

E-Health Program for Patients with Chronic Disease

Elsa Marziali, Ph.D.

Kunnin Lunenfeld Applied Research Unit, Toronto, Ontario, Canada.

Abstract

The aim of this pilot study was to examine the feasibility and benefits of a computer Internet-based videoconferencing healthcare support program for community-dwelling older adults with chronic disease. Eighteen participants (n = 18) who met inclusion criteria were recruited from a community health clinic, provided informed signed consent, and were assigned in groups of six to an Internet-based support group program. Where needed, participants were supplied equipment (computers, Web cams, audio headsets) and trained to access an easy-to-use, password-protected Web site that uses videoconferencing to support group member-facilitator interactive communication. The aim of the intervention was to support group member bonding and sharing of challenges and strategies for managing a chronic disease. Following 10 weekly professionally facilitated sessions, the groups met weekly in a self-help mode for an additional 3 months. Participants were interviewed at 6-month follow-up. An interview guide was used to gain feedback on using the Internet to access a health service and to ask about the benefits of having participated in the videoconferencing support group program. At follow-up, participants responded positively to using technology to communicate with healthcare professionals and other group members. They also valued the information shared regarding self-care, and reported reduction in feelings of loneliness and isolation. Our Internet-based, videoconferencing intervention program can be viewed as a prototype for designing technology platforms for the delivery of professional healthcare services to home-based older adults with chronic disease.

Key words: videoconferencing; e-health program; chronic disease; home-based healthcare services

Introduction

As people continue to live longer, many older adults will need to manage one or more chronic illnesses/disabilities. Following diagnosis, acute care, and educational support provided by the formal healthcare system, maintenance of the prescribed medical regime for ongoing management of a chronic disease is largely the responsibility of the older adult and his/her family support system. For older adults who live alone with few familial supports, the management of a chronic condition is even more challenging, frequently resulting in an increased risk of destabilization of health maintenance behaviors. We postulate that although community-dwelling, chronically ill older adults may understand the medical regime to be followed post diagnosis and acute care, they will need professional healthcare support that includes a) practical advice regarding the management of medications and disease-related symptoms, and b) psychosocial support for managing the emotional impact of living with a chronic and frequently debilitating disease. To meet the healthcare needs of older adults with chronic disease, we designed and evaluated an Internet, videoconferencing-based support group intervention. The focus of the intervention is on updating information for self-management of a chronic illness, reflecting on psychosocial barriers to self-care, sharing challenging experiences, and generating strategies for implementing effective health-promoting behaviors. The aim was to demonstrate parallels between an Internet-based support group intervention and a face-to-face clinic-based educational support groups for older adults with chronic disease.

In North America and in most Western European countries, approximately 80% of adults over age 65 have a chronic disease. Of these, 30% have three or more chronic conditions.¹ In the United States, 33 million Americans are older than 65, approximately 80% have at least one chronic disease (e.g., diabetes, heart disease, cancer, arthritis), and 50% have at least two.² Similar prevalence statistics apply to third-world, low-income countries.³ The majority of older adults with chronic physical conditions live at home and report limitations in their ability

to perform tasks of daily living. Physical limitations decrease quality of life, increase the need for costly long-term care, and make challenging demands on family members and other caregivers. Furthermore, chronically ill older adults who live alone and lack support from family and friends are more vulnerable to exacerbation of their illnesses. Sixty percent of all hospitalizations are due to chronic disease and two thirds of attendees at hospital emergency departments are due to exacerbations of chronic illnesses. Consequently, it is not surprising that 60%–80% of general medical costs are related to the care of persons with chronic disease.⁴ From the perspective of chronically ill patients, there is evidence to show that many patients want more involvement in decisions about their care, better information about treatments, self-care and lifestyle issues, and greater help from health professionals to support efficient self-care.⁵ Concerns about the availability and costs of adequate health services for chronically ill older adults has resulted in analyses and revisions to long-term care health policies.^{6,7} Studies of adherence to medical regime by patients with chronic disease show 50% adherence rates. Factors that affect adherence include socioeconomic status,⁸ personality and cognitive factors,⁹ depression,¹⁰ and medication frequency, complexity, and side effects.¹¹

