Nursing Informatics
U. Gerdin et al. (Eds.)
IOS Press 1997

The ComputerLink Projects: a Decade of Experience

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Telecommunications technology provides a pathway for nurses to reach patients and their family caregivers. The ComputerLink, an experimental computer network, enabled home-bound persons to access information, communications, and decision support services from their homes. Persons naive to computers can and will use telecommunications to maintain contact with peers and professionals. While participants in experimental networks used communication services most often, the access to relevant health information in a timely and convenient fashion may contribute more to the positive health benefits. Nursing interventions need to be tailored to capitalize on the unique features of computer network. The timing, cadence and content of interpersonal interactions must be modified to account for lags in the transmission of messages. Strategies for interpreting written text, which lacks the aural cues found in spoken speech, must be developed.

Introduction

The development of inexpensive, reliable, telecommunications technology enables caregivers, patients, and the general public to access health information and health care resources directly from their homes and from public gathering places such as libraries, schools and workplaces. Through computer networks, telephone messaging service and other initiatives, nurses have a unique opportunity to reach patients and clients with health promotion, disease prevention, and illness management nursing interventions. Telecommunications-based health services also pose unique challenges to modify existing nursing interventions and devise new ones to take appropriate advantage of the electronic environment. Telecommunications initiatives hold great promise for extending the ability of nurses to reach individuals in the community. Research is progressing in this area, and demonstrations of innovative network-based nursing interventions are emerging. Over the past 10 years colleagues at Case Western Reserve University developed, implemented, and evaluated the ComputerLink, a computer network-based intervention for ill persons and their family caregivers. Slowly, through the professional literature, presentations at conferences, and informal discussions, the characteristics of telecommunications-based health services, illustrates key lessons learned with evidence from the ComputerLink experiments, and proposes modifications in nursing interventions.

The ComputerLinkprojects

ComputerLink provided three services to users: information, organized in an Electronic Encyclopedia; communication, including public bulletin boards and private mail, and a decision support service. One ComputerLink served persons living with AIDS (PLWA: NR 2001)[1] ; the second targeted caregivers of persons with Alzheimer's Disease (AD Caregivers; AG 8614)[2]. Participants in the research projects used Wyse30 computer terminals based in their homes and linked via plan, ordinary telephone systems (POTS) to a computer network. Each of the ComputerLink networks had a project director who served as the nurse moderator of the system. The nurse moderator made an initial in-home visit to each participant to assess his/her needs and trained the user in the use of the ComputerLink system. The nurse moderator reviewed electronic messages, monitored user log-on behavior, responded via

electronic mail to users' questions, and facilitated electronic discussions. The ComputerLinks each provided three services. The Electronic Encyclopedias consisted of information screens designed to enhance self-management, promote effective home-based treatment of patients and promote patient/caregiver understanding of illness-specific issues. The Communication service included several public/private options: (1) an unrestricted public bulletin board, which allowed users to post by name or anonymously anything that was on their minds for open, ongoing discussion; (2) private electronic mail, through which users could send and receive their own private electronic mail, including messages from the nurse moderators answering their personal health care inquiries; (3) a question/answer area, in which answers to questions posed anonymously by users were posted by the nurse moderators. The third service, Decision Support, helped ComputerLink users make choices about which personal decisions were necessary, how they could best express these decisions, and how they could best generate insights for such decisions.

The effects of the ComputerLink interventions were evaluated in field experiments. Sixty PLWAs participated in a 6-month field evaluation; 102 AD caregivers participated in a 12-month field evaluation. Each group was randomly halved, with one group receiving typical home care and the other using ComputerLink. The operational period lasted for a four-year period (1989-1992) to accommodate the two field experiments. There were approximately 15,000 log-ons to both ComputerLinks, averaging 10-13 minutes per log on.

All PLWAs in the experimental group accessed the ComputerLink (mean access count per subject 297; median 129); generally subjects accessed the system twice a day. Over the entire experimental period, PLWAs accessed the system a total of 8,449 times. A typical encounter with the PLWA ComputerLink lasted 12.5 minutes. PLWAs used the ComputerLink at all hours of the day and night. Most encounters occurred between 10 PM and 3 AM and included use of at least two ComputerLink functions. All AD caregivers in the experimental group also accessed the network, making a total of 3,875 accesses to the AD ComputerLink. AD caregivers accessed the ComputerLink a mean of 83 times (s.d.101.86). The mean length of encounter was about 13 minutes; most accesses involved the use of two or more features. In both ComputerLink studies, users accessed the communications area most often (in at least 85% of all encounters) and spent most time in this area (average of 10 minutes in a 12-13 minute encounter). Participants in both experiments used the Decision Support areas less often than other services of the ComputerLink (89 times by the AD Caregivers; 140 times by the persons with AIDS).

