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The Design and Evaluation of e-Health Intervention Programs for Older Adults

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Abstract

Reported are several developmental feasibility studies that focus on the use of an interactive Internet environment to replicate clinic-based face-to-face health care support programs for chronically ill older adults and their caregivers. A series of studies of consumer response to online, interactive communication and video-based technologies for the delivery of health care services were designed and implemented. An initial pilot study with a small group of older adults provided feedback for website design and content. Following this initial usability study and modifications to the website, two feasibility studies were implemented. The first study randomized family caregivers of persons with neurodegenerative disease to an Internet-based videoconferencing support group intervention or 'services as usual' (community-based health services). The second study examined pre-post responses of older, disabled adults to participation in an Internet-based videoconferencing support group. Analyses of both qualitative and quantitative outcome data for both feasibility studies showed clinical benefits for the intervention group participants. We assessed participants' responses to receiving health care via the Internet. Most reported high levels of involvement in the groups, and in many instances preferred the online group to meeting face-to-face. There were unanimous positive responses to being able to participate in a support group from the comfort of home. This Internet-based videoconferencing intervention program can be viewed as a prototype for setting technology and professional practice standards for the delivery of health services to home-based chronically ill older adults and their caregivers.

Introduction

Advances in computer and communication technologies have made it possible to provide health information and health intervention programs to consumers. There are many challenges to the design, development, and implementation of Internet-based health care interventions that target the needs of consumer groups with specific health care needs. The problems are compounded when **a)** the consumers, as for example older adults, have had little or no prior computer experience and possess limited knowledge about the complexities of the Internet; **b)** the authenticity of the health information exchanged is unknown;

c) consumer identity and health information is unprotected; and **d)** the health benefits of using the Internet to access and exchange information are unknown.

Many of these problems exist because computer-based health support systems are provided in an unregulated digital world. Despite the fact that government health jurisdictions and health professional organizations have developed guidelines for the development of technology-based health service programs, there is no regulatory body or monitoring system that holds organizations accountable for the authenticity of health information or the

standards of health services provided.^{1,2} Consumer guidelines for evaluating the risks associated with the adoption of web-based health information and interventions have been developed, but the frequency with which they are accessed and applied is unknown.³ Consequently, the consumer of web-based health information may be at risk for negative health outcomes due to **a)** the inaccuracy of the information, **b)** consumer use of information in ways that compromise prescribed treatments, and **c)** consumer purchase of health remedies that, despite claims on the web, are ineffective and may interact negatively with prescribed medications.^{4,5}

The Internet supports thousands of websites with information about health, disease, and remedies. Yet, navigating this plethora of information places the consumer at risk for misinterpretation of disease symptoms and treatments. The Spry Organization³ has generated guidelines for judging specifically the merits of health information websites. However, the effectiveness of the guidelines in helping consumers distinguish between accurate and faulty information is unknown. While all consumers of web-based health information may be at risk of misinformation affecting their self-care decisions, older adults may be especially vulnerable to persuasive advertisements about the benefits of unregulated remedies frequently promoted by vendors who develop and support many health information websites.⁴ These potential negative consequences for consumers can be avoided when health professionals adhere to evidence-based protocols for the development, implementation, and evaluation of Internet-based health information and intervention programs.

Background

In the development of any Internet-based health care program emphasis must be placed on knowing the needs/abilities of the end users. For example, the experiences of older adults contrast sharply with those of younger adults who have been immersed in a digital world. Older adults approach the Internet with motivations, knowledge, and skills that differ from younger adults. Seniors in their seventies and eighties may not have used computers prior to retirement, and they may reject the idea of acquiring new skills late in life. In contrast,

younger adults tend to have experience in accessing the Internet and using an array of software for communication, uploading and downloading content, playing video games, and engaging in virtual reality space. Thus, the design, content development, and functionality of web-based healthcare programs must address the end users' prior experiences in using the technology as well as consumer-specific barriers to full engagement with any e-Health program of care.