The use of technology to support self-care of chronic conditions is not new. Following discharge from acute care, patients are trained to observe changes in symptoms, vital signs, and behaviors that signal problems and the need to contact their healthcare provider. Some hospitals and clinics provide home-based vital sign monitors and train patients to use them and transmit readings electronically to the healthcare provider. Examples of these programs include monitoring patients with heart disease,¹² diabetes,¹³ and stroke.¹⁴

While technology has been used to provide support to older adults with chronic illness, we found no reports of using Internet-supported videoconferencing as a vehicle for replicating online a face-to-face education support groups for persons with chronic disease. Internet-based e-health programs are especially relevant in an environment where older adults are the fastest-growing novices to computer use. Seniors access the Internet in increasing numbers, largely to obtain health-related information. Significant advances have been made to modify hardware and screen interface to accommodate the limitations of persons with physical disabilities (e.g., Microsoft Assistive Technology¹⁵; Apple Computer Worldwide Disabilities Solutions Group¹⁶; IBM National Support Center for Persons with Disabilities¹⁷). However, these technical enhancements do not ensure efficient and unambiguous communication between an older adult and a healthcare provider when the Internet is used as the platform for the exchange of text-based information. Preferable is a technological environment, such as videoconferencing, that replicates, in large

measure, the typical clinic-based face-to-face encounter between a professional care provider and patient.

Our technology-based intervention for chronically ill older adults is based on a deterioration prevention model of care. The focus is on enhancing healthy lifestyle behaviors, transforming negative lifestyle behaviors, reducing the risks for negative health outcomes, and reducing the rate of use of costly healthcare services. These outcomes are achievable by emphasizing the importance of “health engagement control strategies”¹⁸ and by providing informational, behavioral, and psychosocial support.^{19,20}

Materials and Methods

The aim of the reported pilot feasibility study of an Internet-based videoconferencing support group intervention was to a) evaluate the challenges of using technology by older adults with little prior experience using computers and the Internet; b) examine the usability of a Web site designed to accommodate physical, visual, and hearing limitations of older adults with a chronic disease; and c) evaluate benefits, if any, of an Internet-based educational support intervention delivered to older chronically ill adults.

The project was located in a community health clinic that provides an array of health services to families residing in a large urban center. Eighteen participants ($n = 18$) were referred by the clinic staff, with six assigned to each of three groups. The inclusion criteria were average age of 60, presence of a chronic disease, and absence of acute phase of illness or mental illness. Informed signed consent was obtained prior to enrollment into the study. Computers, Web cams, audio headsets, and Internet access were provided for participants who did not have equipment. All participants were trained to access the Internet and negotiate the project Web site. At 6-month follow-up, a guided interview schedule was used to ask participants about a) their responses to learning to use computers to access the Internet and a health service program; b) the ease of use of the Web site layout, links, and content; and c) their perceptions of the benefits of participating in an online videoconferencing educational support group as compared with a clinic-based face-to-face group.

Technology

A password protected Web site (Caring for Me [CFM][®]) was built with the same structure and functionality of a previously evaluated caregiver online support group program (Caring for Others[®]).^{21,22} For the design of the Web sites, guidelines that specify design criteria for older adult users were used and yielded intuitive, user-friendly Web sites.^{23,24} Use of the keyboard is minimized. The CFM Web site provides links to a) an e-mail link with pull-down list of e-mail addresses

for peer group members and healthcare providers; b) a threaded discussion forum; c) a videoconferencing link for one-on-one communication; and d) a videoconferencing link for group meetings. A function for scheduling weekly meetings allows participants to go to the "scheduled meetings" page and click on the date/time of their meeting. A simplified computer training manual is used to train participants to negotiate the Web site links.

