy included no benefit from conventional hearing aids, but they did not specify the length of time a child was required to wear a hearing aid before that decision was made. Some centers strongly advised or required participation in an auditory verbal or oral program and refused to consider children and families using sign language. There was no mention of how candidacy was determined for children with special needs. One important piece of information that was missing from all of the sampled Web sites was that in each medical center there are unique candidacy requirements beyond the general ones published by the FDA.

3. The evaluation procedure. The third most frequently mentioned topic, included by 10 of the Web sites (38.5%), concerns the evaluation procedure. The information in this section usually described the testing included in the evaluation process, such as audiological, speech and language, medical examinations, and psychological testing. In some Web sites this information is descriptive, whereas in others the types of evaluation are merely listed. With the exception of about 4 Web sites, all of which were either manufacturing companies or surgical centers, the evaluation information provided was very brief.

4. Factors affecting outcomes following implantation. Fifteen of the Web sites (57.7%) provided information with regard to factors that affect outcomes following implantation. In order to categorize and examine these factors, the information mentioned in the different Web sites was compared to a document, namely, a chapter that was considered to be the most recent and comprehensive critical review of research on outcomes of cochlear implantation in children (Spencer & Marschark, 2003). In the chapter, Spencer and Marschark categorized factors related to or directly affecting outcomes as follows: (a) anatomical, physiological, and technological factors; (b) duration of profound deafness before implantation; (c) duration of cochlear implant use; (d) age at implantation; (e) communication approach; (f) positive family involvement and support; (g) cognitive skills; and (h) degree of hearing loss before implantation. The categories that were mentioned most frequently by the Web sites were age at implantation (11), duration of deafness before the implant (9), habilitation/communication modalities (9), and anatomical, physiological and technological factors (8). The remaining factors described by Spencer and Marschark were mentioned in two to three Web sites. On average each Web site mentioned 3.13 factors that affect child outcomes. There was little reference to documented research contained in the Web sites, and those that did provide this information tended to be academic departments and one manufacturing company.
5. The surgery. Information about the surgery was provided by only 10 of the Web sites (38.5%). The information covered a variety of topics in differing degrees of detail, such as how to prepare the child for the surgery, explanation of the surgical procedure, expectations with regard to recovery, and the surgical risks. Some Web sites made extensive use of visual aids, with one even using video animation, to explain the surgical process.

6. Habilitation: mapping and fitting. Only six of the Web sites (23.1%) provided information concerning the processes of mapping and fitting. The information on this topic included when to expect the initial fitting to occur (i.e., how long after surgery) and the potential reactions to it. Of the six Web sites providing this information about the initial fitting, six described possible reactions and four mentioned the time required. Five of the six Web sites (19.2% of the total sample) provided information about mapping, although only two (a consumer advocacy group and a professional organization) provided very detailed information on this topic. All six Web sites mentioned the long process of adjustment to sound, especially for children.

7. Habilitation: education. Only approximately one third (8, or 30.8%) of the Web sites addressed educational issues following implantation as part of the habilitation. The information that was provided tended to be very narrow in content, including only general information about the need for parents to be involved in habilitation, the professionals involved in the habilitation, the services available to cochlear implant recipients, and basic information about what the habilitation program includes. Only one Web site, that of a manufacturing company, provided broader information, including practical resources for parents. This site provided parents with teaching tips and techniques for auditory therapy at home, as well as resources for teachers and professionals working with children. Another Web site, belonging to a consumer group, provided three articles on educational issues in schools with regard to children with cochlear implants.

It is interesting to note that important issues relevant to the habilitation and education of deaf children with cochlear implants were largely neglected on the Web sites. Information with regard to different choices of communication modes for deaf children who are cochlear implant users was not mentioned, even though parents need to make this vital decision. The use of sign language for children who have cochlear implants was not raised on any Web site. In addition, information about considerations for educational placement and different approaches to habilitation was not delivered.