Despite their initial reluctance, older adults are the fastest growing novices to computer use and they access the Internet in increasing numbers, largely to obtain health-related information and for travel planning. In conjunction with the incremental use of computers by seniors, software developers have begun to address the common characteristics of aging that frequently impede the older adult's effective use of technology. Failing eyesight, problems with muscle coordination, lags in learning and retaining new concepts and behaviors, contribute to seniors' difficulties with managing computer hardware and software. Significant advances have been made to modify hardware and screen interface to accommodate the limitations of persons with physical disabilities (e.g. Microsoft Assistive Technology; Apple Computer Worldwide Disabilities Solutions Group; IBM National Support Center for Persons with Disabilities).⁶ However, these technical enhancements do not insure efficient and unambiguous communication between an older adult and a healthcare provider when the Internet is used as the platform for the exchange of information. Preferable is a technology-based environment that replicates, in large measure, the typical clinic-based face-to-face encounter between a professional care provider and patient.

Methods

System Development

Our initial e-Health program was developed to address the needs of spousal caregivers of older adults with dementia. The aim was to replicate in an Internet environment the typical clinic-based support group programs provided for caregivers. A password protected website (Caring for Others [CFO]) was built based on usability guidelines (Web Content Accessibility Guidelines, 1999)⁷; Web Accessibility Initiative (WAI, 2003)⁸ that specify design crite-

ria for older adult users. The website includes large, obvious icon images and uncluttered pages with subtle color contrasts. Use of the keyboard is minimized. The website provides links to **a)** online disease-specific handbooks that provide information about each disease, it's course and it's management as well as self-care strategies for the caregiver; **b)** an e-mail link with pull-down list of e-mail addresses for peer group members (within disease groups) and health care providers; **c)** a threaded discussion forum; **d)** a videoconferencing link for one-on-one communication; and **e)** a videoconferencing link for group member communication. Parallel with the development of the website, a simplified computer training manual was developed with a primary emphasis on strategies for negotiating the website links.

Through an iterative test, re-test process implemented in a computer lab format, we obtained usability feedback from a group of spousal caregivers of persons with dementia. This initial pilot online support group with caregivers, resulted in continual feedback responses that contributed to modifications to the website, and revisions of an intervention training manual and revisions of a computer training manual for older adult users. The aim throughout was to simplify the steps for accessing and negotiating the website links. In particular, the initial design and modifications to the website addressed the physical and behavioral characteristics of older adults that could potentially impede ease in accessing and negotiating the website. This approach was especially important for addressing the concerns of spousal caregivers who had not used computers previously.

Website Technical Development

The Caring for Others website offers innovative features for seniors, and was built in a Microsoft environment that utilizes traditional ASP (Active Server Pages) for much of the functionality. To meet the security needs of the user, access information is stored in a Microsoft Access database that can easily be up-sized to a Microsoft SQL Server database, when necessary. Beyond the traditional form-based functionality, the website also offers video-conferencing, and video chat interaction. The video components were built using Macromedia's Flash Communication Server. This

technology allowed us to build a videoconferencing environment that did not require any client desktop software installation. The user only required the free Macromedia plug-in in order to use the videoconferencing and video chat components. The Flash Communication Server acts as the hub that manages the incoming and outgoing streams. The conferencing component was built with efficiency and ease-of-use as primary goals so as to meet the unique challenges experienced by the caregiver users. The number of streams has been kept to a minimum with only one outgoing stream at any one time, and this is controlled by the conference facilitator. As many as nine viewing streams can be assigned. The outgoing stream is passed around by the facilitator to the live speaker, while the remaining participants view the central stream. The active window picture located in the center of the screen (160 by 120 pixels) has high resolution and little to no lag in the voice component. The active window is surrounded by video snapshots of the participants and facilitator. The video components of the website require high speed Internet connections for all users. In addition, the site offers access to a conferencing scheduling application, and a complete administration component that allows maintenance over all aspects of the site.

The website includes libraries of educational materials – power point presentations and videos. Currently, 6 videos portraying care giving scenarios for caregivers of dementia patients are available for viewing at times convenient to the participant. The website database is used to log traffic throughout the site for research purposes. We also customized a tool that allows researchers to review the recorded conferences. The video footage is downloaded and burned to a CD that includes functionality for 'coding' the video footage. With SAVI Viewer developed by MeLogic⁹ it is possible to score, comment, or code at precise moments in the video.

The Caring for Me website is a modified version of the Caring for Others website. The same features are available – information handbooks specific to the needs of the particular consumer group, the threaded discussion forum, the e-mail and the videoconferencing links. The Caring for Me has been customized according to the characteristics of the user

group. It was initially evaluated with isolated, community dwelling older adults needing social connection and monitoring of health status.

