An E-Health Community of Practice: Online Communication in an E-Health Service Delivery Environment

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Abstract. Results of a series of studies of consumer response to online interactive communication and video-based technologies for the delivery of health care services are presented. The studies include development, evaluation and usability studies of two interactive, video conferencing web sites; Caring for Others© [CFO] designed for older adults caring for a family member with a chronic disease, and Caring for Me© [CFM] designed to support an e-health program for obese adolescents. Stages of web site development, usability analyses, and evaluation of consumer response to the customized e-health programs are reported.

Keywords: E-health, Internet, interactive communication, health risks, benefits.

1 Introduction

Advances in computer and communication technologies have made it possible to provide, world wide, information and health support programs to consumers. However, 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 provided 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 therapies 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]. 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 therapy programs. In addition, specific characteristics of different consumer groups need to be taken into account when building e-health programs and protocols.

2   Background

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 to no prior computer usage experience and possess even less 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 the using the Internet to access and exchange information are unknown. In the development of any Internet-based health care program emphasis needs to be placed on knowing the needs/abilities of the end users. Older adults approach the Internet with motivations, knowledge, and skills that differ from younger adults and adolescents. Seniors in their seventies and eighties may not have used computers prior to retirement and may reject the idea of acquiring new skills late in life. In contrast, most adolescents are highly skilled and have considerable experience in accessing the Internet and using an array of software for communication, uploading and downloading content, playing 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 with using technology as well as consumer-specific barriers to full engagement with any e-health program of care. 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. In other words, when health information is communicated using computer-Internet technology how is it interpreted and applied? What are the risks for misinterpretation and subsequent negative health consequences for the patient? Do patients involved in e-health programs benefit in ways comparable to clinic-based health care programs?

Despite the fact that the Internet supports thousands of web sites with information about health, disease, and remedies, the interpretation of numerous web-based

versions of disease diagnoses and treatments, and judgments as to their authenticity, are the responsibility of the consumer. Yet little is known about how Internet-based health information is understood or applied by individuals to manage their health concerns. The Spry Organization (www.spry.org) [3] has generated guidelines for judging the merits of health information web sites but the effectiveness of the guidelines in helping consumers distinguish between accurate and faulty information is unknown. In addition to being at risk of accessing inaccurate information, 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 web sites [4]. The challenges in designing e-health programs for adolescents diverge significantly from those that need to be addressed when providing healthcare for seniors via the Internet. Adolescents have the technical knowledge and skills and in most instances surpass those of the professional health care providers with whom they communicate. For the adolescent consumer the challenge is to design web pages and content that will capture and maintain their interest for the duration of the e-health intervention program. There are also risks to consider when dialogue between the adolescent and the health care provider is dependent on Internet-based communication tools such as text messaging, voice over IP, or video meetings. Given the adolescent's developmental propensity to mistrust adults, the possibilities for miscommunication, misunderstanding, and imprecise communication are many. Furthermore, adolescents are more vulnerable to the views of peers in situations where they are risk of being perceived as being 'different'. Consequently e-health programs that use chat rooms or group video conferencing tools need to include options for securing anonymity when building the web platform for delivering health care interventions to adolescents.

3   System Development

Our initial e-health program was developed to address the needs of spousal caregivers of older adults with chronic disease (Alzheimer's, Parkinson, Stroke). 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 criteria for older adult users. It includes large, obvious icon images and uncluttered pages with subtle color contrasts. Use of the keyboard is minimized. The web site 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 video conferencing link for one-on-one communication; and e) a video conferencing link for group interactions. Parallel with the development of the web site, a simplified computer training manual was developed with a primary emphasis on strategies for negotiating the web site links. Through an iterative test, re-test process we obtained usability feedback from caregivers in a computer lab format. Based on participants' responses we modified both the web site and training manual. The aim throughout

was to simplify the steps for accessing and negotiating the web site links. In particular, the initial design and modifications to the web site addressed the physical and behavioral characteristics of older adults that could potentially impede ease in accessing and negotiating the web site. This approach was especially important for addressing the concerns of spousal caregivers who had not used computers previously.