8. Insurance coverage. The issue of insurance coverage was mentioned by eight of the Web sites (30.8%). The accuracy of this type of information is context-dependent because medical coverage is related to the medical health services policy that exists in a particular country. Two of the Web sites pointed out that the information about reimbursement services or insurance services for cochlear implantation is applicable to the Americas region only. There was great variance in the material provided, ranging from general answers about insurance coverage to extensive information on a specific insurance program. It was not always clear which aspects of habilitation, if any, were covered by insurance beyond the surgical process, the equipment, and the hospital stay. Interestingly, the two Web sites that gave the most extensive information on the topic were a consumer advocacy group and a manufacturer with its own special service designed to assist candidates and clinical centers to obtain preauthorization of coverage for cochlear implant surgery. Only one professional organization Web site and one government Web site mentioned some potential difficulties concerning financial coverage for the surgical process. Several Web sites emphasized the variability in insurance coverage for cochlear implantation, and some manufacturers and clinic Web sites described their involvement in communicating with the insurance agencies.

Finally, we summarized the information coverage of the above eight topics in the different Web sites. Web sites received one point if a topic was mentioned (without taking into account the empanse of the information or its accuracy). Scores ranged from 0 to 8, with a score of 0 indicating that the Web site did not cover any of the topics, whereas a score of 8 indicates...
that the Web site covered all eight topics. Almost one fourth, or six, of the Web sites (23%) received 7 to 8 points. These Web sites were devoted exclusively to the issue of cochlear implants and they were created by a variety of sources, including cochlear implant manufacturing companies, academic departments, professional organizations, and consumer advocacy groups. The Web sites that received the lowest scores (0–3) were those that disseminated the most limited information on cochlear implants. These tended to be Web sites that posted only one article on the topic, Web sites that offered cochlear implant surgical services, and Web sites that disseminated information on topics in addition to cochlear implants (for example, government affiliate organizations that disseminated information on communication disorders). The Web sites receiving the lowest scores were created by a variety of sources, with the most frequently occurring ones being academic departments and health care providers.

Properties and Usability of Web Sites.

Several properties affect the extent to which a Web site is reliable, current, and easy to use. Foremost among these factors are the stability of a Web site, service/design features and ease of use.

1. Stability of Web sites. Stability is an important criterion in establishing information quality. A site should be well maintained for it to be in high quality, and the facts about when the Web site was created and material initially posted, as well as when the site was most recently updated, should be clearly evident. In order to assess the stability of the sampled Web sites, Martland’s (2001) subscale, which had previously been found to be a valid and reliable instrument, was used. This subscale is part of the evaluation tool that Martland developed to assess Web information dissemination in the area of child development. The stability scale is context-free and, hence, it was found suitable for the evaluation of Web site stability in any context. The scale scores range from 0 to 6 points, and the scale examines whether a copyright date or “last updated” indication was given on the Web site, whether the site had been updated recently, and whether the date of posting was provided for most pages.

Eighteen Web sites were rated according to the stability scale. Web sites that disseminated an article were not evaluated by the scale; instead, the range of dates of these articles will be provided for the current analysis. The scores on the stability scale for the sampled sites ranged from 2–6 (M = 4.22, SD = 1.52). Nine of the 18 Web sites (50%) received a score of either 5 or 6, indicating high maintenance level, and 7 Web sites (38.9%) obtained a score of either 2 or 3, demonstrating a low quality of maintenance. The eight publications in the sample included a wide range of dates, from an article written in 1994 to one written in 2001, and they were spread equally between this range of years.

2. Service/design features. In this part of the analysis, Web sites that have only one publication posted (i.e., articles), as well as the online shops (e.g., online bookstores), were excluded, leaving 18 Web sites for analysis, because one-page postings did not provide sufficient design features for analysis. Evaluation of the Web-based design services was based in part on Rayport & Jaworski’s (2003) E-commerce framework, also known as the 7Cs customer interface design. The 7Cs framework was selected to examine the implementation of sites from a customer interface perspective. In the current study we used only four of the 7Cs; the remaining three Cs were not used because they pertain to marketing concerns. The 4Cs that were selected were (a) content, (b) community, (c) communication, and (d) connection. This descriptive analysis was aimed to shed light on the services offered by Web sites that disseminate information on cochlear implants. The first of the four Cs—content—has been previously described.

