

Completing a Life: Comfort Level and Ease of Use of a CD-ROM Among Seriously Ill Patients

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Purpose/Objectives: To evaluate use of a CD-ROM titled *Completing a Life* among patients diagnosed with serious illnesses for comfort level with content and ease of computer use.

Design: A prospective pilot study collected a convenience sample of 50 people diagnosed with life-limiting illnesses during a six-month period.

Setting: The hematology/oncology department of a large healthcare system located in a metropolitan area in the midwestern United States.

Sample: Convenience sample of 50 patients diagnosed with life-limiting illnesses. Of the patients enrolled (age range = 38–93 years), 72% were female, 68% were Caucasian, 50% were diagnosed with breast cancer or nonsolid tumors, and 40% were newly diagnosed.

Methods: Subjects viewed the CD-ROM and completed pre- and postintervention surveys.

Main Research Variables: Comfort level with educational media, comfort level of information viewed, and areas of CD-ROM viewed compared to age and stage of illness.

Findings: Ninety percent of patients reported that they were somewhat or very comfortable with the CD-ROM as a learning tool, and ease of use was rated at 98%. Patients' comfort level with the material increased from 76% to 90% after they viewed the CD-ROM.

Conclusions: The pilot study suggests that the *Completing a Life* CD-ROM can be used with patients facing serious or life-limiting illnesses as an additional resource tool for information.

Implications for Nursing: Nurses typically provide the bulk of educational material for their patients. With limited resources available regarding management of life-limiting illnesses, this resource may provide an excellent addition to resources currently available.

Nursing care extends beyond providing care and treatment. Educating patients is an important process in patient care. Diagnosis of cancer may elicit many feelings from patients, including uncertainty regarding progression of the disease, quality of life, expected lifespan, side effects, coping, and communication and family dynamics. People also are living longer with an increased possibility of facing multiple debilitating and life-threatening illnesses. Quality care at the end of life has become an increasingly important component of healthcare expenditures. Last-year-of-life expenses for 2001 constituted 20% of all medical, 26% of Medicare, 18% of all non-Medicare insurance, and 25% of Medicaid expenditures (Hoover, Crystal, Kumar, Sambamoorthi, & Cantor, 2002). Millions of dollars from private foundations and healthcare institutions have been allocated to programs that focus on pursuing excellence in end-of-life care.

Education of patients regarding their disease processes is important to helping them cope. Education provides knowledge,

Key Points . . .

- Education of patients with cancer is important to help them cope with their disease.
- Use of computer technology is increasing in all aspects of medical care.
- Education via a CD-ROM method is effective in providing appropriate information for patients dealing with life-limiting illness.

which can increase coping and control of the disease process. With advances in medical technology that have the ability to sustain life, communication between patients and providers about end-of-life treatment decisions, care, and management is essential. Unfortunately, patient concerns, questions, and decisions about end-of-life care often remain unspoken because of a lack of communication between patients and providers. Pendergast (2001) found that patients and physicians experience discomfort in discussing death, and both often wait for the other to initiate the topic of end-of-life care. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment ("A Controlled Trial," 1995) involved a two-year prospective observation study of 4,301 patients followed by a two-year controlled clinical phase II trial of 4,804 patients and their physicians at five teaching hospitals in the United States. Trained nurses interacted with patients, families, and providers to elicit preferences, understand outcomes, and improve communication. The results demonstrated little to no change in the frequency of discussions about patient preferences or physicians' knowledge of patient preferences.

As an alternative to or in conjunction with open, one-on-one discussions with providers, people sometimes seek healthcare

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information from other sources, such as the Internet (Fox & Raine, 2000). Organizations such as Last Acts, the National Hospice and Palliative Care Organization, and Partnership for Caring have Web sites for sharing pertinent information and valuable resources for people searching for peace and quality care at the end of life (see Figure 1). A literature review evaluating research regarding online cancer support groups was examined. Nine of 10 research articles confirmed that the use of online support groups was helpful to the study groups examined (Klemm et al., 2003). However, discrepancies remain in overall Internet usage according to income, education level (Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002), ethnicity, and race (Fogel et al., 2003).