Comments from users revealed that ComputerLink served as a "support system without walls" for homebound PLWAs and Alzheimer's caregivers. Statistical resolution of hypotheses revealed modest effects of ComputerLink on decision making and social isolation. Among PLWAs, use of ComputerLink led to a reduction in social isolation once the effects of depression were controlled (r2 .39; F 16.24; df 2, 48; p .01). Among AD caregivers, ComputerLink led to improved confidence in decision making (net change ComputerLink Group +1.53; Control Group -0.20; F = 9.73; df 1,93; p 0.001). The randomized field experiments employed to evaluate the ComputerLink projects revealed that access to ComputerLink improves decision making confidence but not decision making skill, and, for some persons, leads to a mitigation of the negative effects of caregiving[3]. In a collaborative effort with local community service groups, the experimental network services were migrated to free, public access systems and continue to be accessible to interested persons.

Community health information networks and patient care

The ComputerLink is one example of an emerging type of Community Health Information Network (CHINS[4]). CHINS initially served as data transfer pathways, linking hospitals, physician offices and community health centers. Recently, CHIN functionality has expanded to include clinical applications such as point-of-service decision support and outreach to patients and families using telecommunications technology. The Comprehensive Health Evaluation and Social Support project (CHESS[5]) employs a client-server model to implement disease-specific counselling and support services. Like ComputerLink, CHESS provides home-care support to ill persons, targeting women with breast cancer and persons living with AIDS. CHESS differs from ComputerLink in two important ways: (1) CHESS is a free-standing system, not a special set of services within a larger network; (2) CHESS employs a more sophisticated interface than ComputerLink, one that supports graphics and sound but that also requires a more complex and expensive personal computer platform. Other community-based telecommunications endeavors do not require computer devices but make use of common telephones. Telepractice[6] uses a voice-telephone platform to provide social support and clinical management for women in high-risk pregnancies, and has been expanded to assist visiting nurses in caring for persons with chronic cardiac disease. Health maintenance organizations have initiated telephone-triage and Internet connections for patient education[7].

Lessons learned

Persons naive to computer systems can and will use computer networks.

Stereotypical concerns about computer network interventions consider certain groups (elders, the poor, minorities, persons in impaired health states, etc.) as unlikely to use computer network interventions. The experiences of the ComputerLink projects, as well as that of all other clinically-focused CHINS, dispels this concern. Over 500 persons identified as ill with a given problem or as a caregiver of an elder have successfully used these interventions. Training is required; generally one-to-two hours of training is sufficient to gain adequate skill to use the basic features of the system. Additionally, the ComputerLink evidence shows that participation will endure; at 6 months into the study, 50% of all participants access the system at least twice a week; at 12 months into the study, 33% were still making regular access, and five years after the close of the experiment, 20% of the original group remains active.

Participants use communications features extensively.

When a computer network system provides several services (for example, the ComputerLink provided information services, communication and decision support services) the communications services are used most often. Over 80% of the time that AD caregivers accessed the ComputerLink they used at least one of the communications features. The ratio of communication use to any other service use was 1:9, indicating that for every access to the information or decision support services, there were 9 accesses to the communication services. This ratio approximates the 10:1 ratio found in other computer network services[4].

Participants develop characteristic patterns of use.

Computer network communication is particularistic and unique to individuals. Some participants used the system only rarely; others, like the champion user in the PLWA ComputerLink, accessed the network almost 1,500 times in a 6-month period. Individuals also demonstrated a range of active behaviors (typing, conducting a decision analysis) and observing behaviors (reading messages, reading the encyclopedia), with observing behaviors being the more common. Understanding the range of user behavior provides a basis to plan interventions. Recognizing that most participants will be observers rather than display an active presence alerts the nurse to be mindful of the unseen, yet present, participant.

Computer-mediated communication can be as rich and as expressive as face-to-face communication.
Post-experimental interviews of the participants in the AD Caregivers ComputerLink revealed communication with others as the primary reason why persons used the ComputerLink. The messages addressed issues of caregiving, living one's life as a caregiver, and commentaries on events of daily living. Many times the messages included content that was highly emotional. For example, phrases such as "I feel so helpless sometimes" contains manifest content of the feeling of despair. In addition to explicit emotional language, affect is also demonstrated through alterations in character spacing and case. Typing in uppercase, for example, makes an explicit emotional statement through the electronic equivalent of shouting. Electronic communication is purposeful, requiring that the sender and receiver must deliberately turn on the computer and access the specific communication sections of the ComputerLink. Because printed words are the only aspect of a person that is visible on a computer network, the act of typing words initiates the sending part of a communication. Unlike members of a support group, where posture, eye contact, and orientation serve as a non-verbal invitation to respond, computer network users required action to communicate.