Only two Web sites, both manufacturing companies, have interactive community features. Each of these Web sites provides the opportunity for user-to-user communication through a discussion forum. However, in order to participate in the discussion, one of the Web sites required user registration. Another way that this manufacturer promoted community features was by providing opportunities for potential consumers to contact cochlear implant users or parents of deaf children with cochlear implants, again with the requirement for user registration. These
online communities provided the opportunity to receive advice from other members of the community, thereby potentially impacting a user’s decision making, and to establish relationships through personal contact with other recipients. These types of communities share a special interest and may function as a support group. The degree of member participation is decided by each individual user; users can be active or passive, or any degree in between, in the virtual community.

Another kind of community feature includes non-interactive communication, which does not involve the direct and continual exchange of responses between users. Sites can present static information and allow unidirectional communication with users. Four of the 18 Web sites (15.3%), all manufacturing companies or developers of cochlear implants, made use of non-interactive communication. One example of non-interactive communication is stories posted by cochlear implant recipients or their parents in order to share their experiences with others (e.g., “Read stories from all over the world, and share your own,” “View the stories of children, from the parents’ perspective,” “View stories about the teen experience with cochlear implants”). Only one Web site provided the opportunity for users to submit a story online. Other services provided that promote a sense of community were the opportunities to become a member (2 Web sites), posting of event information on the Web sites (6 Web sites), and posting of information about support groups for users or their families (3 Web sites).

Communication, which refers to the dialogue that unfolds between the site and its users, was also examined. The majority of the 18 Web sites included contact information (16, or 89.0%), although 8 of these encouraged users to contact them via a specified contact person or by e-mail (e.g., “Ask the cochlear implant team a question.”). With regard to user-to-site communication, 4 Web sites provided an opportunity for users to give their feedback. Five Web sites had an option to request additional printed information.

Another important feature of communication is the issue of language. It is important to note that three manufacturing companies provided some or all of their information not only in English, but also in other languages. At the time of writing, one manufacturing Web site was available in two languages, another was available in eight languages, and a third manufacturing company translated some of the articles posted on its Web site into languages other than English. In addition, one consumer group translated its fact sheet into Spanish. The most common additional language used across Web sites was Spanish.

The final “C” design feature that was examined was connection, that is, the extent of the formal linkages between the site and other sites. One major concern of Web site developers is how easily Web users can find their site. Many users locate material by following links from other sites or by using a Web search engine. Of the total sample of 18 Web sites, 14 (77.8%) provided links to other sites, and all of these had at least one link to a manufacturing company. The number of links offered ranged from 0 to 83 ($M = 11.77, SD = 19.86$).

3. Ease of use. The Web sites’ ease of use was determined by adopting the ease of use portion of Martland’s (2001) evaluation tool, which evaluates the accessibility of material on the site, ease of navigation, and whether language is user-friendly, easily read, and understood by a lay audience. Each property was assessed by means of a three-point sub-scale that determined the extent to which it was evident in the individual Web sites. The same 18 Web sites for which services/design features were evaluated were included in the analysis. The evaluations were completed by the second author at an early point in the investigation when the sites were still unfamiliar to her. The ratings were discussed with the first author and the minimal disagreements noted were resolved by discussion and consensus. Variability was noted in the ease of use across the Web sites, particularly in terms of accessibility of information, ease of navigation around the site and layout consistency. Six sites, representing two manufacturing companies, two consumer/professional organizations, one government agency, and a health care program, achieved the highest possible rating. These sites shared certain noteworthy characteristics, including extensive coverage of well-organized information and the use of clear and jargon-free language. Among the remaining Web sites, there was too much variation to describe their weaknesses in a unified way.
Discussion