The Internet provides a quick and easy tool to access information. It is now viewed by society as an integral means to access information (VanBiervliet & Edwards-Schafer, 2004). The Internet is a powerful tool to disseminate health information, including obtaining opinions, searching for information on diseases, identifying specialists, participating in support groups, and consulting with healthcare professionals (Huang, 2003). Older adults are the fastest-growing population of Internet users (National Telecommunications and Information Association, 2000). Stern (2000) identified that people aged 55 and older use the Internet to research disease processes and medication information, explore fitness and wellness programs, and purchase exercise equipment.

Computer-based learning can be tailored to age and specific learning needs. Although computer access remains a barrier for some, socioeconomic disparities have no reported impact on patients' ability to use computer-based technologies (Lewis, 2003). Computer-based learning is convenient for patients because they can access information when they are ready and have the time to learn.

Literature Review

Several studies have evaluated programs and information available on the Internet. Murray et al. (2003) evaluated 92 people who used the Internet to obtain healthcare information. Most of the sample consisted of Caucasian (71%) young adults aged 25–34 years (18.5%) or 35–44 years (22%) who had completed high school or higher education

(95%). Seventy-one percent of patients who took the information obtained from the Internet to their doctor visits were looking for opinions, and 67% believed that their physicians reacted positively. The overall interactions were viewed as positive as long as physicians had adequate communication skills and did not appear to feel challenged. Bynum, Cranford, Irwin, and Denny (2003) evaluated participant satisfaction in a telehealth education program in rural Arkansas. A convenience sample of 2,567 people participated in the program from 1996–1999. Older adults, African Americans, Native Americans, participants who lived in smaller rural communities, and those with a high school degree or less had significantly greater satisfaction with that educational method.

Treweek, Glenton, Oxman, and Penrose (2002) assessed the effect of computer-generated patient education materials on health practice and patient outcomes. Using a random controlled trial that lasted two years, the researchers found that when the computer-generated coronary heart disease risk profile was given to patients and physicians, it led to a significant increase in the proportion of high-risk patients being reassessed at three months when compared to low-risk patients. Providers also increased their completion rates with respect to rectal examinations, Pap tests, pelvic examinations, diet assessments, fecal occult blood testing, and smoking assessment and counseling. One primary care setting identified an increased rate of breast screening mammography and clinical breast examination in women aged 50 years and older.

Office-Based Internet Programs

Goldschmidt and Goodrich (2000) provided Internet computer stations in ophthalmology waiting rooms with access to Web sites specific to ophthalmologic conditions. Of the 176 patients who participated, most were older adults with no previous experience in computer use (73%). Ninety-two percent reported that the computer was conveniently located, and 84% were interested in learning more about their eye conditions. Helwig, Lovelle, Guse, and Gottlieb (1999) found that of the 50 patients who participated in an office-based Internet patient education program, 94% found the Internet helpful.

Even though people use the Internet more frequently for information, the quality and accuracy of that information are often questionable. Bichakjian et al. (2002) identified that many Internet sites focused on melanoma lacked complete basic melanoma information, and 14% of sites contained inaccuracies. Jones (2003) showed that the Internet demonstrated variable reliability with a lack of quality control.

Additional sources of information can be obtained through educational programs available on computers in CD-ROM format. A CD-ROM is capable of delivering high-performance media, including video, audio, and animation elements that can engage users and supply clear information (King et al., 2004). The information can be provided in a consistent manner that is portable and cost effective, allowing people to review the content at their convenience and in the privacy of their own homes. In addition, the information provided is less vulnerable to external interference such as viruses.

Interactive CD-ROM Use

Nebel et al. (2002) evaluated a computer-based, interactive diabetes education program. Acceptance and operator convenience were assessed among 126 users: 58% were male,

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- www.agingwithdignity.com
 - www.completingalife.msu.edu
 - www.familydoctor.org/handouts/003.html
 - www.growthhouse.org
 - www.uslivingwillregistry.com
 - www.medicaldirective.org
 - www.partnershipforcaring.org
 - www.cancer.gov/cancertopics/factsheet/support/end-of-life-care
 - www.legacywriter.com
 - www.legaldocs.com
 - www.mindspring.com/~scottr/will.html
 - www.legalzoom.com
 - www.hospicecare.com
 - www.athealth.com/Practitioner/Newsletter/FPN_4_25.html
 - www.lastacts.com
 - www.healthlink.mcw.edu/article/1001710698.html
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Figure 1. Patient Web Site Resources for End-of-Life Care Planning

and average age was 58 years for type 1 diabetes and 74 years for type 2 diabetes. The majority of the users (63%) rated the exercises on the program as a best tool for improving behavior. Most of the participants (85%) evaluated the structure of the program as good or very good. Previous computer use according to age was not addressed. King et al. (2004) developed an interactive health CD-ROM used in conjunction with three diabetic office visits. Seven hundred seventy-three adults who participated found the program effective in aiding adherence to the American Diabetic Association diabetic care guidelines.

