

Educating the Families of Nursing Home Residents: A Pilot Study Using a Computer-based System

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Objectives: To enhance family participation in nursing home care through a Web-based system of interactive video training and interactive communication with the facilities.

Design: In this pilot study, focus groups guided the design and development of a prototype computer system for family members of nursing home residents. Its usability and functionality was tested with family members of diverse age and ethnicity.

Setting: Nursing home sites around Pittsburgh, Pennsylvania.

Participants: The study comprised 18 family members who were primary decision makers for nursing home residents. Most were elderly females, and 33% were African-Americans.

Intervention: Computer-based education on dementia, agitation/aggression, and caregiver strategies.

Measurements: Knowledge was assessed with a 16 question pretest and posttest. Satisfaction surveys were completed.

Results: Knowledge of key principles of dementia care improved significantly (paired *t* test, $t = 5.9_{17}$, $P < 0.0001$). User satisfaction and "ease of use" received high ratings.

Conclusion: Computer-based interactive videos can be used to educate family members of nursing home residents on dementia care. A complete curriculum of education and interactive bulletin boards for family inclusion in care planning are currently under development and will be tested to determine any impact on resident quality of life and quality of care outcomes. (*J Am Med Dir Assoc* 2003; 4: 128–134)

Keywords: nursing home; families; education.

For the relatives of elderly residents in more than 16,000 nursing facilities across the country, institutionalization of an elderly family member can be extremely stressful.¹ Although placement relieves the family of the physical aspects of care, the emotional burden is often compounded by feelings of helplessness and guilt.^{2–4} For the family, continuing to be involved and supportive after placement can often be confusing. This is compounded by poor communication and unrealistic expectations. All of this leads to families criticizing both the care and the environmental conditions in the facilities⁵ and an adversarial relationship between families and nursing homes.^{6–11}

This manuscript describes the rationale for developing a

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Web-based system to provide education and enhance communication for families of nursing home residents. It also describes the data from family members who used a fully functional prototype of the computer system for dementia caregiver education. This data includes assessments of knowledge attained as well as overall satisfaction and perceived ease of use of the prototype.

Organizational Theory: Informal Networks Embedded in Formal Systems

A theoretical framework that has been applied to various social relationships proposes that modern society uses both large-scale formal organizations and informal embedded networks to manage the task of elder care.¹² For almost 1.5 million elderly in the United States, the formal organization is a nursing home and the informal embedded network is the family. Both the nursing homes and the families share the responsibility of optimizing resident comfort, safety, and care. The facility and its staff approach this task using policies and procedures developed by "experts" and aided by technology and medical science. They are legally bound to provide a safe and therapeutic environment, and are inspected and moni-

tored by the State Departments of Health and other regulatory agencies to ensure compliance with federal and local regulations.¹³

The families of residents approach their task from a different perspective. Because they are not experts and are unable to continuously monitor the resident's condition, they can only deduce changes in the resident through perceived differences in behavior or demeanor. Further, their direct input into care is predominantly of a social nature, such as enhanced attention and more frequent visits, rather than specific medical interventions.

Thus, the family and the nursing home have divergent mechanisms for assessing residents and for contributing to care. As such, the potential for conflict between the formal organization, the nursing home, and the informal network, the family, is high. From a sociological perspective, Weber proposed that the potential for overt conflict is most problematic when formal and informal systems collide.¹⁴ This is because formal bureaucracies are designed to reduce subjectivity and impose rationality and standardization of care. Families, who typically strive for personalization and individualization of the care of their family member, are likely to view this approach as overly mechanistic and insensitive. Although the families' observations and information are essential to optimal care, the nursing home staff may systematically undervalue the importance of their input.⁹ This can precipitate a downward spiral, further distancing the family and the professional caregivers, leading to suboptimal care and high conflict potential.

It has been suggested that mechanisms that bring the family and the nursing home together would lead to better quality of care for the resident. A model of "shared functions" posits that goals related to resident care have dual components: some components are best handled by nursing home staff whereas others, requiring an emotional connection, are best handled by the family.^{15,16} However, in order to "share function" in caring for nursing home residents and to be able to work synergistically with the staff, the family must first be familiar with "what the staff does." In the absence of such understanding, the potential for poor care and high conflict increases astronomically.

