Developing Internet-Based Occupational Therapy Services

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The purpose of this paper is twofold: (a) to provide a guideline for occupational therapists to follow in the development of Internet-based services, and (b) to illustrate how this guideline has been applied in the development of an Internet-based service for family caregivers of individuals with Alzheimer’s disease and related dementias (ADRD). With increasing Internet use to access health information (Statistics Canada, 2002; U.S. Census Bureau, 2001), the Internet has become a means for health care professionals to supplement information and support clients. Occupational therapists who want to develop Internet-based services require additional knowledge that is typically not acquired in their professional education. The problems, standards, and ethical issues concerned with health care delivery via the Internet are only beginning to be addressed. This paper attempts to contribute to these domains.

Internet-Based Services and Occupational Therapy

The Internet serves as a new and popular means of communication for clients, family caregivers, and occupational therapists. Internet-based communication can be unidirectional or multidirectional. One-way communication provides health information as sets of pages or documents with functions that support searching and following links. When the services are designed for two-way (or multiway) communication, they are interactive and open a stream of communication across various groups. In addition, Internet-based communication can be between clients, between clients and professionals, or between clients and the Webmaster. The means (the way information is exchanged) include contact lists, chat rooms, message boards, and e-mail. Users can access Internet-based services for free or for a fee. Internet-based services may be informative, interactive, or expressionistic in style or may be for the purpose of retail (Henderson & Chiu, 2003).

When exchanging health information with or about clients on the Internet, occupational therapists must be cognizant of relevant laws and guidelines that are developed in response to patient rights. Health information regulations are designed to address confidentiality, privacy, and security of information. In some jurisdictions, some regulations already exist; in others, regulations are under development or revision. Therefore, Internet-based occupational therapy services must deliberately and vigilantly research and observe health information regulations (College of Occupational Therapists of Ontario, 2001; Office of Health and the Information Highway, 2003).

Internet-Based Service Development Model

An Internet-Based Service Development Model (IBSD Model) has been developed and used at COTA Health, Toronto, Ontario, Canada. COTA is a not-for-profit, accredited community health and social services organization that is a leader in providing comprehensive rehabilitation, mental health and support services to...
people of all ages. Established in 1973, COTA delivers quality services through its dedicated team of approximately 70 community service providers and 330 health regulated professionals, including 140 full-time equivalent occupational therapists.

The IBSD Model was first applied at COTA in a project to support family caregivers of people with ADRD (ADRD Project). Family caregivers often experience high levels of stress, leading to depression, physical symptoms, and psychosocial problems (Gräsel, 1995). Despite the fact that caregiver support services are effective in lessening caregiver burden and depression and improving caregiving ability and knowledge (Sörensen, Pinquart, & Duberstein, 2002), researchers consistently find that caregivers underutilize such services. Time constraints, competing commitments, lack of respite care, health issues, and transportation are the common reasons identified (Galinsky, Schopler, & Acorn, 1997). Recent studies have shown that caregivers are interested in using computers to access informational support (Colantonio, Cohen, & Pon, 2001; Colantonio, Kostisky, Cohen, & Vernich, 2001). To fill the service gap in caregiver support services, we applied the IBSD Model to develop Internet-based services for family caregivers of individuals with ADRD.

A Comprehensive Approach

There are seven development activities in the IBSD Model to assist with service design. Each activity is distinct, but they are not necessarily sequential. In the case of the ADRD Project many activities overlapped or took place simultaneously. The design was modified after each activity, such that design modifications made in an earlier activity were further refined in the subsequent activity. This iterative process is typical for the design and testing of information communication technology (ICT) applications. The seven activities were established when we developed the project plan of the ADRD Project. We selected these seven activities to ensure a comprehensive approach of Internet-based service development. The comprehensive approach integrated program development methods, ICT application design principles, and applied research methodologies.

1. Conduct a Web Site Survey

The first activity is a Web site survey, which systematically searches existing Web information through search engines and literature to identify potential sites that provide useful information and service. The content, purpose, host agency, target users, and types of interaction (static or interactive) are reviewed. This survey helps the designer to understand what Internet-based services exist in the topic area. It also identifies the range and scope of available services and whether a gap in service quality, location, or accessibility exists. This step ensures that a service has a potential market and prevents a duplication of services. Details of the review process are described elsewhere (Henderson & Chiu, 2003).