The purpose of this study was to conduct a preliminary investigation of disseminators and content of the most frequently accessed Web sites pertaining to cochlear implants, and to discuss the practical issues of Web-based information and its implications for professionals working with parents of deaf children. Most of the Web sites that disseminated cochlear implant information represented medically oriented academic departments and government organizations, although a wide variety of other sources, such as manufacturing companies and consumer groups, also had Web sites containing information about cochlear implants. The Web sites’ content tended to fall into eight categories, namely cochlear implants and how they work, candidacy criteria, the evaluation procedure, factors affecting outcomes following implantation, the surgery, habilitation (mapping and fitting), habilitation (education), and insurance coverage. Previous research has revealed that the vast majority of topics disseminated in the sampled Web sites have been evaluated as highly important by parents of deaf children with cochlear implants (Most & Zaidman-Zait, 2003; Nunez & Ceh, 2001). The findings from these studies underscore parents’ need for extremely diverse information regarding cochlear implantation, all of which parents considered important, during the period extending from the decision-making interval until the surgery and throughout habilitation. This need for multifarious information is consistent with findings from previous research that assessed the needs of parents of children who are deaf in general (Bernstein & Barta, 1988; Dromi & Ingbar, 1999; Harrison, Dannhardt, & Rousch, 1996). The results of the present study show that most of the wide variety of information typically requested by parents is disseminated on Web sites, particularly information explaining what a cochlear implant is and how it works. Most of the other topics that are of interest to parents are covered, but less extensively. It is worth noting that across the Web sites there were virtually no comments critical of cochlear implants, and cautionary comments tended to refer variation in outcomes and surgical risks.

However, perhaps equally important as what was covered in the Web sites is what information was not included. Information relating to education, key aspects of habilitation, and choice of communication approaches—all vitally important topics to parents of deaf children—were either barely addressed or neglected altogether. These topics are very relevant to parents in light of the existing debates related to habilitation approaches involving different communication modalities, especially the use of sign language, with deaf children who are cochlear implant recipients. This information is particularly vital because parents often make decisions concerning their child’s educational placement and mode of communication concurrent with the decision for cochlear implantation. In fact, the issue of education has previously been reported as one of the greatest concerns to many parents of deaf children with cochlear implants (Christiansen & Leigh, 2002).

Both researchers and professionals involved with deaf children and their families, particularly those concerned with early intervention, should be aware of the increased use of the Web for obtaining health-related information (Dryburgh, 2001; Pew Internet and American Life Project, 2002; Statistics Canada, 2002), that parents are accessing the new medium of the Web for cochlear implant information (Christiansen & Leigh, 2002; Zaidman-Zait & Jamieson, 2004), and that a great deal of information is available there for parents. However, little attempt was made among the sampled Web sites to direct parents to the public domain of published research. Willinsky (2000) discussed the need to push beyond the current standard of conducting research for the sake of research, and promoted the notion that research knowledge should play a role in democratic education and action. Consistent with this, Pereira and Bruera (1998) suggested that an acceleration of electronic publishing would help in the dissemination of easily accessed, balanced, peer-reviewed data. It is important to increase parents’ accessibility to this type of information to help them make evidence-based decisions about cochlear implant choices, and one way of doing that is through the dissemination of research findings on the Web.

The Web has created a transformation in power of knowledge, in that the locus of information control has shifted from the expert to the consumer (Gerber &
Eiser, 2001; Smith, 1999). Rather than dispensing information to parents, it seems highly likely that professionals increasingly will be confronted with parents coming to early intervention programs with established beliefs and expectations, according to the information gathering they undertook on the Web. Professionals in early intervention, who have often been the “gatekeepers” of information in their dealings with parents of deaf children, need to understand and enhance their knowledge about the advantages, as well as the limitations, of obtaining information from the Web. Parent needs now include support and guidance in the process of information gathering on the Web and help in organizing the information into a useful form that can be applied in the decision-making process concerning their deaf child.