Families and Nursing Homes: A Conflicted Relationship

Although families are typically invited to participate in care conferences, little else is done to prepare them to effectively contribute to care. A recent survey of 143 facilities in southern Michigan reported only 25% of facilities encouraged family members to attend classes to learn about chronic illness, and only 33% of the facilities encouraged families to "attend family group to help solve nursing home problems." On the other hand, three out of four facilities reported involving families in medical decisions.¹⁷ Therefore, it appears that while families participate in medical decision making, facilities do little to enhance their knowledge. In another study of 28 relatives of nursing home residents, Bowers described families as providing the "nontechnical" care.⁵ They, in turn, expected staff to have knowledge about medications,

disease processes, insurance regulations, and nutritional requirements in addition to providing the technical skills of caregiving. Failure of the staff to promptly recognize clinical changes in the resident was interpreted as "poor care" by the families. This study concluded that "quality care requires simultaneous use of both types of expertise (technical and nontechnical). . . . This collaboration depends on a mutual education process."

The frustration of families, their conflicts with nursing home staff, and the lack of communication between facilities and families are supported by a study of 70 nursing homes in Florida. Over a 6-month period, there were 1193 reports of verbal aggression and 13 physical assaults by family members against staff. Dissatisfaction over care was the most frequently cited cause of conflict.⁴ Furthermore, a flood of lawsuits initiated by family members against nursing facilities is devastating the industry with skyrocketing insurance rates.¹⁸ Clearly, some suits are justified and address poor treatment or abuse within a facility. Other suits result from family distress over a predictable but bad outcome. Poor communication, unrealistic expectations, and minimal family involvement in care all contribute to this problem. During a series of focus groups that we conducted as a part of the current study (see below), family members discussed the lack of access to caregivers and complained that care conferences were scheduled by the facilities without consideration of the family's ability to attend.

Educating Families to Enhance Resident Care

Enhancing family participation in care presents many challenges. At the very basic levels, it necessitates that families be familiar with (1) clinical problems that are associated with frailty, dementia, and nursing home placement; and (2) mechanisms of formal and informal communication with professional caregivers. Efforts to engage families may include (1) in-person lectures or discussion sessions, (2) videotaped presentations, or (3) novel use of Web-based technology.

Live, in-person education provided by professional caregivers ("classroom format") could improve the families' role in care. Obstacles to this modality of education include the difficulty and expense of recruiting and hiring educators with all the necessary skills. In addition, the multiple scheduling demands and geographic dispersion of family members are logistical obstacles that make this modality impractical for most facilities. Finally, families are not a static group. As residents are admitted and discharged, the families change, making a formal lecture format impractical to meet the constantly changing needs and constitution of the family groups.

Videotaped lectures or professionally produced videotapes are more practical and less expensive than live, onsite education. They can be viewed by individuals or by a group of families at convenient times. However, videos can only present information in a preordained linear way. They are not interactive and cannot provide feedback. Unless purchased by families, videotapes are only accessible when borrowed from the facilities and would not be readily available for reference or review. Videotape education does not enhance direct communication between the family and the caregivers around care planning.

Family education and enhanced involvement in care could be facilitated via the World Wide Web. Families could access a Web site at home, at work, on vacation or conceivably, in the nursing facility at a “family work station.” Through this modality, families could choose to learn about specific topics relevant to their needs, such as dementia, incontinence, or advance directives. Using professionally produced videos that include clinical vignettes and interactive exercises, families could explore various approaches to common problems and receive immediate feedback regarding their “decisions” on interactive tests. Using Web-based technology, a nursing home could provide private “bulletin boards” through which family members would participate in care. Changes in clinical conditions, medication changes, outside appointments, and other information could be shared with the family. Families, in turn, could use the technology to communicate their questions or concerns directly to the nursing staff or administrators. Conceivably, there could even be “electronic care conferences” in which far-away family members could participate live through Web technology. Indeed, technology is capable of meeting some of these challenges. The question is, however, would families be receptive to using technology for this purpose?

Technology Acceptance: A Stumbling Block?

In implementing a Web-based strategy, a potential roadblock is the technology readiness of family members. Even among those familiar with computer technology, one cannot be sure that they will be accepting of interactive-tutorial and communication programs to assist with nursing home care of a relative. Furthermore, many family members, including those who are elderly, have not had the experience of using computers in their daily lives.

Research has shown that people vary in the level of their technology readiness. Using a nationally representative sample of 1,000 people, the Technological Readiness Index (TRI) was recently validated.¹⁹ The TRI reflects the propensity to embrace and use new technologies to accomplish goals at home and at work. Furthermore, it is predictive of people’s future usage of technology-based products and services. In brief, people with a high TRI are more likely to use existing technology on a regular basis. Clearly, the elderly are likely to have a low TRI. It is therefore imperative to explore if family members, including the elderly who are low on the TRI, would be willing to use an interactive program designed to assist them in participating in the care of nursing home residents.