Nebel et al. (2004) also evaluated a conventional and adaptive computer-based program with respect to diabetic education. Of 120 diabetic patients, 37% had previous computer use and gave the user friendliness of the adaptive program significantly better ratings with respect to usage (75%), presentation (83%), content (86%), and adaptivity (83%). Parents who used a computerized pediatric motor vehicle safety discharge instruction program found the information educational, with 57% remembering the information provided (Zonfrillo, Mello, & Palmisciano, 2003).

Hogg et al. (2000) evaluated a waiting room computer-based information system for patients at obstetric offices and their families. More than 4,000 online questionnaires were completed. Subjects liked the system and found that it was easy to use (68%) and provided useful information. Although personal contact with a healthcare professional still was essential, the computer information was viewed as an additional source of information.

A computer-based education system was evaluated among patients with HIV or AIDS who were opioid-dependant injection drug users (Marsch & Bickel, 2004). Thirty patients were randomly assigned to a computer-based program or a therapist-delivered education program and then evaluated. Participants who received the computer-based intervention learned significantly more information about HIV prevention, retained significantly more information at a three-month follow-up, liked the teaching method significantly more, and requested additional information at a greater frequency. Comfort level with computer use was not addressed.

Acceptability of computer-based learning was explored using a semistructured interview schedule with 33 patients receiving renal dialysis (Luker & Caress, 1992). No difficulties were experienced with computer operation, and 80% of the subjects found the experience useful. Seventy-three percent of subjects found the method as informative or more informative than nurses providing the information verbally. Computer-based learning allowed subjects to proceed at their own pace.

Computer Use Among Older Adults

Few studies have evaluated computer use in older patients. Ogozalek (1992) identified that older adults with little prior computer experience were successful in accomplishing learning tasks when using interactive videos. Ten women aged 55 years or older with incontinence problems found a computer-based incontinence program a favorable experience (Boyington, Wildemuth, Dougherty, & Hall, 2004). A breast self-examination computer program was used by 58 women older than 40 years (40% were Caucasian and 52% were uninsured) at community health centers (Reis, Trockel, King, & Remmert, 2004). Compared to a group receiving only pamphlets, the women

reported a higher sense of self-efficacy in performing breast self-examination.

Cancer-Focused Computer Programs

Several CD-ROM programs have been developed for patients with cancer. *Breast Cancer Lighthouse*, developed by Michigan State University (Greene & Heeter, 1998), combined medical information with personal stories in a virtual environment. *Easing Cancer Pain* (Greene, Ogle, & Winn, 1998) refined the earlier format, providing a focus on cancer pain management. *Symptom Report* (Wilkie et al., 2001) is another interactive software program designed to assess pain and fatigue in patients with cancer. The CD-ROMs have not been assessed for effectiveness as a teaching format or for patients' comfort level with the information.

Few studies have focused on the use of computer programs for patients with a cancer diagnosis. Gustafson et al. (2001) evaluated the impact of a computer-based support system on the quality of life of younger women with breast cancer. The study patients were more competent at seeking support and had better social support. Ramirez and Mondragon (2002) evaluated a computer-based education program called *CancerHelp*TM for Latino patients with presumed minimal prior computer use. The use of *CancerHelp* was independent of age group, ethnicity, and education and was geared toward patients and their families. Comfort level and ease of use were not evaluated.

A pilot study to evaluate an interactive video system providing information about risks and benefits of treatment choices for women with early breast cancer (Maslin, Baum, Walker, A'Hern, & Prouse, 1998) examined acceptability of the interactive video system, whether providing information in that format reduced anxiety, and satisfaction with the treatment option chosen via the information video system. Use of the video system for education did not significantly influence the degree of anxiety associated with diagnosis and treatment, nor did it significantly increase satisfaction with the treatment choice made. Overall, the video system was highly rated, but concerns regarding cost were identified. The researchers suggested that the comprehensive, individual support that patients received from physicians, clinical nurse specialists, and other healthcare professionals was the key factor in satisfaction and adjustment to the disease rather than the specific method of information sharing. The video method of delivering educational information remains highly regarded for its ability to store and provide consistent protocol-based information, but it is limited by an inability to gauge patients' readiness for the information.