The current findings emphasize the fact that the Web is an open environment without peer review (Pereira & Bruera, 1998). It is essential, thus, that professionals carefully screen Web sites to determine which are potentially most helpful and, alternatively, most dangerous, to the parents with whom they work. Professionals may even develop Web sites as part of their service delivery for parents, and they may also refer parents to those Web sites they deem most clearly presented, accurate, and informative, taking into consideration problems in the dissemination of information on the Web, missing information on existing Web sites, and the need to represent different perspectives in the education of deaf children. For example, the Laurent Clerc Center of Gallaudet University has recently established an excellent Web site designed to help parents “navigate the forest” of cochlear implant information—and handle the overload of information—available on the Web (Nussbaum, 2003). (This site was initiated after the current analysis was completed, and so it was not included in the study.) Overall, then, professionals have a responsibility to guide parents in how to use the Web efficiently, promote parents’ awareness of its disadvantages, discuss the information parents found on the Web, and refer parents to high-quality Web sites. Professionals may also opt to use Web resources for parent education and possibly even create Web sites to provide information, to inform families and to communicate with parents.

Online communities may provide the opportunity for site users to interact with each other, enabling parents to communicate with other parents of deaf children who have received cochlear implants and deaf adults who have experienced implantation, and also to tell their own stories and potentially be a valuable source of support to other parents. In addition, another possible support can be established through communication that unfolds between the site and its users. For example, the “ask the expert” option allows parents to communicate with professionals and pose questions about cochlear implants.

Previous research has indicated that parents experience stress during the cochlear implantation process from decision making through habilitation (Beadle, Shores, & Wood, 2000; Perold, 2000; Quittner, Steck, & Rouiller, 1991) and that parents have a need to receive social support by meeting with other parents of children who use cochlear implants (Most & Zaidman-Zait, 2003). Consistent with this, Nunez and Ceh (2001) reported that 77% of the parents of children with cochlear implants in their study wanted information about parent support groups. Although this parent support function exists elsewhere on the Internet in the form of “chat rooms” among parents of deaf children, its importance to parents seeking information on the Web should not be underestimated. Given that there is existing evidence that parents seek and use online support (Christiansen & Leigh, 2002; Zaidman-Zait & Jamieson, 2004) and turn to the Web in increasing numbers for health-related information, the community-building function that some sites provide may be perceived as vitally important by some families, especially those living in rural areas, where contact with other families with deaf children may be minimal or nonexistent.

The need to meet with other parents has been described in the literature as an “emotion-focused” coping strategy (Feher-Prout, 1996), and corresponds with the literature suggesting that peer support leads to a feeling of well-being among parents of children with special needs (Dromi & Ingbär, 1999; Dunst & Trivette, 1990; Shonkoff, Hauser-Cram, Kraus, & Upshur, 1992). The encounter with other parents from similar backgrounds who face comparable problems provides support, alleviates feelings of isolation, and
offers models and strategies for coping (Christiansen & Leigh, 2002; Cooper & Allred, 1992). It is important that Web sites that provide information on cochlear implants be aware that that the information-seeking behavior of parents occurs in the context of a stressful situation. This behavior serves a dual purpose: On the one hand, the information that parents obtain helps them make their decision, and on the other it serves to lessen their distress (Feher-Prout). It seems reasonable to assume, then, that cochlear implant Web sites whose main target audience is parents of deaf children would increase their online support design features by building online communities for parents. However, the Web sites that provided opportunities for the most online support among parents were manufacturing companies that required parents to register and supply extensive personal information in order to participate. One practical recommendation stemming from the current study is that a Web site be developed to help parents build an online community and to promote communication among parents, professionals, and researchers that is separate from commercial agendas.

It is clear from the present investigation that one increasingly used tool available to parents in their rigorous search for information about cochlear implants is the Web, and professionals, Web site developers, and researchers would do well to recognize the power—and the danger—inherent in the new technology. The findings from the current investigation suggest several avenues for both future research and Web site development. The involvement of parents in user-based evaluations of Web sites would shed light on the effectiveness of online parent support. In turn, the findings from this avenue of research would inform Web site developers how they might enhance the usability of Web sites to better meet the needs of parents as they make critical decisions concerning their deaf children.

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References


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