The videoconferencing component of the CFM Web site consists of an active window located in the centre of the screen (Web cam image and voice). This is surrounded by digital photos of the participants and facilitator. During group discussions, all participants can see and hear the person in the active window. Each participant clicks on his/her picture when wishing to speak and the facilitator moves him/her into the active window. 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 and code the recorded video meetings.

To ensure security of the Web site users and content, the Web site is accessible only through the use of unique passwords for each user. Within the Web site, there are three levels of security: site administrator access to all links and user groups, professional facilitators access to other facilitators but only to members within the groups that they facilitate, and participants access only to their group facilitator and members within their group. All e-mail messages and videoconferencing sessions are encrypted and stored on a secured server. Subsequently, all information was copied to CDs and stored in locked cabinets for analyses. At the end of the research program, all electronic data were destroyed.

GROUP VIDEOCONFERENCING INTERVENTION

Participants logged onto the Web site and selected the videoconferencing link to enter the scheduled group meeting. The group met weekly for 1 hour. The first 10 sessions were facilitated by a professional healthcare provider. The aim was to replicate as closely as possible face-to-face group interaction, bonding, and mutual problem-solving strategies. At the end of the 10 weeks, the group converted to a mutual self-help group technically monitored by one of the group members and continued to meet weekly for an additional 3 months. During this phase, the members could invite the professional facilitator to attend on as-needed basis.

CFM[®] Intervention Guidelines were developed to orient the professional facilitators to providing a healthcare intervention in a technology-based environment. The guidelines specify an unstructured format for engaging group members in a process that focuses on self-care. The aim of the intervention was to help the participants a) understand emotional and psychological responses to disease diagno-

sis and treatment; b) identify barriers to implementing and sustaining the prescribed medical regime; c) identify significant lifestyle changes; and d) acquire strategies for enhancing self-efficacy and control in order to maintain a healthy lifestyle. During the implementation of the online group intervention each facilitator received weekly consultation to ensure reliable adherence to the intervention guidelines.

Data Analysis and Results

Data analyses focused on two aspects of the project data: a) qualitative analysis of the archived videoconferencing intervention sessions for each group; and b) analyses of the follow-up interviews. For the analyses of the intervention sessions, two research assistants were trained to use qualitative analytic strategies to extract consistent theme content from the group interaction dialogue during the videoconferencing intervention session. Content analyses of two early, two middle, and two late sessions for each of the three groups were conducted. Codes were developed, and initial themes recorded, noting similarities and differences across sessions and groups.^{25,26}

Detailed researcher notes provided documentation for the selection and ratification of each content code. Codes generated by phase of group process were subsequently categorized into consistent themes that reflected stages of group development. Both the professionally facilitated sessions and the member-facilitated sessions were submitted to content analyses by phase of group process.

A similar strategy was used for the analyses of the follow-up interviews. Themes were identified within each of the three areas explored during the schedule-guided follow-up interviews. Examples of participant responses were recorded in support of each extracted theme.

For the analyses of both data sets (archived video sessions and follow-up interviews), differences in interpretation of the data between the research assistants was clarified through discussion. The analyses were systematic and verifiable, moving from the raw data, to descriptive accounts, to identification of consistent themes.

PARTICIPANT CHARACTERISTICS

The average age of the participants was 60.8 and the majority (83%) were women. Approximately one half lived alone and the remainder lived with family members. Disease categories included lupus, spinal cord tumors, poliomyelitis, multiple sclerosis, heart disease and hypertension, and diabetes.

GROUP DISCUSSION THEMES

The qualitative analyses yielded four salient themes, each supported by dialogue extracted from the session analyses.