More recently, *Completing a Life* (Greene et al., 2002), an interactive CD-ROM, was developed to empower people living with advanced illness and facing the end of life. The impetus was the lack of information specific to advanced illness symptoms and emotional issues available in a concise format. The CD-ROM provides more than 50 hours of information in four categories: (a) Taking Charge (staying active in decisions about health care, family, and everyday living), (b) Finding Comfort (easing pain and suffering and living with dignity at this time of life), (c) Reaching Closure (coming to terms with the past, present, and future and exploring the possibilities of spiritual growth), and (d) Personal Stories (brief videos of patients who express their experiences with terminal illness) (see Figure 2). Direct Internet content links are provided for additional information. *Completing a Life* CD-ROM allows users to choose a

Taking Charge

- Setting goals
- Dealing with loss of control
- Family decision making
 - Challenges to good decision making
 - Unrealistic promises
 - The relative who has just arrived
 - How to include children
- Money matters
 - Health insurance
 - Medicare and Medicaid
 - Private insurance
 - Hospice and homecare coverage
 - Other income sources
 - Home loans
 - Life insurance options
 - Funeral costs
 - Sharing financial control
 - Financial documents checklist
- Healthcare needs
 - Hospice and palliative care
 - The hospice team
 - Other hospice services
 - Other palliative care models
 - The doctor you need
 - Your doctors and hospice
 - Good communication
 - Talking tips
 - Including your family and friends
 - Good communication at office visits
 - Being a partner in your health care
 - Questions to ask
 - Identifying your main healthcare contact
- Advance medical planning
 - Getting the facts
 - What is important?
 - Learning how to handle emergencies
 - Planning ahead for change
- When not to call 911
- Who do you call?
- Do not resuscitate at home.
- Exploring life-prolonging therapies
- Cardiopulmonary resuscitation
- Mechanical breathing
- Artificial feeding
- Dialysis
- Antibiotics
- Ventilators and respirators
- Transfusion
- Choosing treatments on a trial basis
- Advance directives
- Frequently asked questions about advance directives
- Looking at specific treatment choices
- Tools for creating your advance directive
- Organ donation
- Planning for last hours and after

Finding Comfort

- Pain
 - Myths and misconceptions about pain
 - Pain treatment
 - Medical treatment
 - Complementary treatments
- Other physical symptoms
 - Shortness of breath
 - Fatigue
 - Reduced appetite
- Nausea and vomiting
- Constipation
- Dry mouth
- Bed sores
- Understanding your illness
- Emotional symptoms
 - Depression
 - Anxiety
 - Anger
- Suffering
 - Suffering that comes from a loss of purpose in life
 - Finding meaning in suffering
 - Ways to ease suffering
- Maintaining dignity
- Support groups

Reaching Closure

- Completing relationships with family and friends
 - Who to talk to
 - People who are far away
 - What about children?
 - When to say goodbye
 - Family communication
 - The way you communicate
 - Emotional honesty
 - Including family in medical visits
 - Sharing expectations and goals
 - Seeking reconciliation
 - Special concerns
- Reviewing your life
 - Getting started
 - Making peace with your past
 - Finding meaning
- Ethical will
- Spiritual issues
 - What you believe
 - Why me?
 - Making meaning
 - What lives on
- Growth and change
 - Growth in dying
 - Redefining yourself
- Being dependent
- Being a “burden”
- Concerns about how you look
- Sexual and physical intimacy
- New roles in life
- Passing on your family role
- Giving to others
- Grieving your dying
- Holding on and letting go
 - Letting go of guilt
 - Unresolved family issues
 - Needing “permission” to let go
- The meaning of hope

Figure 2. Content Topics of *Completing a Life*

personal pathway through more than 100 separate topic pages identified via subject heading or through a link from the Personal Stories section.

The CD-ROM has been made available to all patients with cancer in the authors' healthcare system. Given the uniqueness of the information and its format, the authors believed that evaluating the effectiveness of the *Completing a Life* CD-ROM as a learning tool specifically was necessary to see whether the CD-ROM program was easy to use and whether patients were comfortable with the information provided.