Complex social and psychological processes give rise to frames of reference within which we experience and interpret interpersonal communication. Interpersonal communication in an electronic environment rests on presentation of words on a computer screen. Certain words, however, may evoke gender-specific images or attitudes. Lacking aural cues, clinicians must scrutinize their own perspectives to insure that the messages read are interpreted to reflect the content and contribution of the sender, not the interpretive frame of the receiver.

Information use is powerful.
Participants in both ComputerLink projects accessed the Electronic Encyclopedia on about 10% of the encounters. Despite rather sparse use, reading this material appears to have had strong, positive benefits. Consistent with the experience on other networks, accessing information services is more beneficial than the familiar, but potentially neutral, act of communication.[3,4] It remains to be determined whether the effects emerge from convenient access to information at a time when it is most needed by the individual, or if it arises from information delivered in the context of the computer network, where peer support may provide a propitious environment for acquiring and incorporating information into self-care.

Partnering with service providers helps create content.
Teams involved in the construction of electronic networks for patient care strive to include members with expertise in the identified clinical area. These clinical experts provide guidance in the developing of information. Additionally, partnering with health service providers or voluntary groups provides ready access to up-to-date clinical content. In the case of the PLWA ComputerLink, our group partnered with the hospital-based AIDS clinic. For the AD Caregivers, the local chapter of the Alzheimer's Association became the clinical partner. The partnership benefits both parties; the computer network intervention gains access to relevant, appropriate information and the clinical service partner gains a vehicle for dissemination.

Partnering with service providers promotes system endurance.
Successful endurance of computer network interventions depends on building in from the beginning a plan for partnership and technology transfer with service providers. Features of the experimental systems that provided popular and valuable can be re-created in computer network delivery systems. The Alzheimer's Association of Greater Cleveland now operates the "Caregiver's Forum", a second generation of the ComputerLink now accessible via the

Internet to all interested persons (to access, telnet to freenet-in-b.cwru.edu, enter as a visitor and enter "go alz" at the menu).

Summary: New directions for nursing interventions

Computer networks both exist as discrete nursing interventions and provide pathways within which nurses can reach patients and deliver nursing interventions. They have the potential to provide a gathering place where persons sharing like concerns can congregate and exchange ideas, obtain social support, and participate in problem solving.[2] Electronic networks serve as educational vehicles wherein interested persons can obtain information, try out new behaviours and attitudes, and evaluate life style options. Finally, because they can be constructed to meet the specific needs of populations, electronic networks provide a means for focusing on and solving the problems of a specific group.

Examples of nursing interventions that can be delivered via electronic networks[8] include guiding, teaching, and creating an environment that supports development. Interventions requiring intensive, interpersonal contact over time may best be delivered via networks. The delivery of nursing care via computer networks requires that nurses modify their verbal behaviours to capitalize on the unique features of the medium. Words selected for presentation in this environment should be explicit, rich, and expressive. It is key to select unambiguous terms for communication, and to eschew jargon and casual speech which may look unnatural or uninterpretable when written on a computer screen. Words should be rich, evoking visual images or specific attitudes consistent with the goal of communication. Finally, words should be expressive, convening the range of emotions necessary to insure full interpretation.

Careful planning of nursing communication can make effective use of the medium. It is key for the nurse to understand the behavioral patters of the persons connected to the network. Sometimes understanding gross behaviors, such as frequency of access, is sufficient. This understanding allows the nurse to anticipate the time lag between when a message is posted and when it is received. Awareness of more atomic behaviors, such as individuals' tendencies to read rather than post messages, aids a nurse in establishing guidelines for interventions.

Screen layout and graphical design strategies may also help the nurse make effective use of the unspoken language of nursing. Considering how a message appears to the sender, or establishing certain familiar positioning rules in posting content in messages insures that a nurse capitalizes on the medium's ability to convey presence.

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Acknowledgments:
Key Participants in the ComputerLink Project included: Jeanie Overholt (PLWA & AD), Shirley Moore, PhD, RN (Moderator, AD), Stefan Ripich, RN, MSN, C (Moderator, PLWA), Kathy Smyth, PhD (AD), David Bass, PhD, (AD), McKee McClendon, PhD (AD), Victoria Cargill, MD (PLWA), John Carey, MD (PLWA), Sid Schneider, PhD (PLWA and AD) and graduate students, research assistants, consultants and friends. Support for the ComputerLink came from grants from the US PHS National Institutes of Health (NR 2001 and AG 8617), the Gund Foundation, the Cleveland Foundation, and Case Western Reserve University.