

Computer Networks Promote Caregiving Collaboration: The ComputerLink Project*

Patricia Flatley Brennan, RN, PhD, FAAN
Associate Professor of Nursing and Systems Engineering
Case Western Reserve University
Frances Payne Bolton School of Nursing
2121 Abington Road, Room 304F
Cleveland, Ohio 44106-4904

Voice: 216-368-5130
FAX: 216-368-3813
e-mail: pfb@po.CWRU

*Supported by a grant from the National Institutes on Aging, AG8617

ABSTRACT

ComputerLink is a specialized computer network designed to support caregivers of persons with Alzheimer's Disease. ComputerLink delivers information, communication, and decision support, accessed through home terminals. It stands as a unique demonstration of how information technologies support collaboration among family caregivers of persons with Alzheimer's Disease, and between caregivers and professionals. In a randomized field experiment involving 102 AD caregivers, 47 caregivers had access to ComputerLink for 12 months, during which they accessed it 3888 times. Behavioral indicators of use demonstrate that ComputerLink promotes collaboration by providing pathways for communications among caregivers and by facilitating their access to information.

INTRODUCTION

Information technologies play a well-recognized role in supporting collaboration among health care professionals. Less well-recognized is the important role of information technologies in promoting collaboration between health care professionals and the family caregivers of persons with chronic illness, and among the caregivers themselves. As part of a larger experiment on technology in home care, the ComputerLink was constructed to provide information, communication, and decision support to the caregivers of persons with Alzheimer's Disease (AD). This paper employs behavioral measures of use to show how ComputerLink fostered collaboration between AD caregivers and health care professionals and among the group of AD caregivers.

Caregiving collaboration occurs along two dimensions: collaboration with the professional health care system, and collaboration with peers facing similar challenges. To collaborate implies that one acts with another towards a similar goal, each starting from positions of power (Power, in this case, means knowing

participation in an endeavor). Communication among collaborating parties is necessary for it is through interaction that shared concerns emerge and joint solutions arise. Information and the opportunity to evaluate options and rehearse decisions also prepares the caregiver to collaborate. Information technologies, such as computer networks, provide portals to information and pathways of communication that enhance AD caregivers' ability to collaborate in the challenge of providing quality care to the person with Alzheimer's Disease.

BACKGROUND

Approximately three million persons in the US suffer from Alzheimer's Disease (AD). Alzheimer's Disease leads to a progressive destruction "of a person's ability to understand events and people in his or her environment and to plan and take care of himself or herself" [1]. Family members and friends must take on a caregiver role, insuring the AD patient's safety and providing assistance with activities of daily living. AD caregivers face a myriad of challenges as they attempt to care for their loved one [2]. A major challenge lies in accessing peer support and professional consultation. A second challenge lies in gaining sufficient information and resolve to make choices about care. Although formal health and social service programs exist to meet these two needs, at least one-half of the caregivers who could benefit from services do not use them [3]. Several reasons are advanced for this: stigma, lack of time and transportation, lack of knowledge about the service, and no one to care for the elder person [1]. Through appropriate use of information technologies these barriers can be surmounted, and AD caregivers can maintain contact with peers and professionals, and gain access to information in a timely and convenient manner. This contact facilitates development of a collaborative relationship; additionally, the information available enhances the caregivers' abilities to fully participate in health care decisions.

The most common use of information technologies in health care is communication among and record-keeping for, health care professionals. However, these technologies also make effective devices for delivering health promotion, risk assessment, and clinical services in the community [4]. Some of these computer applications are free-standing, special purpose programs, such as Balance, a program created to plan balanced diets [5]. Other systems use telephone lines to make links from computers placed in remote sites. In an innovative early program, the "Electronic Grandparent" project linked elders in a nursing home with children in a day care setting via computer terminals and telephone lines [6]. The *Senior Net* [7] employed a computer network to provide elders with home-based interaction via an electronic network. ComputerLink differed from earlier efforts in that it was systematically designed to reach AD caregivers, give information and facilitate communication.

ComputerLink

ComputerLink is an electronic network designed to bring support services to AD caregivers in the home. Computer networks, electronic links between remote sites, provide the foundation for creating collaborative pathways between caregivers and health care professionals, and among caregivers. Technologically-based interventions, like ComputerLink, hold great promise for reaching caregivers in a timely, convenient manner. These technologies bring to caregiver too busy or unable to leave home many of the benefits of support groups and other service interventions [8], relevant information, peer advice and professional counsel. ComputerLink helps caregivers stay in touch with each other.