Web Site Technical Development: The Caring for Others© [CFO] website offers innovative features not seen before on websites for seniors and was built in a Microsoft environment that utilizes traditional ASP (Active Server Pages) for much of the functionality. Latterly, ASP.NET was incorporated in the final version. To meet the security needs of the user, access information is stored in a Microsoft Access database that can easily be upsized to a Microsoft SQL Server database when necessary. Beyond the traditional form-based functionality, the CFO 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 our own video conferencing environment that did not require any client desktop software installation. The user only required the free Macromedia plug-in in order to use the video conferencing 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 whoever is the live speaker, while the remaining participants view the central stream. The active window picture located in the centre 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 web site require high speed Internet connections for all users. In addition to the video communication components, the site offers access to disease specific educational materials, a threaded discussion forum, a personal message centre, a conferencing scheduling application, a contact form, personal profiles, video streaming, and a complete administration component that allows maintenance over all aspects of the site. The web site includes libraries of educational materials – power point presentations and videos. Currently, six videos portraying care giving scenarios for caregivers of dementia patients are available for viewing at times convenient to the participant. The web site database is used to log traffic throughout the site for research purposes. We also customized a tool that allows the 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 MeLogic (www.savisys.com) [9] it is possible to score, comment, or code at precise moments in the video. The Caring for Me© [CFM] web site is a modified version of the CFO web site. 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 video conferencing links. The CFM has been customized according to the characteristics of each user group. It has been used with isolated, community dwelling older adults needing social connection and monitoring of health status.

Currently it is being modified for an obese adolescent group. The e-mail feature has been omitted since adolescents have independent e-mail addresses and can choose whether or not to disclose them to other teenagers in their e-health support group. In the video conferencing mode the adolescent participant has the option of having their own picture posted (as is the practice with the older adult user groups) or substitute an avatar of their choosing. During video conferencing sessions the avatar would appear in the circle and move in and out of the active window while the voice of the adolescent would be heard. Two other features have been added to the CFM customized for the adolescent group. Six animations of typical scenarios involving obese adolescents and their peers have been developed. These will be available for streaming by the facilitator during specific video conferencing sessions. The animated scenarios can be viewed as vehicles for stimulating active exchange of information among the group participants. A second feature consists of personal eating patterns and activity diary imbedded in the web site. A list of foods color coded as to their caloric values is provided so that the adolescent can enter the color code with each entry of food consumed throughout the day. Similarly, the adolescent can choose from a list of physical activities with estimates of calories burned to record daily activities. Only the adolescent will have access to the diary and can choose whether or not to share it with the other group members. Parallel with the e-health support group program for the adolescents, Internet-based video conferencing support groups will be offered to their parents using the CFM web site. For this program we have included an information handbook for the parents with a focus on the health risks of adolescent obesity as well as strategies for changing family life patterns that will enable the adolescent to alter his/her own eating patterns and activity choices.

Web Site Security: To insure security of the web site users and content we decided to make the CFO web site accessible only through the use of unique passwords for each user. Consequently the web site is not and will never be available in the public Internet domain. Within the web site 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 that 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 is destroyed.
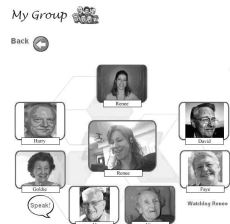

Fig. 1. Photo shot of CFO home page   Photo shot of video conf group

System Evaluation: Usability: Following the completion of the first caregiver online support group a usability study was implemented. Each of the five participants were interviewed and asked to respond to a series of questions about specific web site 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'. Because of the number of incoming and outgoing streams during the video conferencing meeting there were lags and sometimes a participant would be 'bounced' out of the session requiring them to log on again. This proved to be very frustrating for the participants. Frequently the problem with maintaining contact with the web site was due to Internet server used by the participant. Multiple Internet server providers were used by the participants depending on location and consequently were out of the control of the web master and the server hosting the CFO web site. From the participants' feedback some features of the web site were modified. A major change had to do with adding the participants' pictures to the page that supported the group video conferencing. In the first version of the video conferencing 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 we now archive pictures of all of the participants so that when they enter the video conferencing group their picture is programmed to appear in the circle surrounding the active window. In summary, the usability study following the initial pilot trial of the Internet supported video conferencing support group was essential for making important modifications to the web site.

System Evaluation: Older Adult Response: The initial pilot study with older adult caregivers yielded the following: the modified version of the CFO web site, an Intervention Training Manual and a Computer Training Manual. These program products were developed to insure that during the next phase of evaluation of the e-health program the procedures would be carried out reliably. A feasibility study was implemented with the goal of evaluating the responses of a cohort of caregivers to using the Internet to obtain health information and participate in a video conferencing support group. The study was located in two remote areas of two Canadian provinces. Thirty four caregiver-care recipient dyads were recruited (17 at each site with 5 to 6 caregivers of persons in each of three disease groups – Alzheimer, Parkinson and stroke). With informed, signed consent the caregivers agreed to baseline and follow up interviews as well as having the video conferencing sessions archived for subsequent analyses. Technicians at each site 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. Using the Intervention Training Manual a clinician at each site was trained to carry out the intervention. To insure reliable adherence to the model of intervention the facilitators received weekly supervision using televideo conferencing facilities at each of the participating sites. 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 the caregiver participants in their homes prior to participating in the online group intervention and six

months later. At follow up they were 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.