To evaluate the likelihood of acceptance, the pilot project (see below) followed the logic of the Technology Acceptance Model (TAM).²⁰ This model posits that people’s intention to use technology is largely based on: (1) the ease of use and (2) satisfaction. It has been verified by both cross-sectional and longitudinal studies.²¹

METHODS

To design and assess a Web-based system for families of nursing home residents, experts in geriatrics from the University of Pittsburgh teamed up with a multimedia medical edu-

cation company, Fox Learning Systems Inc. (FLS). FLS specializes in interactive-video medical education and uses a technique called “interactive documentary” or *Interdoc*TM. The trainee has the experience of watching a television news program, such as “60 Minutes,” but the computer interface provides interactive exercises and questions. FLS is familiar with nursing homes and many of the educational needs through the firm’s previous experience developing and evaluating a comprehensive educational curriculum for nursing home staffs.²² Two focus groups involving a total of 10 family members of nursing home residents were conducted to develop the Web-based system. All participants were decision-making family members of a nursing home resident. Eight of the ten focus group members were women, and five were over the age of 60. Four participants were African-Americans. Focus group members were recruited from the family councils of four local nursing homes and volunteered to participate in this project.

Curriculum Design

The initial proposal focused specifically on providing educational content to families. However, focus group members complained of their frustration with being inadequately apprised of essential information, such as new medical events, medication changes, appointments or scheduled care conferences. This led to our expanding the system to include interactive bulletin boards for private communication between families and professional caregivers.

Based on this input, the proposed Web-based “*The Elder-care Family Center*” includes two modules: the “*Family Learning Center*” and the “*Family Communication Room*.” The Family Learning Center provides a Web-based educational curriculum for families of nursing home residents using interactive video. Focus group members identified 25 topics that were of interest. Of those, 11 were ranked by the group members as having the highest priority and were selected to be developed as the initial curriculum of the Family Learning Center (see Table 1).

The facility-specific Family Communication Room uses Web technology to promote communication between the families and staff of a particular nursing home through two primary functions: (1) introducing newly admitted family members to their role in “sharing” nursing home care through an interactive exercise that establishes the initial communication link between family members and the professional caregivers (“Essentials of Admission”) and (2) maintaining an ongoing Web-based “conversation” between family and facility using private bulletin boards called “Shared-Care Rooms” (see Table 1).

Development of Pilot-project Curriculum

A subset of the planned curriculum was developed to determine if computer-based video education could be used by family members of diverse ages and cultural backgrounds. An educational program explaining the behavioral disturbances associated with dementia was developed for this pilot project. To create this interactive video, 12 hours of videotape were obtained onsite at five different nursing homes (see Table 2).

Table 1. *The Eldercare Family Center*

Family Learning Center (Web-based and available to public)		Family Communication Room (Facility-specific information) (Web-based or on-site work station, accessed via facility-specific password)	
Clinical	Administrative and Legal	Essentials of Admission	Shared-Care Room
<ul style="list-style-type: none"> • Dementia* • Agitation and aggression* • Caregiver skills* • Depression • Skin care • Incontinence • Falls 	<ul style="list-style-type: none"> • POA and guardianship • Wills and living wills • Rights and abuse • Medicare and Medicaid 	<ul style="list-style-type: none"> • Continuing your role as caregiver • Changes of aging • Common problems: falls, skin tears, memory loss, depression 	<ul style="list-style-type: none"> • Private communication between facility and family • "Chat room" for families • Information for family advocacy provided by facility

POA = power of attorney
 * Completed for pilot study.

This video library, which included interviews with families, residents, nursing home staff and other professional experts, was edited to provide 45 minutes of interactive video and animation. To address the needs of family members who are not computer users, we designed an interface that was uncluttered and easy to use. We also developed an instructional "page" to teach the novice user how to use a mouse or touch screen monitor.

Testing the Pilot Curriculum

Family members were recruited through existing family support groups of several nursing homes and through the family support network of the Alzheimer's Association of Pittsburgh. Subjects were given a 16-question pretest (see Appendix) before exploring the prototype on the computer. Following completion of the program, an identical posttest was administered. The pretest and posttest questions were designed to assess key concepts that are essential to under-

standing and working with residents with dementia exhibiting agitation or aggression. A satisfaction survey was administered following completion of the posttest. Participants were compensated for their time.