ComputerLink is a specialized set of computer programs accessible to caregivers from their homes via computer terminals and phone lines. ComputerLink includes three functions: information, communication, and decision support. This report details the second ComputerLink experiment; the first ComputerLink, designed to reach AIDS victims, is reported elsewhere [9].

ComputerLink Functions

Functionally ComputerLink provides three services to caregivers: information, communication, and decision support. The Electronic Encyclopedia (EE) includes over 200 pages of information relevant to AD, designed to help caregivers enhance self care, understand illness-specific issues, and promote home-based management. Information is organized under four themes: Caring for Oneself, Caring for the Person with AD, Services, and Current AD Research. Users can browse through the Electronic Encyclopedia in a screen-by-screen manner, select topics from a key-word listing, or search using specific words and phrases for desired information.

The communication area permits several options for public and private communication among users. In an unrestricted bulletin board ("The Forum") any user can read, post and respond to issues of concern and interest. Private electronic mail affords one-to-one interaction away from the scrutiny of others. In a special feature

combining private mail with The Forum, "Q & A", users can send questions anonymously to the nurse moderator, who answers the question and posts it for all to read.

In the decision support module English-language questions guide users in an analysis of a self-defined decision problem. For some users, the decision problems focus on selecting living arrangements. For other users, intimate questions of relationships are the focus of the analysis. The analysis strategy, decision modelling [10], helps the user focus on the values and trade-offs that occur during difficult choices. The decision support module permits users to explore their values, and to select choices that best meet their own stated values.

ComputerLink Equipment

The ComputerLink consists of hardware, phone lines, and software. The core computer is an IBM B600. The specific programs and utilities that make up the ComputerLink run within the Cleveland Free Net, a six-year old free, public access computer network. All programs were written in 'c' by the CWRU Information Network Services staff. Caregivers access ComputerLink via Wyse 30 terminals placed in their homes. A 1200 baud modem provides the connection between the terminal and standard telephone line. Users enter the ComputerLink through the CWRU modem bank. Successful access occurs in over 95% of desired encounters.

ComputerLink Clinical Staff

One project nurse oversees the ComputerLink. As moderator, the project nurse reads all public areas daily, maintains the currency of the electronic encyclopedia, and troubleshoots for participants. The project nurse plays two key roles: group facilitator and clinical expert [11]. In the group facilitation role the project nurse monitors public communication and individual participation, and contributes messages to the public forum designed to systematically foster member-member collaboration. The ComputerLink serves as a "support group without walls", and the project nurse leads the group. This role is complicated by communication challenges facing the nurse, who relies solely on written communication to interact with the group. As clinical expert, the nurse applies nursing and supporting theories to answer questions posed by users in the Q & A area, as well as facilitating collaborative problem solving on the Forum.

ComputerLink provides a vehicle for interaction, thereby directly facilitating collaboration. ComputerLink also indirectly influences subsequent collaboration by preparing caregivers to participate in health care decisions. Several features of ComputerLink may also help caregivers better collaborate in the health care of their loved one. Through ComputerLink's Electronic Encyclopedia, caregivers can learn about other services; information about services introduce caregivers to new options, thus preparing them to discuss alternatives with health care professionals [12]. The communication utilities help caregivers stay in touch with each other thereby enhancing the likelihood that caregivers can share common wisdom and information. ComputerLink also

provides a vehicle for peer support; this support in turn can provide the motivation or resolve to initiate service use. Through ComputerLink, caregivers can get professional advice and counsel from the nurse moderator. Finally, the decision support system available on ComputerLink permits caregivers to rehearse decisions and clarify values, two necessary steps in the collaborative participation with health care professionals.

The mere existence of an innovation does not ensure that it will be adopted [13]. Evidence suggests that despite the almost universal availability of telephones, and the relative ease of maintaining phone contacts, telephone reassurance services are rarely used [14] [15]. One must first demonstrate that an innovation is accessible, understandable, and comprehensible, congruent with the values of the intended user, and presents a relative advantage over other services required by an individual [16]. ComputerLink meets these first tests of successful innovations [17]. However, its place as a vehicle for collaboration can only be demonstrated by evidence that the interaction and information deemed necessary for collaboration did occur. This report presents behavioral evidence that ComputerLink promotes collaboration.

PROCEDURES

Sample

100% of the sample needed for the randomized ComputerLink experiment (n = 102; 51 experimental ComputerLink; 51 comparison) was recruited. Four subjects dropped out during week one; two after month 6.