In the ADRD Project, the search results of 55 Web sites identified a gap in Internet-based services for caregivers of individuals with ADRD. Six sites targeted caregivers of individuals with any health needs, and five sites focused on ADRD (not just caregivers). Only one site provided specific service to caregivers of people with ADRD. Many sites were the official Web sites of organizations such as the Alzheimer Society. Typical site content included disease-specific or caregiving information, descriptions of programs and services, and links to other sites. Some Web sites posted disease-specific or caregiving information in the form of previously published articles, book chapters or pamphlets. Links to other caregivers through chat rooms and message boards were featured on four sites, and professional contacts through “Ask the Expert” were found on four sites. None of the 11 sites provided personalized support services offered by regulated health professionals to family caregivers of individuals with ADRD (Henderson & Chiu, 2003). Results promoted a need for an online therapy service that would allow caregivers to ask individualized questions to an occupational therapist and obtain answers similar to the consultation they would receive in face-to-face services.

2. Develop User Profile and Needs

Internet users are the group of individuals who access Internet information. A user profile describes demographic information, clinical characteristics, experience with Internet use, as well as perceived Internet service needs. A special type of user profile, “persona,” is a design tool used by ICT professionals. It is a description of fictitious persons that have the characteristics and specific goals of different types of users (Cooper & Reimann, 2003; Rosson & Carroll, 2002). Thus an important activity of Internet service program development is to create a detailed user profile.

A user profile can be identified from the literature, interviews, focus groups, and/or clinical experience. Internet-based service, due to its open-referral process, addresses the needs of different users who have diverse backgrounds. For this reason, it is important to determine what goals each type of user has, whether or not current Internet-based services meet his or her needs, and hence, what features to include or exclude. User profiles or personas help designers to determine what product should do and how it should behave. They help with communication, building consensus, and measurement of effectiveness (Cooper & Reimann, 2003; Rosson & Carroll, 2002).
In the ADRD Project, we identified from the literature that Canadian family caregivers were mainly women 45 to 65 years of age, with the majority married with children and having work commitments outside the home (Cransick, 1997). We then held a small focus group of representative caregivers who also encompassed a range of Internet skill (beginner to advanced) and frequency of use (weekly to daily use). The focus group interview was tape-recorded, transcribed, and thematically analyzed. The caregivers expressed much interest in online support services. Specifically they underlined the importance of being able to ask health care professionals questions online and receive answers that were individually tailored to their needs.

3. Follow Regulations and Legislations

Many jurisdictions establish professional organizations that regulate professional practices. This is to protect the public interest by setting standards for skills, knowledge, and behavior for the organization's members. Professional standards may be written as guidelines, codes of ethics, standards of practice, or competencies of practice. For this reason, the third activity of Internet-based service development requires identification and incorporation of these requirements in the Web site design.

In Canada, federal and provincial legislation protects personal health information that involves the following: (a) privacy: the right of individuals to determine when, how, and to what extent they share information about themselves with others; (b) confidentiality: the obligations of one person to preserve the secrecy of another's personal information; and (c) security: the procedures and systems used to restrict access and maintain the integrity of information (Office of Health and the Information Highway, 2004).

Abiding by regulatory and legislative requirements is imperative to consider at the outset of service development in order to prevent spending time on a design that does not meet the fundamental legal and ethical requirements. As this aspect of the field is changing rapidly, keeping abreast of the changes in regulations of eHealth or telehealth practice is crucial.

In the ADRD project, we reviewed the telepractice pamphlets from the regional professional associations, the Federal Privacy Act and Personal Information Protection and Electronic Documents Act, and the proposed Provincial Personal Health Information Act (College of Occupational Therapists of Ontario, 2001; Office of Health and the Information Highway, 2004). Features such as encryption, firewalls, passwords, and backup procedures were incorporated into our design to ensure confidentiality, privacy, and security as required.

4. Define the Purpose of the Service

As a fourth activity of program development, a purpose statement must be developed for the Internet-based service that describes end users and service goals. All previously collected information provides essential information to specify the purpose. The purpose statement sets the scope of the service program and defines the outcome measurements for formative evaluation.

In the ADRD Project, the Web survey, user profile, and regulations directed us toward limiting services to only family caregivers residing in the province of Ontario. We defined the service goal by identifying the strengths of our organization. The purpose statement of the ADRD Project was refined after this step as: “Ontario family caregivers will be better able to meet the demands and responsibilities of the caregiver role.”

