

Creating a CD-ROM Program for Cancer-Related Patient Education

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Purpose/Objectives: To describe the process of developing a cancer-related patient and family education CD-ROM program and initial evaluation results.

Data Sources: Published research, theory, practice, and personal experience.

Data Synthesis: CD-ROM programs can be far more comprehensive than the booklets and videotapes used more commonly in patient education. Developing CD-ROM programs requires funding, organizational skills, access to content experts, and a team composed of people who have the varied skills required for a finished multimedia product. The time frame for CD-ROM production is often longer than that of other patient-education formats. Published reports and this institution's experience confirm that patients accept this medium. Evaluation to date suggests that CD-ROMs may be more useful to patients and their families than any other single information source.

Conclusions: CD-ROM technology is more expensive than videotapes and booklets, but it allows for greater depth of content and may satisfy a broader range of educational needs than other media. Funding often can be obtained through foundations and with unrestricted educational grants from pharmaceutical companies.

Implications for Nursing: Nurses can lead multidisciplinary teams to produce CD-ROMs for their patient populations. These programs can be used before a patient has a first consultation to introduce a cancer or treatment and anytime during cancer diagnosis and treatment. They can reinforce one-on-one teaching or provide greater depth of content than ever could be provided in individualized teaching sessions. They can facilitate patients' self-directed learning and may allow nurses and doctors to teach on a different level. These programs also can complement patients' Internet searches either by creating a solid foundation for further investigation or by confirming the reliability of information gained through a variety of Internet sources.

The number of computer-assisted learning (CAL) programs for patient education is increasing, as is the research testifying to their usefulness. Multiple studies have found that computer programs are accepted across educational and socioeconomic levels (Gustafson et al., 1993, 1999; McTavish et al., 1994) and ages (Mercer, Chiriboga, & Sweeney, 1997; Petersen, 1988). Many more have demonstrated a knowledge increase (Consoli et al., 1995; Flood et al., 1996; Mercer et al.; Tibbles, Lewis, Reisine, Rippey, & Donald, 1992) and positive outcomes (Douglas, Mann, & Hodge, 1998; Glasgow et al., 1997; Huss et al., 1992; Huss,

Key Points . . .

- Multiple studies have found that computer programs increase knowledge and are accepted across educational and socioeconomic levels.
- CD-ROM technology can handle vast amounts of information without having it appear overwhelming to the user.
- Computers do not intimidate most patients. Older patients and new computer users often are willing to use a computer to get information.
- Further research will help to establish the best opportunities to provide these programs to patients and determine how they should be incorporated in a program that covers a patient's educational needs from diagnosis through treatment and beyond.

Salerno, & Huss, 1991; Lo, Lo, Wells, Chard, & Hathaway, 1996) when the programs are compared to standard teaching. This article describes CAL program development using CD-ROMs at a major urban comprehensive cancer center, the barriers encountered, early evaluation results, and future plans.

Advantages of CD-ROM Technology

In the mid-1990s, Memorial Sloan-Kettering Cancer Center (MSKCC) committed to using multimedia for patient education for a variety of reasons. Adult-learning theory strongly supports the premise that adults are self-directed in their learning (Galbraith, 1991; Knowles, 1977; Stipek, 1988). Multimedia is an excellent teaching tool for the independent learner because it can handle large amounts of information. For example, one compact disk can hold hundreds of pages of text or narration, animation, video, and still images. Also, differing learning styles can be accommodated through its use. Illustrations, video clips, and animations help the visual learners, and narration helps both auditory learners and poor readers. Self-pacing fa-

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cilitates attention and retention. The choice to pick topics, selectively sample information, and revisit areas of interest supports self-directedness and reinforces learning.

The rationale for choosing CD-ROM technology over the Internet (Web) and other computer-based platforms was based on the limited technology at the time it was introduced. In the mid-1990s, the Web was not a good solution for deploying patient-education programs because of the small number of people with Web access and its narrow bandwidth. CD-ROM programs were much more common, and most new computers were equipped with CD-ROM drives. A third possibility, videodisks, were (and still are) much more expensive than CD-ROMs to develop and deploy. Typically, a videodisk system is a location-based kiosk primarily because videodisk players and their disks are expensive. This requires the user to go to the location of the program rather than the other way around.

Today, the choice between CD-ROMs and the Web is more difficult. Clear differences exist between CD-ROMs and the Web, and decisions about which format to choose might depend on personal preference, target audience, and program goals. The advantages of the Web are the speed of adding or updating content and the ability to reach a wider audience. Once new or revised information has been created, it can be uploaded and viewed immediately, whereas a CD-ROM would require a much longer and more costly production and distribution process. A user can connect to any Web address anytime, day or night, from any computer connected to the Internet. CD-ROMs, on the other hand, must be physically distributed by mail, handed out in person, or purchased from specific locations.