LOSS OF ABILITY, IDENTITY, AND INDEPENDENCE

A recurrent theme across phases of the group sessions within each of the three groups was concerned with the loss of function and changes in personal identity due to the illness. Participant comments included, “Worst thing about being disabled is that you can’t do the things you did before”; “I haven’t been out in 6 years except for doctors appointments”; and “I have a new walker and that may help me to get out more.”

ANGER AND FRUSTRATION

Participants identified a number of issues associated with having a disability such as needing to retire early and concomitant financial difficulties. Others had to rely on public transportation because they could no longer drive a car. An overarching troubling issue was the demeaning way in which they were viewed by others. The following statements convey their frustrations. “I used to work as a nurse – now I’m on welfare”; “It’s so frustrating arranging wheeltrans (public vans for transporting persons in wheelchairs)”; and “The disabled are treated like second class citizens.”

ACCEPTANCE AND ADJUSTMENT

One of the most difficult challenges for the group members was learning to live with their disabilities and accept the fact that they would not return to their previous healthy states. For most, it was difficult to acknowledge that they needed the help of others in order to manage their disease conditions as efficiently as possible. Most painful of all was accepting the fact that they could not change society’s negative attitudes toward the disabled in general. Statements included, “At times I feel resentful, and I guess angry, frustrated but I have to live with it”; “I don’t like asking for help”; and “A major problem is not adjusting to disability, but adjusting to peoples attitudes.”

SOCIAL SUPPORT

The group members rarely discussed the people in their lives that they could count on when in need. Instead, there were frequent comments about not wanting to be a burden to anyone. In contrast, they saw the group as an important source of social support: “At least we have each other,” and “These meetings are the highlight of my week.”

HEALTH ISSUES

In general, the group members felt that they were managing their health issues as well as could be expected given the stage of progress of their individual diseases. Perceptions of the limitations imposed by the disease were balanced against reports of how well they were

managing. Example responses, “I can’t do as much but I can still get around the house, do some cooking and watch television” and “I always take my medications at the right time—things would get worse if I didn’t.”

GROUP BONDING

An important finding was our observation of the degree of group bonding and cohesiveness that was evident in all three groups. Because the Internet-based videoconferencing could support only one person in the active window, we had expected that the development of group cohesiveness typical of face-to-face groups would be compromised. Contrary to expectations, analysis of the group sessions showed that group members bonded, identified with each other’s self-care situations, and provided each other with empathic support throughout the intervention program.

FOLLOW-UP INTERVIEWS

The analyses of the follow-up interviews were organized in three categories that paralleled the interview guide questions: a) responses to learning to use technology to access health services; b) responses to the usability of the Web site that supported the intervention program; and b) the benefits, if any, of having participated in the online support group.

RESPONSE TO USING TECHNOLOGY TO ACCESS HEALTH SERVICES

More than half of the participants had never used computers. All were willing to have hardware installed in their homes and were very receptive to the training sessions provided by the project technician. A simplified training manual that focused primarily on negotiating the CFM Web site links was used. The follow-up feedback regarding using computers revealed some negative comments concerned with malfunction of equipment, Web site software problems, and problems with their Internet service provider. Despite these equipment-related frustrations, the majority of the participants persisted in accessing the Web site to engage in the group support program.

Participant feedback on the usability of the Web site was in large measure positive. Most accessed the Web site for the weekly videoconferencing group sessions. Participants who had no prior experience with computers or the Internet particularly valued access to the easy-to-use e-mail service imbedded in the Web site. Examples of participant responses to using technology to communicate with each other and health professionals follow: “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 a government health program)”; and ‘Great opportunity to learn about technology.’ Seventy-eight percent indicated that the Web site was easy to use and 95% felt that using computers to meet in the online group was very positive or moderately positive.