Caregiver subjects in the entire experiment included 96 individuals who considered themselves to be the primary caregiver of a person with AD, sixty-four females and 32 males, with a mean age of 60. Care recipients were spouses (57%) and parents (30%), and required care for an average 34.5 months (s.d. 26.8). This sample is representative of other study samples of caregivers of elderly patients [18]. Thirty-two percent of the subjects stated that they care for someone in addition to person with AD. Twenty-six of the subjects (26%) in this sample placed their loved one in a nursing home during the one-year study period. Subjects were randomly assigned to conditions; caregivers in the experiment did not differ from comparison subjects on any demographics.

Installation and Unexpected Events

The project nurses visited each participant, installed the computer terminal in the home, and provided initial and on-going training for the system. Two masters' prepared nurses with community health nursing experience established the 90 minute training protocol, and conducted all training in the subjects' homes. A demonstration and return strategy was employed; only four subjects required follow-up visits to review training. Subjects had access to the ComputerLink for a period of twelve months. Technological problems in ComputerLink use (telephone line interrupts, equipment breakdowns) occurred only 10 times during the project period. When possible, staff handled all problems via telephone; where this was not possible, additional home visits were made.

Variables

Behavioral indicators of use (counts of access, content of messages) serve as the data for this report. Behavior is the most common [19] and most accurate [20] measure of computer network use.

ComputerLink Use. At each encounter, a passive monitor created a record of all functions accessed by the subject on the ComputerLink. The record includes the time of day, duration in each section, and sequence of function access. Data were recorded on subject use of the Forum, Q& A, Mail, Electronic Encyclopedia, and Decision Support sections.

ComputerLink Transcripts. Transcripts of all Forum communication and all Q and A activity are available in paper form and electronically. Caregivers could post messages or questions on any topic. No restrictions were placed on caregivers in terms of topics or frequency of message postings or questions.

RESULTS

This report demonstrates how ComputerLink use facilitated collaboration through enhancing communication and providing information to caregivers. The 47 experimental group members accessed ComputerLink 3888 times over the course of the experiment. Subjects accessed the ComputerLink a mean of 84 times; one subject use reached 600 times. A typical encounter lasted 12 minutes, and included use of two or more functions. AD caregivers accessed the communication areas most often, spending an average of 10 minutes of each encounter reading the Forum.

Table 1 summarizes ComputerLink use, an access to a specific function on ComputerLink, by the time spent in each function. Following the table, a discussion provides an exploration of the substantive content read or posted by the caregivers within each function.

Table 1: ComputerLink Feature Uses

Feature	# of Uses	Minutes Duration (SD)
Electronic		
Encyclopedia	541	9.34 (10.32)
Private Mail	2019	5.78 (9.34)
Forum	3312	9.87 (12.15)
Q & A	878	3.14 (4.95)
Decision Making	106	7.65 (7.92)

(Note: More than one function accessible in an encounter).

Caregivers sought information from the Electronic Encyclopedia over 500 times, and spent an average of ten minutes reading in this area each time they entered it. Caregivers could access as many sections as they desired; they reviewed information on Caring for Oneself, 143 times; Care for the Person with AD, 241 times; Services, 107 times; and Current AD Research, 159 times. Private mail was used extensively (over 200 of the 1000 connect hours were spent in this area); private mail is unavailable for analysis out of respect for the privacy of the users.

Caregivers posted 749 messages in the Forum. Caregivers could initiate a new topic or respond to another member's contribution. Some messages were brief, with

fewer than 50 words. Others were lengthy. Message content was highly reflective of all dimensions of social support identified by Antonucci and Jackson [21] [22]. Discussion topics included the behavior of the AD person, choosing care sites such as day care or nursing homes, local news events and reminiscing about family events. A sample dialogue is included below in Figure 1.

From: Dorothy
Subject: Idle time
My husband is in the middle stages of the disease and I would like Some suggestions on how to occupy his time other than walking. When he doesn't have anything to do, he seems to want to nap during the day.
From: e.k
Subject: Re: Idle time
Dorothy I also have a problem with my wife who likes to walk and gets bored! She loves to rearrange her draws in her dresser! I fix and she rearranges them it gives her something to do! They always seem to want to be occupied and want to help but is a hard for her! do your best on this subject
From: SB
Subject: Re: Idle time
... I noticed a reply to Idle Time. Idle time is a real tough one. My mother in-law is ... in middle stages. She always wants to be doing something when she is home. I have a real hard time trying to figure things for her to do. She loves to go shopping. I try doing that a few times during the week or I take her for a ride. I have children books we try reading. I have her read and sort playing cards. ...believe me it is not enough. The weekends are the worse. Are there things for them to do without you or I should say me having to be right with them Are there things for them to do without you or I should say me having to be right with them. That is the problem!! Has anyone out there found something for our love ones' to do on there own? ...