Methods

A convenience sample of 50 patients diagnosed with serious illnesses was targeted for study. Institutional review board

approval was obtained, and patients aged 18 or older with serious illnesses who were engaged in active chemotherapy treatment or enrolled in hospice were eligible. Computer experience was not a requirement.

Procedure

Subjects were identified by multiple sources, including physician referral, self-referral, and hospice referral. Physicians in the Division of Medical Oncology were made aware of the study's purpose and procedure and were given a copy of the CD-ROM for content review; they referred patients who met inclusion criteria. The study was advertised in three oncology clinics in the healthcare system to promote patient self-referral. A study RN contacted interested patients to explain the purpose of the study, answer questions, and schedule an

appointment to go over the CD-ROM with those who agreed to participate. Because of the low enrollment of patients via self-referral or referral by physicians, the study RN approached patients during chemotherapy, introduced herself, provided a copy of a study introduction letter, explained the study's purpose, answered questions, and ascertained potential participants' level of interest. Patients had the option of either evaluating the CD-ROM that day or at a future date. Involvement of patients in hospice was considered particularly important to obtain critical responses regarding the program content from people who were aware of their serious or terminal prognoses. Thus, the hospital's inpatient hospice team identified potential participants, who then were approached by the study RN in similar fashion.

Physicians were informed of their patients' voluntary participation in the study. Written patient consent was obtained. Subjects agreed to spend as long as one hour viewing the *Completing a Life* CD-ROM and answering a series of questions.

A preintervention questionnaire was administered to elicit information regarding personal experience with computer use and comfort level using a computer. Subjects then viewed the *Completing a Life* CD-ROM, sometimes receiving computer assistance from the RN or family members without guiding content. All subjects used headphones for listening privacy; curtains were available as an added privacy option.

A postintervention questionnaire administered immediately after patients viewed the CD-ROM addressed comfort level with content, ease of computer use, and personal demographic information. Patients identified the different topics and sub-topics viewed. At the conclusion of the appointment, the study RN recorded the date, time, and length of the appointment; length of time the subject spent viewing the CD-ROM; whether family or friends were present during the appointment; length of time the subject received computer assistance; and qualitative comments regarding the process and patient response. Finally, a personal copy of the CD-ROM was offered to all participants. Patients also were given additional counseling resources, if requested.

Results

Of the 50 patients prospectively enrolled, 72% were female and 68% were Caucasian. Ages ranged from 38–93 years, with similar mean ages for men (62.6 years) and women (61.2 years). Fifty percent of patients were younger than 65 years. African American subjects were significantly younger than Caucasians (57.3 years versus 64.9 years). In addition, 54% of subjects reported education attainment beyond high school. Cancer diagnoses were primarily breast ($n = 12$) and nonsolid tumors ($n = 12$). Three patients (6%) had noncancer conditions, including chronic anemia, dermatomyositis, pulmonary infiltrates, and aortic valve stenosis. Patients with newly diagnosed cancers (i.e., less than six months from time of diagnosis) represented 38% of the total group enrolled (see Table 1).

Eighty percent of patients participated while receiving chemotherapy; the remainder were inpatient (4%), at home (4%), in a nursing home (2%), or in hospice (10%). Twenty percent of patients died within six months of participating in the pilot study (median = 75 days, range = 11–164 days), an indication that the pilot study had captured the appropriate

Table 1. Participant Characteristics

Characteristic	n	%
Age (years)		
< 65	25	50
≥ 65	25	50
Gender		
Male	14	28
Female	36	72
Race		
Caucasian	34	68
African American	15	30
Other	1	2
Education		
High school or less	21	42
More than high school	27	54
Unknown	2	4
Cancer or other illness		
Breast	12	24
Lung	9	18
Other solid tumor	14	28
Cancers of the blood	12	24
Noncancer	3	6
Time since diagnosis and/or recurrence		
Less than six months	19	38
More than six months	29	58
Unknown	2	4

N = 50

population of patients approaching terminal phases of their illnesses.

Of the total sample, 56% reported having a home computer, 66% reported having used a computer at least once, and 76% were either somewhat or very comfortable using a computer for learning. Eighteen of 34 patients (52%) also reported using a computer frequently. Internet access was not assessed (see Table 2).