Website Security

To insure security of the website users and content we made both websites accessible only through the use of unique passwords for each user. Consequently, the websites are not available in the public Internet domain. Within the website, there are three levels of security; the site administrator has access to all links and user groups, the professional facilitators have access only to the members within the groups they facilitate, and the participants have access only to the members within their own group. All e-mail messages, threaded discussion text, and video conference sessions are encrypted and stored on the server. Subsequently, all information is copied to CDs and stored in locked cabinets for analyses. Following data analyses all electronic data are destroyed.

Caring for Others Feasibility Study with Caregivers of Family Members with Chronic Diseases

A feasibility study was implemented with the goal of evaluating the responses of a cohort of caregivers to the use of CFO website to obtain health information and participate in a videoconferencing support group. 66 caregiver-care recipient dyads were recruited and randomly assigned to the online intervention or 'service as usual'. There were two caregiver groups in each of three care recipient disease categories – Alzheimer, Parkinson and stroke). With informed, signed consent, the caregivers agreed to baseline and follow up interviews. The intervention groups agreed to have the videoconferencing sessions archived for subsequent analysis. For these groups, technicians installed equipment (computer, video camera, audio headset and high-speed Internet connection) in the homes of all participants and provided two computer training sessions using the project Computer Training Manual.

For the intervention groups the Intervention Training Manual, developed during the initial pilot study, was used to train the clinical facilitators. To insure reliable adherence to the model of intervention, the facilitators received weekly supervision. Subsequent to the 10 facilitated sessions, in each group a member

assumed the facilitator role and the groups continued to meet weekly for an additional period of three months.

Research assistants interviewed and completed questionnaires with all caregiver participants in their homes at baseline and six months later. At follow up, caregivers in the intervention groups were also asked to comment on their experiences with using computers for communicating with other caregivers in a support group and to compare this experience with meeting in face-to-face groups.

Caring for Me Feasibility Study with Chronically Ill Older Adults

The Caring for Me feasibility study of an Internet-based support group intervention for community dwelling older adults with chronic disease largely replicated the procedures developed for the Care for Others intervention program for the caregiver groups. The same training materials were used for training the facilitators and for training the participants to access the websites. The CFM study was implemented at a community health clinic. With informed signed consent 18 older adults agreed to participate. Disease categories included Lupus, spinal cord tumors, Poliomyelitis, Multiple Sclerosis, heart disease and hypertension, and diabetes. Computers, web cams, audio headsets and Internet access were provided. Participants were trained to access and negotiate links within the website. Participants were interviewed at baseline and at six month follow up to obtain their feedback about the utility of the support group and their responses to using technology to participate in a support group. Groups of 6 participants met online weekly for 10 meetings facilitated by a professional health care provider and subsequently continued to meet weekly in a mutual self-help format for an additional three months.

Results

System Evaluation

Following the completion of the pilot caregiver online support group a usability study was implemented. Each of the 5 participants were interviewed and asked to respond to a series of questions about specific website features and their ease of use. Overall, the participants found the large icons, color contrasts, and uncluttered pages easy to follow. Also, the large

'GO' buttons insured that they could move forward and backwards without getting 'lost' within the website. Because of the number of incoming and outgoing streams during the videoconferencing meeting, there were lags, and sometimes a participant would be 'bounced' out of the session requiring him/her to log on again. This proved to be very frustrating for some participants. Frequently problems with maintaining contact within the website were due to the Internet servers used by the participant. Multiple Internet providers were used by the participants depending on location. Consequently, they were out of the control of the web master and the server hosting the websites.

From the participants' feedback some features of the Caring for Others website were modified. A major change had to do with adding the participants' pictures to the page that supported the group videoconferencing. In the first version of the videoconferencing link, each participant followed instructions to take their picture (web cam mounted) prior to entering the group. The picture then appeared in a circle surrounding the central active window. This step in the process proved to be challenging frequently resulting in errors, frustration and 'giving up' with regard to participating that day. This feedback resulted in a modification where pictures of all of the participants are stored. When they enter the videoconferencing group their picture is programmed to appear in the circle surrounding the active window.