Figure 1. Dialogue from the Forum (Verbatim)

Thirty questions were posted on the Q and A area. Four main themes emerged in the questions: Managing the Person with the Disease (6), Traveling with an AD Person (5), Managing One's own Feelings (6), Preparing for Death (7). Other topics, including Handling Legal Issues (1) and Individual Member Concerns, consumed the remainder of the 30 posted questions. Despite the few posted questions, subjects accessed Q&A over 800 times.

Caregivers used the decision support system to analyze a wide variety of decisions. Examples included "Shall I place my mother in a nursing home", "communicating with co-caregiver" and "where shall we live". Relative to other functions, the decision making area was used least often (n = 106). Most subjects accessed this section once, and one subject, 38 times.

Comments from the experimental group indicate that they found the computer network as a place to come to communicate and receive support from others who share similar concerns. Content analysis of the messages placed on the Forum indicated that subjects gleaned instrumental

assistance about how to obtain services or deal with a caregiving problem, and contributed expressions of emotions, moods, and feeling states. Statements of perceived social support were frequently expressed. Individual and group therapeutic responses were used on the network by the nurse moderator [22].

Individual caregivers varied greatly in their use of ComputerLink. Some posted messages on the Forum daily, contributing comments about their daily lives, querying others about situations, and asking for advice. These are called these users "active" users. Another pattern of use is labeled "observers" -- these individuals accessed ComputerLink frequently but rarely typed messages or sent private mail. Their activities consisted of reading the Forum or the EE. It is plausible that both of these patterns facilitate collaboration.

DISCUSSION

Forty-seven caregivers of persons with Alzheimer's Disease successfully used ComputerLink. Their behavior on the ComputerLink attests to its value as a vehicle for promoting collaboration. The extensive use of the communications area indicates that ComputerLink facilitates peer communication, and fosters collaboration among caregivers. The most commonly used section of the Electronic Encyclopedia, "Caring for the Person with AD", suggests that ComputerLink also fostered collaboration by providing caregivers with information necessary to provide care and interact with professional caregivers. ComputerLink was least often used by these caregivers as a mechanism for interacting with professionals (the project nurse).

ComputerLink was designed to mimic the functions of social service interventions that facilitate collaboration, including support groups (peer interaction, socialization, group support); counselling (decision making, advice from an expert nurse) and educational service (information). Evidence from the transcript in Figure 1 further demonstrates how ComputerLink supported collaboration.

ComputerLink offers several advantages over formal services. ComputerLink communication is written rather than spoken and asynchronous. This creates a situation of social anonymity and reduced stigma, which in turn leads to less inhibited and more assertive communication. Relationships formed over computer networks are as likely to reflect intimacy as those found in face-to-face encounters [23], and occur in a manner more convenient and timely than support groups. Because the messages posted to the computer remain permanent, the content can be retained and accessed for long periods of time [24].

In several important ways ComputerLink differs from other social services. This differences do not diminish the appropriateness of considering ComputerLink a vehicle for collaboration; rather, they serve to illustrate the unique benefit and potential value-added dimensions of information technologies. ComputerLink served as a 24-hour-a-day channel through which caregivers could exchange experiences, therefore, collaborate, and gain information. This availability not only provided

caregivers with easy access at a time convenient to them, but also engendered a sense of omnipresent support. Additionally, caregivers had a maximum amount of control in using ComputerLink (their very presence on the network as they read messages or information could not be easily detected). This control is evident in the choices for "active" and observing behavior. The sense of control and access to peer support engendered a sense of power that in turn enhanced the caregivers' abilities to collaborate.

ComputerLink fostered collaboration with professionals in three ways: rehearsal of decisions, acquisition of information and direct contact with the project nurse. The low numbers of contacts with the project nurse may have been due to the fact that this nurse was not viewed as a primary care provider. Perhaps a more precise tests of ComputerLink's availability to foster collaboration with professionals would be through providing a link directly with an individual caregivers primary health care professional.

Behavioral evidence of computer use, although common [6] [19] provides only one dimension of evidence. Further evaluations of ComputerLink's effectiveness will include subjective measures of caregivers' senses of social support, decision making confidence and skill.

