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Responding to Health Information and Training Needs of Individuals with Disabilities

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Abstract

The role of a medical librarian includes guiding consumers to search for information related to specific health needs and interpret information for personal use. Little is known about barriers to accessing health information and clinical services for those with cognitive and physical disabilities. The purpose of this paper is to describe a statewide needs assessment of the health information and services needs of individuals with disabilities and their caregivers.

Data from the needs assessment conducted by the Health Services Training Project of more than 1,000 respondents indicate unmet needs for outreach to increase effective use of library and information resources. Fewer consumers and their caregivers utilized the Internet to search for health information as compared to clinical service providers and students in health professions. A majority of consumers reported difficulty obtaining and understanding online health information. Service providers and students shared concerns about information quality. Consumers and caregivers expressed highest levels of trust in information provided by service providers, nonprofit health agencies, reference books, and libraries.

Keywords

Caregivers; cognitive disabilities; health care providers; online health information; physical disabilities; surveys

INTRODUCTION

According to the Agency for Healthcare Research and Quality, health disparities disproportionately affect minority groups, people with disabilities, those with limited income and education, and rural residents.¹ It is more difficult to identify and access sources of valid and reliable health information and interpret information for personal health enhancement among individuals with cognitive disabilities and their caregivers. The roles of medical librarians, which include providing consumer health information and aiding with its comprehension, may be especially relevant to this group of current and potential users. The purpose of this paper is to describe a statewide needs assessment of the health information and services needs of individuals with disabilities and their caregivers.

Appleyard of the Oregon Institute on Disability and Development concluded that “individuals with cognitive disabilities have difficulty using the Internet even after they have gained physical access.”² This was interpreted by the authors to mean errors made while accessing the Internet by individuals with cognitive disabilities – i.e., access does not translate to usability and understanding. It is important to increase Internet access to and usability of informational resources, for shared socialization and peer support. In response to this need, the Alabama Council for Developmental Disabilities and the National Network of Libraries of Medicine (NNLM) funded a needs assessment within the state of Alabama.

The purposes of the Health Services Training Project are to build a database of health information and service needs among those with disabilities and to improve clinical service access through educational outreach activities. These purposes are consistent with the NNLM Strategic Plan for Addressing Health Disparities 2004-2008, which includes emphasis area 3.1, *Promote use of health information by health professionals and the public*. Fulfilling objective 3.1.1 will “improve delivery of health information, through the development of easy-to-use information resources such as MedlinePlus that are sensitive to cultural diversity issues, educational level, and language.”³ Achieving objective 3.1.18 will “expand partnerships among various types of libraries and community-based organizations with the goal of forming community coalitions to improve access to health information for members of minority and underserved populations as well as health professionals serving these populations.”³ The content of this article includes a brief summary of research methodology, selected results, and discussion of implications for medical librarians.

METHODOLOGY

A collaborative team formed two working groups to guide a statewide needs assessment. Members included university researchers, medical librarians, clinical service providers and consumers. Surveys were developed for four audiences: individuals with disabilities (identified as “consumers” in the context of this article), family members and others who provide care to persons with disabilities, service providers, and health profession students (future service providers). It was important to the authors to include those who provide care, health services, and education for individuals with disabilities. Respondents self-identified as disabled, permitting participation from a broad range of Alabamians. Online and written surveys were developed for each audience, including those whose first language is Spanish. (Data from the 2000 Census indicated approximately 4% of Alabamians speak a language other than English at home.⁴)

Several items were selected from the Health Information National Trends Survey (HINTS 2007)^{5, 6} and modified with permission. Survey items included demographics, access to and use of information technology, use of general and specialized health care, service providers’ awareness of needs of individuals with disabilities, and training needs and modalities.

Working groups reviewed survey content and format and guided revisions. The surveys for consumers and family caregivers were also translated into Spanish.