HELPFULNESS OF SUPPORT GROUP

Attendance at the weekly meetings varied within each of the three groups. One group had good attendance throughout the facilitated and mutual self-help sessions. For the other two groups, a core group attended regularly, while several members attended more sporadically. However, despite this variation in attendance, most participants reported benefits from their involvement in the project. Sampled dialogue portrays an array of feedback from the participants. “People in the group are trying to help each other and nobody is there to laugh at you or judge you”; “We are all in 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”; and “This was a new and very positive experience for me.”

When asked to compare the helpfulness of the online support group compared with a clinic-based face-to-face support group, the following comments were made: “It is better for people who have a 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”; and “It’s better because you are not distracted by anything, it is better than (clinic group).”

Discussion and Conclusions

The analysis of the project results show that older adults with a chronic disease can be trained to use computer hardware and software to access the Internet and negotiate links of a Web site (Caring for Me [CFM][®]) specifically designed for older adult users. The aim of the program was to deliver an in-home healthcare intervention to chronically ill older adults who manage their own healthcare, frequently without the support of family members or friends. The challenge was to demonstrate that older adult computer nonusers could be trained to use hardware and software to access a Web site that was designed to address the physical limitations of aging disabled adults. A second challenge was to show that the analysis of the online support group discussion themes would be clinically relevant in terms of the concerns shared by older adults living with a chronic disease.

In terms of responses to the use of technology to access health services, the qualitative analysis of the follow-up interviews showed

that older adults with limited prior experience using computers could be trained to manipulate hardware and software to access the Internet and negotiate the CFM[®] Web site links. Some participants reported initial hesitation in learning to use the equipment. However, as familiarity with the CFM[®] Web site increased, participants became more confident in using each of the links and were pleased with their ability to acquire a new and useful skill. At follow-up, what the participants valued the most about the technology platform was being able to communicate with others and being able to access a healthcare support program from the comfort of their homes.

Session analyses of the CFM[®] online group model of intervention with older disabled adults showed that the intervention could be professionally delivered and that the extracted group discussion themes appear to address key issues of importance to persons with a chronic health condition. For example, the analysis showed that the disabled feel marginalized and in some ways lose a sense of positive self-identity. Although not measured, we can speculate that depression may be a comorbid condition with many chronic diseases. Despite the limitations of our online group videoconferencing, the CFM[®] Web site videoconferencing format appears to support group cohesion similarly to what occurs in face-to-face groups. Analysis of the participants’ perception of the usefulness of the online support group intervention follow-up interviews showed that participation in the online support groups reduced the participants’ sense of isolation and loneliness, while encouraging maintenance of optimal healthcare strategies.

In conclusion, our Internet-based, videoconferencing intervention program for older chronically ill older adults was readily adopted by the participants, even those who had no prior experience in using computers or accessing the Internet. Of particular note was the positive response to being able to access healthcare services from the comfort of their homes. Because of the lack of transportation and harsh winter weather conditions, many of the participants lived an isolated existence. Consequently, they were grateful to be able to make new friends during the course of their involvement in the online groups. The weekly meetings provided an occasion for socializing as well as gaining self-care information and sharing strategies for optimizing self-care of their chronic conditions. The CFM[®] program shows promise as an effective way of providing supportive interventions to older adults with chronic disabilities.

Study Limitations

Due to the small and heterogeneous sample, the results of the study cannot be generalized. An important lesson learned was that disabled older adults are not resistive to using technology to access healthcare

services. Our current work involves the development and evaluation of e-health intervention programs for disease-homogeneous groups of adults: type II diabetes, first stroke survivors, and chronic obstructive pulmonary disease. We continue to focus on understanding and addressing the barriers to compliance with recommended self-care medical regimes following diagnosis and postacute care of a chronic disease.

Disclosure Statement

No competing financial interests exist.

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Address reprint requests to:

Elsa Marziali, Ph.D.
Kunin Lunenfeld Applied Research Unit
Baycrest
3560 Bathurst Street
Toronto, Ontario M6A 2E1
Canada

E-mail: elsa.marziali@utoronto.ca

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