CONCLUSION

Information technologies like ComputerLink provide vehicles for peer collaboration around complex health care problems. Effective use of existing technologies overcomes barriers to collaboration, and supports the caregiver in a timely and convenient fashion. This report is one of the first to demonstrate that computer network services do achieve the goal of fostering collaboration among peers sharing a similar problem, and prepare individuals to better participate in health care decisions.

References

- 1 [OTA] U.S. Congress, Office of Technology Assessment. (1990). Confused minds, burdened families: Finding help for people with Alzheimer's & other dementias (Report No. OTA-BA-403). Washington, DC: U.S. Government Printing Office.
- 2 Brody, E. M. (1985). Parent care as a normative family stress. The Gerontologist, 25(1), 19-29.
- 3 Noelker, L. S. & Bass, D. M. (1989). Home care for elderly persons: Linkages between formal and informal caregivers. J Geron: SocSci, 44(2), S63-70.
- 4 Gustafson, D. H., Bosworth, K., Chewing, B. J., & Hawkins, R. (1987). Computer-based health promotion: Combining technological advance & problem solving technique to effect successful health behavior changes. AnnRev Pub Health, 8, 387-415.
- 5 Clark, K., & Ellis, L. (1982). Balance: An interactive program for the design of balance study diets. In B. Blum, ED. SCAMC Proceedings. Los Angeles, CA: IEEE Computer Society.
- 6 Kerr, E. B. & Hiltz, S. R. (1982). Computer-mediated communication systems. NY: Academic
- 7 Greenberger, M. & Puffin, J. (1989). Facilitating communication with the older person, 2(2), 153-170.
- 8 Gonyea, J. G. (1989). Alzheimer's disease support groups: An analysis of their structure, format and perceived benefits. Soc Wrk in Hlth Care, 14(1), 61.
- 9 Brennan, P. F., Ripich, S., & Moore, S. M. (1991). The use of home-based computers to support persons living with AIDS/ARC. J Com Hlth Nsg 8(1), 3-14.
- 10 vonWinterfeldt, D. & Edwards, W. (1986). Decision analysis and behavioral research. Cambridge, MA: Cambridge Press.
- 11 Ripich, S. F., Moore, S. M., & Brennan, P. F. (1992). Using group interventions for clinical problem via a computer network. Journal of Psychosocial Nursing, 30(7), 13-20.
- 12 Fortinsky, R., & Hathaway, T. J. (1990). Information and service needs among active and former family caregivers of persons with Alzheimer's Disease. The Gerontologist 30, 604-609.
- 13 Romano, C. A. (1990). Diffusion of technology innovation. Adv in Nursing Science, 13(2), 11-21.
- 14 Collins, C., Stommel, M., Given, C. W., & King, S. (1991). Knowledge and use of community services among family caregivers of Alzheimer's Disease patients. Arch Psychiatric Nursing, 2, 84-90.
- 15 Goodman, C. C. & Pynoos, J. (1988). Telephone networks connect caregiving families of Alzheimer's victims. The Gerontologist, 28(5), 602-605
- 16 Rogers, E. M. (1983). Diffusion of Innovations. New York: Free Press.
- 17 Brennan, P. F., Moore, S. M., & Smyth, K. A. (1991). ComputerLink: Electronic support for the home caregiver. Adv Nursing Science, 13(4), 14-27.
- 18 Stone, R., Cafferta, G. L., & Sangl, J. (1987). Caregivers of the frail elderly: A national profile. The Gerontologist, 27(5), 616-626.
- 19 Bosworth, K., & Gustafson, D. (1991). CHES: Providing decision support for reducing health risk behavior & improving access to health services. Interfaces, 21, 93-104.
- 20 Srinivasan, A. (1985). Alternative measures of system effectiveness: Associations and implications. MIS Quarterly, 9(1), 243-253.
- 21 Antonucci, T. C., & Jackson, J. S. (1990). The role of reciprocity in social support. In B. R. Sarason, I. G. Sarason, & G. R. Pierce (Eds.). Social Support: An Interactionist View. (pp. 173-198). NY: Wiley.
- 22 Brennan, P. F., Moore, S. M., & Smyth, K. A. (1992). Alzheimer's disease caregivers uses of a computer network. Western J of Nursing Research.
- 23 Mihalo, W. E. (1985). The microcomputer and social relationships. Comp&Soc Sciences, 199-205.
- 24 Rafaeli, S. (1986). The electronic bulletin board: A computer driven mass medium. Comp& Soc Sci, 2, 123-136.