Patients' CD-ROM viewing time ranged from 5–55 minutes ($\bar{X} = 32$ minutes). For some subjects, using a computer and navigating through the CD-ROM were new experiences. The study RN spent an average of 19 minutes introducing the CD-ROM and getting patients started. Older patients (aged 65 and older) received a mean of 25 minutes or more of introduction and assistance with the CD-ROM, whereas more than half (56%) of patients younger than 65 years required five minutes or less of assistance. Once viewing began, older patients spent more time ($\bar{X} = 37$ minutes) to view fewer sections ($\bar{X} = 2.8$ topics) of the CD-ROM compared to younger patients ($\bar{X} = 28$ minutes for $\bar{X} = 3.3$ topics).

In the post-CD-ROM assessment, 90% of subjects reported that they were "somewhat comfortable" with the CD-ROM as a learning tool, 98% reported that they were either "very comfortable" or "somewhat comfortable" with the program content, and 77% of patients said that they would like a free copy for home use. Ninety-eight percent of patients found the CD-ROM easy to use. One older adult in the late stage of lung cancer reported that the CD-ROM was not at all easy to use.

Table 3 summarizes the percentage of patients who viewed each topic during the pilot test. Because patients viewed the CD-ROM for a limited time and it contains many hours of information, no conclusions can be drawn from the pilot study regarding the usefulness of the specific topics.

Table 2. Questionnaire Results

Question	Response	Preintervention		Postintervention	
		n	%	n	%
1. Have you ever used a computer?	Yes	33	66	—	—
	No	17	34	—	—
a. If yes, how often do you use a computer? ^a	Frequently	18	53	—	—
	Occasionally	9	26	—	—
	Seldom or never	7	21	—	—
b. Do you have a computer at home? ^b	Yes	28	78	—	—
	No	8	22	—	—
2. How do you feel about using a computer as a way to learn?	Very comfortable	26	52	36	72
	Somewhat comfortable	12	24	9	18
	Not comfortable	5	10	2	4
	Not sure	7	14	3	6
3. Comfort level with information to be covered in the CD-ROM	Very comfortable	24	48	35	70
	Somewhat comfortable	14	28	14	28
	Not sure	11	22	1	2
	Not comfortable	—	—	—	—
	Missing	1	2	—	—
4. Ease of use	Very easy	—	—	34	68
	Somewhat easy	—	—	15	30
	Not at all easy to use	—	—	1	2
	Not sure	—	—	—	—

N = 50

^a Question added during pilot study, N = 34

^b Question added during pilot study, N = 36

Subjects were allowed to stop the CD-ROM at any time. Patients who stopped reported they had “seen enough” (54%) or that they “lost interest” or found the information “too depressing” (14%). Two subjects receiving chemotherapy stopped when their treatment ended. Seven subjects discontinued viewing with no explanation or comment.

Discussion

This small convenience sample included men and women, young and old, and minority and nonminority patients, all with serious illnesses. Most individuals reported access to a computer, confirming the belief that computer availability is widespread. The majority of subjects agreed to participate in the study after being approached by the study RN. Few physician referrals were received despite medical staff receiving in-service classes on the subject. These findings suggest that a direct patient approach by a nurse is the best means of patient recruitment to this type of study.

Overall, the use of computers as an educational tool was a positive experience. Most subjects were comfortable with the navigation abilities, content, and opportunity to absorb pertinent information. In general, patients with cancer tend to be older adults. The study identified the acceptability of computer-based education for that population. The researchers noted that older adults needed more time to work through the interactive program, perhaps because they were concentrating longer and reflecting on its content. Minimal previous computer use also may have been a contributing factor. In considering this tool for everyday clinic use, healthcare providers should allow for instruction and assistance time, adequate space, and the potential need for postviewing support, especially for older patients.

The overall comfort level with viewing the content of the CD-ROM also was positive. The study RN sensed a higher comfort level among patients in hospice than newly diagnosed patients when presenting the introductory study information to potential subjects. In contrast to long-term patients who have had time to accept a progressive disease state, relatively few newly diagnosed patients chose to participate. The latter group still may be seeking cure and might perceive the information to be less applicable or helpful to them.

Different viewing environments may have generated varying comfort levels for subjects and may have affected other responses as well. A standardized private setting may have altered participants' responses and the study findings.