RESULTS

Eighteen adults participated in this study. Most were females (94.4%), and 6 (33%) were African-Americans (see Table 3). The mean age (SD) was 57.9 (13.4) with a range of 25 to 75 years. All were either currently the primary decision maker for a nursing home resident or had served in this capacity within the previous 12 months.

All of the research participants successfully navigated through the program. The pretest and posttest scores on the knowledge battery were significantly different with mean percent scores (SD) of 62.2 (14.3) and 76.3 (13.4), respectively (paired *t* test, *t* = 5.9₁₇, *P* < 0.0001).

A six-question satisfaction survey assessed ease of use and user-satisfaction. As shown in Table 4, ease of use and satisfaction were extremely high. In fact, 89.5% of all responses received the highest possible rating.

DISCUSSION

For families to take an increased role in the care of their elderly relatives residing in a nursing home, it is imperative that they understand some of the clinical aspects of care and how this care is dispensed by the nursing home organization. This would better enable the informal (families) and formal (nursing home) care systems to work in tandem, rather than at odds with each other. We developed and tested a computer-based, interactive training program that would give families some of the necessary tools. By design, participants in the prototype testing included both elderly and African-Ameri-

Table 2. *Pilot Curriculum*

Dementia: Caregiver Challenges
Caregiver Skills
Caregiver Qualities
What it takes to be a caregiver
Communication Skills
Communicating with your family member with dementia
Understanding Agitation and Aggression
What is Agitation and Aggression
Causes of Agitation and Aggression
Internal Stimuli: Pain, Delirium, Depression, Paranoia
External Stimuli: Environment, Caregiver Stress, Bewilderment

Table 3. Demographics of Family Members (N = 18)

Age (SD)	Race	Gender	Relationship to Resident			
	W/Af.Am	F/M	Spouse	Child	Sibling	Other*
57.9 (13.4)	12/6	17/1	5	7	2	4

* other = grandchild (2), aunt (1) and friend (1)

cans, in order to assess the “technology readiness” of a representative sample of family members. Limitations of this study include the small sample size and the additional attention and support that study families may have experienced compared with families using this system in a purely clinical setting.

In the prototype testing, we found that family members were able to use the program with minimal supervision. The Technology Acceptance Model predicts that perceived ease of use as well as satisfaction predicts continual usage.²⁰ We found families of diverse age and ethnic backgrounds to have high scores on both of these factors.

In addition to the high satisfaction ratings, knowledge of dementia care, based on pretests and post-tests, significantly improved following the computer-based training. The test questions were devised to assess core information that could be helpful to a family member with a relative with dementia. Thus, our prototype tests are encouraging. However, these initial data only suggest that the Web-based system is likely to be adopted and used by families, and that usage is likely to increase their knowledge.

What is not known, yet, is if a Web-based system that provides both education and enhanced opportunities for communication will result in improved quality of care or quality of life for nursing home residents. Although no large-scale study has assessed the global impact of family education or inclusion in care planning on objective clinical outcomes, the literature, to some extent, suggests that family involvement or education could be beneficial. A Robert Wood Johnson funded “teaching nursing home” research program demonstrated that improved communication between staff and families, and enhanced training for staff, contributed to reducing the nurse aide turnover rate, improving staff morale, and decreasing resident morbidity.²³ In another study in 6 nursing facilities, parallel educational sessions for professional staffs

and families followed by a joint session for both parties resulted in improved relations between the groups.²⁴ Additional studies support the role of family integration and participation in care.^{25–29}

To develop the complete system that will function for both family education and as a communication link, we are now actively engaged in multiple focus groups with family councils, resident groups and nursing home administrators and staff. Through this process we are learning where communication typically “breaks down” within the nursing home setting and the extensive negative consequences of poor communication from both the family and facility perspectives. The focus groups will continue as we design the system to optimize its utility and usability as a communication tool for all parties.

CONCLUSION

Empirical evidence suggests that education and enhanced involvement of families of nursing homes residents can improve some clinical outcomes. The innovative use of computer technology and interactive videos would enable families to access information at their convenience, thus avoiding some of the logistical obstacles to family inclusion. This pilot study demonstrated that family members, including many elderly with diverse ethnic backgrounds, enjoyed using the computer-based system to gain knowledge. Although these results are preliminary, the reported high levels of user satisfaction and ease of use would suggest continued future usage. Limitations of this study include the small sample size, possible underrepresentation of men, and no measure of retention of knowledge over an extended period of time.