Results – Caring for Others Feasibility

Data analysis included content coding of the archived video sessions to insure that the online intervention had been carried out reliably according to the strategies specified in the Intervention Training Manual. Two raters independently coded a sample of video recorded sessions from each group. Inter rater agreement ranged between 85 and 90%. In addition, an open coding method applied to the archived video sessions of each group was used for extracting salient themes across phases of each of the participant groups. This analysis yielded four major themes.

a) Group bonding and mutual acknowledgment and respect for the collective knowledge about their relatives' disease and coping capacities.

b) Insights into personal emotional and cognitive processing barriers that interfered with managing their lives in the context of care giving.

c) Processing the meanings of the changing relationship with the dependent relative.

d) Anticipatory mourning of the loss of the relative as reflected in planning transfer to a long term care facility.

These themes replicated those observed in clinic-based face-to-face support groups for caregivers of persons with chronic diseases. Of particular note was the fact that the group members formed positive bonds with each other despite the limitations of the videoconferencing mode that allowed only one person at a time in the active window.

Analysis of stress response data showed significant difference between groups, with the intervention group experiencing a decline in stress compared with an escalation in stress for the control group.

Approximately half of the caregivers had never used a computer before participating in the project. 91% of these indicated that they had gained considerable skill in using the computer. Primarily, they used the computer to participate in group conferences, sending emails, playing computer card games and accessing the Internet. 82% reported that they felt either "very comfortable" or "moderately comfortable" using the computer. One participant noted, "*I'm pretty good at it...there's lots I have to learn yet but it will come gradually*". 82% felt the training they obtained at the beginning of the project was sufficient in order to feel comfortable in accessing and negotiating the project website. The other 18% received help from family and friends for several weeks following the formal training sessions.

Questions regarding participants' responses to the website yielded the following: 78% indicated that the website was "very easy" to use, for example, "*Yes, because I think I was taught pretty well*"; "*It was clearly laid out*"; and "*It was very easy, very user friendly*". When asked what they liked most about the website, some of the caregivers responded, "That it was accessible...a lot of great information and being able to have visual contact with other group members"; "One of the things I liked

was the larger print” and “The meetings that we had on the website were terrific”. When asked what they liked least about the website, they referred to initial frustrations in accessing the website due to problems at the server end.

With respect to using videoconferencing to communicate with each other the participants were asked to describe their reactions to using the videoconferencing mode. 96% indicated that they liked being able to see and hear the other members in the group during the videoconferencing sessions. One participant noted, “Yes, definitely. It’s easier to connect with them if you can see and hear them”. 95% of the caregivers found the experience of using the Internet to participate in a support group very positive or moderately positive. For example, some of their responses were “I think it’s great...it seemed much easier to get to know them than in person. In reality, I wouldn’t have talked as much”; “Definitely, I think so...you knew you were going to have that every week, you knew you were going to see them”; “I felt like I got to know them and I’ve been continuing to stay in touch with them”.

At 6 month follow up, over 90% of the caregivers reported benefiting from their participation in the virtual support group either “extremely” or “very” positively. Sample of participant responses: “It’s been really a positive learning experience and avenue through which you could express feelings that others understood, express your day-to-day involvement with living with someone who has Alzheimer’s”. “Participating in this project during the past year has meant a great deal to me and could be aptly described as my lifeline”.

Results – Caring for Me Feasibility

The responses of the chronically ill older adults to the online intervention paralleled those reported by the caregiver groups. Sample response of chronically ill patients’ participation in the online support group included the following: ‘People in the group are trying to help each other and nobody is there to laugh at you or judge you’; ‘We are all on the same boat’; ‘Sharing information was very instructive’; ‘We don’t feel alone, [loneliness] is the worst thing’, “I think it was wonderful, it was great. I have never missed a meeting’; this was a new and very positive experience for me’. In

response to using technology to communicate with each other the overall responses were quite positive; ‘It is better for people who have hard time opening up to other people because you do it in your own living room’; ‘You would not be able to go into such a depth in a face-to-face conversation and in a large group’; ‘It’s better because you are not distracted by anything, it is better than (clinic group)’. Specific responses to the website included; ‘To be able to see a person I was talking to, that was very helpful’; ‘To put a face to a voice, that made a tremendous difference’; ‘It was a great experience and I did not have to use wheel-trans (wheelchair transportation provided by government health program)’; ‘Great opportunity to learn about technology’.