5. Develop a Program Logic Model

A Program Logic Model is a diagrammatical description of service delivery processes and the logical outcomes of a program. In the one-page diagram, each service delivery process (written in a box) is linked by a vertical arrow (drawn below the box) to an outcome statement (written in another box). The model maps out the causal relationship linking output (what services are provided), outcomes (what changes followed), and the long-term goal all on one page (Rush & Ogborne, 1991). The development of a Program Logic Model is an activity that requires the designer to critically appraise what activities are essential to impacting an outcome. The conceptual analysis of the causal relationship between service delivery and client impact can validate assumptions about what must be included in a service in order to have impact on the desired goals.

In the ADRD Project, the service processes and outcomes became more clearly conceptualized after the team debated how the program logic model of the ADRD program should appear. For example, we mapped out the processes of interactive online therapy and identified four key processes (intake, assessment and goal setting, intervention, and evaluation). We conceptualized what changes the caregivers would experience as a result of each process. We expected that caregivers would understand the service and identify their service goals and consequently show improved coping, caregiving ability and knowledge, and have more information and resources.

6. Identify Web Site Design Requirements

Requirement specification has been identified as the sixth activity of program development. To build useful and easy
to use Web applications, occupational therapists need to specify the requirements of the Web application design such as the appearance, accessibility, and information organizational structure. Occupational therapists should convey the user profile, regulatory requirements, and feedback from interviews to the ICT professionals. Because clients who need occupational therapy often have more barriers than the general public, the designer must include specifications that address accessibility and usability (Brinck, Gergle, & Wood, 2002; Rosson & Carroll, 2002).

Adequate support from and communication with ICT professionals are essential. Some ICT professionals have training and backgrounds in user-centered design and Internet accessibility. However, some ICT professionals may not have these backgrounds. Thus, occupational therapists are obliged to identify and explain accessibility and usability requirements to the ICT professionals who help to develop the applications. Existing guidelines in eHealth practice can be used to assist with the explanation of requirements.

Besides considering our user profiles and focus group feedback in the ADRD Project, we established guidelines for the Web application design that enhance accessibility. We used the accessibility guidelines set by the World Wide Web Consortium to specify requirements (World Wide Web Consortium, 1999). For example, we specified that a text equivalent for each nontext element (such as pictures and icons) must be provided, and that color choices must have adequate contrast when viewed in black and white.

We made our Web site more senior friendly by following the recommendations published by the National Institute on Aging that specify writing style, font size, font style, presentation, and use of graphics (National Institute on Aging, 2001). Many of these were found to correspond with recommendations from our caregiver focus group such as: “should have few graphics,” “should be crisp, clean, and professional-looking,” and “should be easy to navigate.” These are all consistent with general usability principles that incorporate ease-of-use and straightforward layout (simplicity, consistency, focus) and style for Web site design (content written in first person, text divided into small chunks, reading level maintained at grades six to eight) (Brinck et al., 2002).

7. Write Quality Content

The final activity of program development requires Web site content to be professionally written and be easily understood. It is also vital to ensure the accuracy of information because users will use it to understand their health, functional conditions, and steps they can take to improve their situation. Incorrect interpretation of content may result in adverse effects. Disclaimers that advise readers to seek professional help and notations that the information provided cannot replace professional services must be included. Quality and accuracy of the information can be enhanced by a peer-review process, and quality standards can be met by following established quality guidelines for eHealth practice.

The ADRD Project team members wrote the content for the Web site based on information from the above IBSD activities. We also adopted the code of conduct for medical and health Web sites recommended by the Health On the Net (HON) Foundation that promotes quality of health information. The eight HON guidelines include: authority, complementarity, confidentiality, attribution, justifiability, transparency of authorship, transparency of sponsorship, and honesty in advertising and editorial policy (Health On the Net Foundation, 1997).

Discussion

Developing Internet-based service is a complex and lengthy process that requires good planning, coordination, and commitment. It would have been easy to underestimate the resources required to learn and plan, as well as to develop and refine the design. We have learned that a team approach that collates diverse expertise with clearly identified roles has made the development process more effective.

As occupational therapy practice on the Internet requires new program development knowledge and skills, we will soon encounter the need for Internet program evaluation. Systematic evaluation will provide a vehicle to refine and evolve Internet practice. Future studies will need to address this aspect of occupational therapy practice via ICT delivery.

The Internet has created a powerful communication medium for occupational therapy practice. It allows the practitioners to reach more people who need occupational therapy services by cutting across geographic and temporal boundaries. The quality of Internet-based services, however, should be consistent with professional standards and postulate a credible, professional image. Hopefully, the comprehensive approach described in this paper will provide some guidelines for occupational therapists to develop new Internet-based services with high-quality standards that are responsive to our clients’ evolving needs.

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References


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