The study RN observed variable behaviors of subjects during the CD-ROM viewings. For example, a female patient sobbed quietly and was perceived by the nurse as having difficulty facing the reality of the information, yet she wanted the opportunity to view the information again at a later date. Another patient “very much appreciated the information” and looked forward to future viewings. Other subjects remarked that the information was not quite what they needed at the time. Because each person is unique in the process of coping with disease, healthcare providers need to determine the best time for someone with a serious or terminal illness to view this type of information relative to the time of diagnosis.

Limitations

The small sample size and use of a nonhomogeneous convenience sample limit the conclusions that can be drawn. The study RN found that approaching some patients regarding this sensitive subject matter was difficult. Body language or description of the information may have biased some people regarding

Table 3. Topics Viewed by Age

Topic	< 65 years (%)	≥ 65 years (%)	Total (%)
Taking charge	88	72	80
Setting goals	68	40	54
Dealing with loss of control	48	52	50
Family decision making	40	52	46
Money matters	44	40	42
Healthcare needs	40	28	34
Advance medical planning	60	36	48
Planning for the last hours and after	16	16	16
Finding comfort	84	80	82
Pain	44	44	44
Other physical symptoms	48	68	58
Suffering	28	24	26
Maintaining dignity	32	24	28
Support groups	24	24	24
Reaching closure	80	64	72
Completing relationships with family and friends	56	44	50
Reviewing your life	28	24	26
Ethical will	36	32	34
Spiritual issues	44	24	34
Growth and change	20	12	16
Holding on and letting go	12	20	16
The meaning of hope	28	28	28
Personal stories	76	60	68
65-year-old African American man with cancer, diabetes, and heart disease	40	44	42
78-year-old Caucasian woman with breast cancer	32	20	26
49-year-old Caucasian woman with uterine cancer	24	20	22
44-year-old Caucasian man with HIV/AIDS	28	16	22
63-year-old Caucasian man with esophageal cancer	28	16	22
59-year-old Caucasian woman with lung cancer and chronic obstructive pulmonary disease	28	12	20
49-year-old Caucasian woman with breast cancer	24	4	14
51-year-old Caucasian woman with rectal cancer	24	4	14
51-year-old Caucasian woman whose husband died from leukemia	24	20	22

interest in participation. Although specific CD-ROM guidelines were set out with a broad perspective, perception of information likely differed among subjects with different diagnoses, points of active treatment, and coping strategies. Determining the best time to offer this type of information remains a challenge. Along the trajectory of illness, patients and families vary greatly in their readiness to discuss issues related to life closure (Ogle et al., 2003). Financial constraints did not permit the use of a

computerized system to track topic and subtopic selection of items viewed by subjects.

Future Direction

This pilot study presents a multitude of opportunities for further study. The pilot study provided only a single contact with each subject. Repeated contacts over three to six months would generate repeated measures for analysis and more in-depth interpretation of findings. Homogeneous groups with respect to disease process may provide more precise information regarding how a specific population might view the content. For example, patients with breast cancer and patients with prostate cancer may cope differently with their diseases. Therefore, the focus of searching information in the CD-ROM could be different.

Sampling of patients in hospice who are in the terminal phase of their diseases may yield findings that differ greatly from those who are not actively dying. Sampling of patients with terminal illness and effectiveness of a computer-based learning tool to assist with end-of-life discussions among family members would be of interest.

Using precise measurement techniques, an assessment of the maximum benefit of this CD-ROM could be made via several small studies in specific disease areas and points in time during the illness trajectory. Cultural diversity continues to be a point of interest for this type of research, in addition to age at diagnosis, emotional status during the continuum of diagnosis and treatment, and acceptance of disease.

In the pilot study, the research RN spent more time assisting patients older than 65 years in navigating the CD-ROM than she did with younger subjects. A future study could evaluate the effectiveness of different media to present the end-of-life information. For example, the major topic headings of the CD-ROM could be offered in a book format or audiotape versus CD-ROM according to age and learning style.

Summary

The *Completing a Life* CD-ROM is an excellent resource for individuals, providing ready access to concise information in a positive, comfortable format. When it is used as a supplement to enhance communication with healthcare providers about end-of-life issues, patients can empower themselves to take control of their lives at a time when they may feel as though they have little control.

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