Data analyses 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%. The results showed that each facilitator carried out the online intervention within each group in a reliable fashion. 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. These analyses yielded four major themes a) group bonding and mutual acknowledgement 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, and 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 video conferencing mode that allowed only one person at a time in the active window.

In follow up interviews we asked about the participants' response to the website. Seventy-eight percent indicated that the web site 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. When subsequently the website was transferred to a provider that specialized in supporting Macromedia Flash Communication Server the problems in linking with the video conferencing mode were eliminated.

We computed the frequencies for total logins by each of the caregiver user groups as well as the frequencies of use of each of the web site links over a period of eight months. The total logins ranged between 2500 (Dementia group) and 5000 (Stroke group). Once logged onto the website the frequencies with which the links were accessed ranged between 15,000 (Dementia group) and 19,000 (Parkinson group). These results show that, on average, all users (N=34) accessed the web site links 15.6 times a day (2.1 logons per caregiver per day) with frequent use of the links during each login episode (on average 5 links per login). The most frequently used link was to the disease-specific handbooks, followed by e-mail, and video-conferencing (either duplex or group). As expected, overall use of the web site increased over time.

With respect to using video conferencing to communicate with each other the participants were asked to describe their reactions to using the video conferencing mode. Ninety-six percent indicated that they liked being able to see and hear the other members in the group during the video conferencing sessions. One participant noted, "Yes,

definitely. It's easier to connect with them if you can see and hear them". Ninety-five percent 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"; and "I felt like I got to know them and I've been continuing to stay in touch with them".

Approximately half of the caregivers had never used a computer before participating in the project. Ninety-one percent of these indicated that they had gained considerable skill in using the computer. Primarily, they used the computer for participating in the group conferences, sending emails, playing computer card games and accessing the Internet. Eighty-two percent reported that they now 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". Eighty-two percent felt the training they obtained at the beginning of the project was sufficient in order to feel comfortable in accessing and negotiating the project web site. The other 18% received help from family and friends for several weeks following the formal training sessions and eventually were sufficiently skilled in using the hardware and accessing the CFO web site.

At six month follow up, over 90% of the caregivers reported benefiting from their participation in the virtual support group either "extremely" or "very" positively. Examples of participant responses follow: "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". "I found encouragement, inspiration, humor, honesty; it was a safe place to vent my feelings, share ideas, explore options". "When providing round the clock care, there is not a whole lot of time to deal with one's emotions and they tend to get buried alive. Sooner or later they surface….anger, guilt, frustration, grief. No longer did I feel so isolated as I quickly found out that other caregivers shared these feelings". "Being able to connect with one another in the comfort of our homes at any time of day or night is a very effective, non-intrusive and reassuring way to communicate…as well, the information provided on the website was excellent and a vital component of this project and I feel would be of great benefit if it could be distributed to all caregivers" [10].

System Evaluation: Adolescent Response: The features of the CFM web site for use by obese adolescents and their parents are in the process of being evaluated. The information handbooks for each group (adolescents and their parents) have been completed and reflect the views of experts in the field of health care for obese adolescents. For the adolescent group we chose language and graphics that would appeal to teenagers. Versions of the handbook were reviewed by several adolescents and modified according to their feedback. Similarly, the animations have been built to reflect obese adolescents' challenges in communicating with peers. In a focus group format we have shown the animations and solicited feedback from health care professionals who provide services to obese adolescents. Their observations and suggestions resulted in further modifications of the animations. The personalized food and activity diary is in the process of being developed. Color coding of food caloric values and calories

burned by activity level have been used by professional health care providers with populations of obese adolescents. For our purposes we will transfer this information to our web based diary module and subsequently evaluate its effectiveness in helping obese adolescents to alter life style behaviors.

Professional Ethics and Standards in an E-health Service Delivery Environment: During the development and evaluation of our e-health programs we were concerned with a) insuring the accuracy of the health information that we 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 extract reports of randomized controlled trials of e-health program (N=26) in order to take at 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. These analyses 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 web site as the platform for engaging in the exchange of information. As described above, levels of protection were built into the web site such that individual participants would be known only to their own groups members and the professional facilitator. Firewalls and encryption were used to protect against any attempts by non participants to access information on the web site. Furthermore, all interactive information generated on the web site (threaded discussion, e-mail, video conferencing) was backed up on the servers and removed daily from the web site. 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 the health information in the 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 intervention would be carried out reliably and subsequently we coded the support group sessions to insure that the intervention had been delivered as intended. Similarly, the computer training manuals that we developed insured that each participant would be trained to negotiate the web site in a consistent manner. Furthermore, technicians were available throughout the project in order to provide assistance and trouble shoot with each participant whenever equipment or software problems arose.

4   Conclusion

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 specified disease group. 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 web site 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 the 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 secured consumer privacy can be provided when technology is used to deliver health care services.

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