Researchers identified key agency contacts (including the Alabama Public Library System), visited individuals, attended professional meetings, and disseminated printed surveys statewide. In addition, contacts received links to online surveys to post on agency Web sites. Finally, working group members and graduate student volunteers administered consumer surveys in-person and by telephone. Including caregivers as respondents permitted consideration of health information and service needs of very young consumers and those with severe communication disorders. A news release was included in print and online editions of an urban newspaper with the largest daily circulation in the state, resulting in additional requests from the public.

ANALYSIS AND RESULTS

Over 1,000 usable surveys were completed. After eliminating surveys with fewer than 10 items completed, responses from 251 caregivers, 110 service providers, 570 students, and 87 individuals with disabilities were included in data analyses. Analysis of data from the needs assessment consisted of descriptive statistics (frequencies and percentages) to identify most common practices and perceptions.

Most caregivers (85%) are parents, college completers (59%), and are employed full- or part-time (59%). One-third of service providers practice family medicine and 32% are nurses or therapists (OT, PT, SLP). Of students, 26% are enrolled in medical school, 31% attend dental school, and 21% attend nursing school. Sixty percent of consumers are employed full- or part-time, and approximately one-fourth earned a college degree. Primary disabilities reported by consumers included cerebral palsy (38% of respondents) and visual impairments (10%). Caregivers reported primary disabilities for individuals as autism spectrum disorders (44%) and Down Syndrome (15%).

Nearly all caregivers (96%), service providers (98%), and students in health professions (94%) have looked for information about health or medical topics from any source. Fewer consumers (58%) have done so. There were apparent differences between groups (based on descriptive data) when asked, "The most recent time you looked for information about health or medical topics, where did you go, FIRST?" The Internet was most often identified by all groups – 75% of caregivers, 66% of service providers, 59% of students, and 57% of consumers. Twenty percent of consumers and 14% of caregivers relied on a "doctor or health care provider" as a first source of health information. Twenty percent of students in health professions and 7% of providers chose a medical library or a reference text.

Respondents were asked to indicate level of agreement with four statements about the most recent search for information about health or medical topics, as shown in Figure 1. In general, consumers and caregivers indicated greater agreement with these statements as compared to students and service providers. For instance, 65% of consumers and 64% of caregivers *strongly or somewhat agreed* that "it took a lot of effort to get the information you needed." Similar percentages felt frustrated during the search for health information. Between 47% and 67% of all respondents, including clinicians and students in health professions, expressed concern about the quality of health information.

Students and service providers expressed high levels of confidence in obtaining health-related advice or information when needed compared with consumers and their caregivers, as shown in Figure 2. Only 44% of caregivers felt *completely or very confident*, as compared to 72% of students and 75% of service providers who felt similarly.

When asked, “How much do you trust the accuracy of information about health or medical topics from each source,” health professions students and service providers indicated most and least trusted sources, as illustrated in Figure 3. Both groups indicated the lowest level of trust in information provided by pharmaceutical companies or Web sites and the highest level of trust for information provided by a medical library or reference text, professional colleagues, and government health agencies, for example, the Centers for Disease Control (CDC) and state departments of public health.

Consumers and their caregivers’ perceptions of trust in health information sources differed. Percentage differences were greatest between consumers and caregivers for four information sources: Internet, brochures or pamphlets; books or libraries; nonprofit organizations; and magazines or newspapers, as illustrated in Figure 4. Consumers and caregivers were most similar in their trust of three sources — doctor or health care provider, radio or television, and telephone information or referral service.

Several items asked respondents about using the Internet for health-related services and information. Few providers (9%) and students in health professions (22%) completed continuing education online. Furthermore, 13% of service providers and 11% of students visited Health InfoNet of Alabama (National Library of Medicine MedlinePlus Go Local partner) or MedlinePlus. Very few consumers (6%) or caregivers (5%) utilized Health InfoNet or MedlinePlus. Overall, few consumers and caregivers in this sample reported using the Internet related to personal health. Twenty-three percent of consumers participated in an online support group for people with a similar health or medical issue.