The Web-based system, which includes the “Family Learning Center” and “Family Communication Room,” is currently under development with funding from the National Institute

Table 4. Training and Education Satisfaction Survey (N = 18)

Question	Not at all	Somewhat	Very Much
1. Was the information well presented?	0	1	17
2. Did the training provide you with information you need as a caregiver?*	0	2	15
3. Was the program enjoyable?*	0	2	15
4. Was the computer program easy to get around?	0	2	16
5. Would the program be helpful to family members who recently placed a loved one in a nursing home?*	0	0	17
6. Would you like to learn about other subjects such as depression, pressure ulcers, or any topics that involve your loved one in a nursing home?	0	4	14

* one missing response

on Aging. The impact of providing education and enhanced communication opportunities to families of residents through the Web will be assessed in terms of objective outcomes of quality of care and quality of life for the residents.

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Learning About Dementia: Test Questions*

<p>1) Reality orientation</p> <p>a) will usually help someone with dementia adjust to their environment.</p> <p>b) <i>can cause increased agitation or aggression.</i></p> <p>c) is the preferred technique for working with people with dementia.</p> <p>2) Telling lies or “fibs” to your family member with dementia</p> <p>a) <i>is OK if it brings comfort.</i></p> <p>b) should be avoided since it is disrespectful.</p> <p>c) is never acceptable.</p> <p>3) Most people with dementia</p> <p>a) <i>will exhibit some agitation or aggression at some time during the course of their illness.</i></p> <p>b) are unable to enjoy life.</p> <p>c) will tell you if they feel depressed.</p> <p>4) Testing your family member’s memory</p> <p>a) is important to give them needed practice.</p> <p>b) <i>should be avoided since it might cause more agitation.</i></p> <p>c) is an important part of each visit with your loved one.</p> <p>5) Agitation and aggression are</p> <p>a) <i>caused by some stimulus.</i></p> <p>b) simply expected in the Alzheimer’s process.</p> <p>c) usually due to too much stimulation in the environment.</p> <p>6) To reduce agitation</p> <p>a) it is essential to eliminate stimulation from the environment.</p> <p>b) the person should be placed in a quiet room.</p> <p>c) <i>it is essential to understand what is causing the agitation by trying to find the stimulus.</i></p> <p>7) Internal stimuli causing agitation</p> <p>a) cannot be prevented since it is happening inside the person.</p> <p>b) <i>can include pain or depression.</i></p> <p>c) are impossible to figure out if the person has lost their verbal skills.</p> <p>8) People with dementia can respond with agitation or aggression</p> <p>a) if the caregiver is overly stressed.</p> <p>b) if they are bewildered.</p> <p>c) <i>both a and b.</i></p>	<p>9) Depression</p> <p>a) <i>is a common problem for caregivers.</i></p> <p>b) should not be treated if there is a “good reason” to be depressed.</p> <p>c) is an indication of personal weakness.</p> <p>10) Families of residents with dementia in a nursing home</p> <p>a) <i>must be invited to attend the “resident care conference” by law.</i></p> <p>b) should attend the care conference only if there has been a problem.</p> <p>c) should not interfere with the facility’s care of their loved one.</p> <p>11) Resisting care</p> <p>a) <i>can be a result of bewilderment.</i></p> <p>b) usually means the caregiver is too rushed.</p> <p>c) means your loved one is paranoid.</p> <p>12) A care plan to reduce agitation</p> <p>a) almost always includes medications.</p> <p>b) always requires that the residents change their behavior.</p> <p>c) <i>usually requires that the caregivers change their behavior.</i></p> <p>13) Someone with Alzheimer’s Disease may exhibit agitation or aggression if</p> <p>a) they are in pain.</p> <p>b) they are delirious.</p> <p>c) <i>both a and b.</i></p> <p>14) Delirium</p> <p>a) is rare in people with Alzheimer’s Disease.</p> <p>b) <i>is often caused by infection or medications.</i></p> <p>c) is not a common cause of agitation.</p> <p>15) People with advanced dementia and depression</p> <p>a) will usually tell you they feel sad.</p> <p>b) should not be given antidepressant medications.</p> <p>c) <i>might respond to antidepressant medications.</i></p> <p>16) Paranoia in someone with Alzheimer’s Disease</p> <p>a) should be treated with medications immediately to prevent worsening.</p> <p>b) always causes distress.</p> <p>c) <i>may or may not require treatment.</i></p>
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* correct answer in italics