Discussion

In summary, based on the qualitative analysis both intervention programs were successful clinically in terms of acceptance of a technology-based healthcare intervention by these users. The programs attempted to replicate the processes of clinic-based face-to-face support groups for older adults. The web page design and content for both provided authentic information and the opportunity to discuss possible misinterpretations of the information. In addition, the website proved to be easily accessed and negotiated.

During the development and evaluation of our e-Health programs we were concerned with **a)** insuring the accuracy of the health information that was generated and shared with the project participants; **b)** how the information would be interpreted and used; and **c)** whether the Internet-based health support program would reflect the same standards of practice evident in face-to-face delivery of health care services. Early in the project we conducted a systematic review of published studies of technology-based interventions delivered to older adults in their homes.¹¹ The purpose of the review was to determine whether or not adherence to professional practice standards and implementation of research ethics procedures were discussed in reports of studies of e-Health service programs. We found that the most common ethical issues addressed included informed consent (50%), presence of a mechanism for monitoring subjects (43%), confidentiality protection (28%), and a mechanism for

contacting the health provider (25%). Among the interventions provided via the Internet, the use of a password (24%), securing data (22%), and encryption (10%) were most commonly reported. As expected, very few of the articles (4%) reported using any theoretical framework or practice standards for guiding the delivery of the service or intervention online. We extracted reports of randomized controlled trials of e-Health programs (N=26) in order to take a closer look at the monitoring of professional practice standards. The analyses showed that 42% (11/26) provided some details as to procedures used for insuring reliable adherence to a specified model of intervention. Only 38% (10/26) reported using protocol guidelines for delivering the intervention, 19% (5/26) provided information about training the clinician prior to beginning the trial, and 12% (3/26) indicated that the clinician received supervision for the duration of the trial. None of the studies reported independent assessment of archived interactions between provider and patient to demonstrate whether the intervention had been delivered reliably according to protocol. Ten studies (38%) provided no information as to the use of strategies for insuring adherence to intervention protocol.

The previous studies guided our approach to the development and implementation of our e-Health programs. We insured that the identity of the participants would be protected through the use of a password protected website as the platform for engaging in the exchange of information. As described above, levels of protection were built into the website such that individual participants would be known only to their own group members and the professional facilitator. Firewalls and encryption were used to protect against attempts by non participants to access information on the website. Furthermore, all interactive information generated on the website (threaded discussion, e-mail, videoconferencing) was backed up on a server and removed daily from the website. The accuracy of the information handbooks provided online to the participants was monitored according to feedback following reviews by health specialists in each disease area. We were able to clarify inaccurate interpretations of health information in weekly meetings with the participants. We were able to monitor the health of the participants by maintaining e-mail

contact as well as scheduling one-on-one video meetings when needed.

In terms of professional standards of practice we developed intervention training manuals to insure that the interventions would be carried out reliably. Subsequently we coded the support group sessions to insure that the interventions had been delivered as intended. Similarly, the computer training manual insured that each participant would be trained to negotiate the website in a consistent manner. Furthermore, technicians were available throughout the project in order to provide assistance and troubleshoot with each participant whenever equipment or software problems arose.

Conclusions

With the rapid development of web applications that can support the exchange of health information and the delivery of health care programs, it will be increasingly feasible for health professionals to use the Internet to provide disease-specific information and standard therapies for specific disease groups. In order to insure the accuracy of the information and its interpretation by consumers, medical experts will need to evaluate the quality of the information for accuracy and clarity of presentation. In interactive modes of service delivery via the Internet, health professionals will need to develop valid and reliable intervention protocols. Protection of patient information and client privacy within an Internet service delivery environment will need to be supported. The use of password-protected website access, encryption, and firewalls should be mandatory for any exchange of information between a healthcare provider and consumer. Similarly, consumers have the right to know that the services they receive in a technology-based environment meet the highest professional standards of health care. Currently there is no regulating system for monitoring the credentials of providers, and whether evidence-based models of therapy are used. Ultimately, an e-Health regulatory body to which health professionals can be held accountable will be required to protect consumers, especially older adults who may be more vulnerable when receiving technology-based services. In summary, answers to the questions raised can be addressed only through research initiatives focused on demonstrating that both high quality health care information programs and se-

cured consumer privacy can be provided when technology is used to deliver health care services.

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