DISCUSSION

The Health Services Training Project study supports the overall need for librarians to encourage use of reliable health information sources while teaching consumers and their caregivers to critically evaluate the resources obtained on their own. This guidance is shown to be especially needed by individuals with disabilities and their family caregivers.

Diaz and colleagues administered surveys to 330 adult patients awaiting health care in four outpatient practices in Rhode Island.⁷ Three-fourths reported at least one chronic health condition. Content of survey items included preferences for acquiring health information and deciding about treatment outcomes, frequency of using the Internet for health information, and ability to find information. One-half of the participants used the Internet to obtain health information or advice. Of these, 62.1% “agreed that their doctors should recommend specific web sites where they can learn more about their health or health care.”⁷ Furthermore, only 4.7% reported that their doctor asked them about their use of the Internet for health information or recommended that they retrieve this information using reliable Web sites (3.0%). This may illustrate an opportunity for medical librarians to assist with pre-service and in-service medical education.

Data from the Alabama Health Services Training Project indicated frustration during their online searches among 50% of the consumer and caregiver participants who do access online health information. Moreover, respondents were concerned about the quality of the results. This was despite reported confidence in obtaining needed health information among caregivers. This percentage is greater than the 31% of e-patients with disabilities and chronic conditions replying to the 2007 Pew Internet & American Life Project survey, who reported feeling frustrated by a lack of information or inability to find what they were looking for online.⁸ Adult respondents to the Pew national telephone survey identified whether they had a chronic condition that prevents full participation in work, school, or other activities; however, specific disabilities were not revealed. Respondents to the Health

Services Training Project needs assessment included individuals with cognitive disabilities, which may have explained the higher percentage in this assessment.

A preponderance of health information is available online, including eligibility and service information for federal, state, and local agencies. Users with cognitive disabilities and their caregivers may require additional assistance from medical librarians and advocates to make optimal use of available information for enhanced health. This position is consistent with Recommendation 2.1 of the NLM Long Range Plan for 2006-2016, which states, “advance new outreach programs by NLM and NN/LM for underserved populations at home and abroad; work to reduce health disparities experienced by minority populations; share and actively promote lessons learned.”⁹

In a related study, the 2005 American Customer Satisfaction Index (ACSI) Survey included questions asked of 901 users of NLM's MedlinePlus. When asked the purpose of the visit to the Web site, 30% indicated it was to find information on a specific disease, condition, diagnosis, or treatment. Eighteen percent were seeking specific information about a drug or medication.¹⁰ Medical librarians may assist individuals with disabilities and their caregivers to fully utilize the quality-filtered resources available through this site.

CONCLUSION

A specific challenge for all users is discerning factual and reliable information from biased information. Medical librarians may guide consumers to begin with a credible online source of medical and health information, such as MedlinePlus. An online tour available at <<http://www.nlm.nih.gov/medlineplus/tour/tour.html>> enables consumers to understand contents and navigation of MedlinePlus. The Health Services Training Project will use the results of the needs assessment to build on the promise of this excellent tool by developing brief training modules for consumers, caregivers, and service providers to include finding valid health information online, avoiding health fraud, preparing for a doctor visit and self-care between visits. The modules feature representatives of the four target audiences from the needs assessment (i.e., consumers, family and other caregivers, and current and future service providers). In particular, the module on using the Internet to find health information includes tips to evaluate quality, using plain language and sample Web sites. A key element in this module will include referrals to the librarian as a helpful navigator for those most in need of guidance in locating and evaluating health information to supplement that of their care providers.

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FIGURE 1.
Level of Agreement with Statements about Information Searches

FIGURE 2.
Level of Confidence in Obtaining Health Care Information

FIGURE 3.
Level of Trust in Accuracy of Information Sources: Students and Providers

FIGURE 4.
Level of Trust in Accuracy of Information Sources: Caregivers and Consumers