Even with the Web's popularity, CD-ROMs still retain some advantages. Animation, video, and narration on CD-ROMs often are of better quality and have faster loading speeds. Most Web sites are composed solely of text or still illustrations because of narrow bandwidth and slow connection speeds. Users may find it difficult to locate specific multimedia programs on the Web given the thousands of sites that many search engines identify for any search term. Many of these sites have no relationship to the topic of interest. CD-ROM programs contain content that is relevant and in a context. Within a CD-ROM program, users with an Internet connection can connect to specific Web sites that have been checked for quality and accuracy, making users' experiences with the information more effective and efficient. CD-ROMs also may offer more design flexibility, especially for producers whose Web pages must conform to an institutional blueprint. Finally, raising the money to produce the program may be easier if the funding agency has a physical product to showcase, something many pharmaceutical companies appreciate. For now, MSKCC has elected to offer the cancer-related patient-education programs in both formats—new programs will be created as CD-ROMs and then converted to a Web environment.

Program Goals

CAL programs usually are designed with a specific goal. The overall purpose of the MSKCC programs is to provide comprehensive information on everything from screening and diagnosis to resources during and after treatment for major cancers and cancer treatments such as chemotherapy and bone marrow and stem cell transplantation. Of the three other known series of CAL programs addressing patient education, only Jack Digital

Productions, Inc., has knowledge as a primary goal. This series, which is being developed in collaboration with Princess Margaret Hospital in Toronto, Canada, also addresses specific cancers and treatments. The videodisk-based Shared Decision-Making Programs are designed to help patients understand their treatment possibilities and facilitate treatment choices (Kasper, Mulley, & Wennberg, 1992). Their goal is to make the patient a partner in treatment decisions. These programs are solely for diseases that have equal treatment options; thus, only two have been developed for cancer, one on breast cancer and a second on prostate cancer. The Comprehensive Health Enhancement Support System (CHESS) is designed to offer both information and social support (Gustafson et al., 1993). This system provides answers to questions, offers help with decisions, and puts patients in touch with professionals and with each other in chat rooms through the use of an intranet. CHESS recently has been made available on the Web. It, too, addresses few cancers.

Program Development

Securing financing for a multimedia program is a challenge. Videodisk-based programs can cost up to \$750,000 (Kasper et al., 1992), whereas CD-ROM and Web programs average \$75,000–\$150,000 or more. Nevertheless, creative solutions exist even for the novice producer. One is to partner with an experienced multimedia developer and share costs and revenues. Another is to apply for unrestricted educational grants from pharmaceutical companies who often have monies available and an interest in patient-education projects. If one company cannot fund the entire cost, several companies might be willing to give a portion if they all receive credit. Local foundations may be willing to support productions targeted at their area of interest. Some development offices have access to philanthropists who want to make a difference for patients in a particular way. Hospital-based societies, such as the Society of Memorial Sloan-Kettering, often have large fund-raising activities and may welcome the opportunity to sponsor programs that would meet needs for large segments of a patient population. MSKCC worked with a young but experienced multimedia producer who was willing to cut her fees for the program prototypes in the hope that they would result in a series.

Two unrestricted educational grants, \$35,000 from a pharmaceutical company and \$25,000 from an anonymous donor, provided the money MSKCC needed to build prototypes. These prototypes helped MSKCC make educated decisions regarding which software to use, the breadth of content, assemble a working team, and the production process. Just as importantly, they resulted in finished products, which paved the way to securing funding for new programs.

The topics for the first two programs, *Bone Marrow and Stem Cell Transplantation* and *Prostate Cancer*, reflected the interests of the funding agencies. The minimal funding necessitated compromises. Instead of a formal needs assessment, the author interviewed many members of the two disease-management teams involved with patients who would be interested in these programs. They identified multiple issues that needed explaining and many topics patients ask about regularly. These topics were confirmed during subsequent meetings with staff and patients. At this point, both projects proceeded along two paths simultaneously. Content was developed

in-house while the multimedia developer began the instructional design process. The author researched and wrote sections and sent them to the disease-team members for review. The multidisciplinary-team members, including doctors, nurses, social workers, and other professionals, were given the opportunity to review their approximately 100-page scripts, but many were asked to take responsibility for the scientific or practical content of specific sections. As each section was finalized, the screen elements (e.g., text, illustrations, photographs, narration) were identified. In general, expensive media (e.g., video, animation) was limited to areas such as anatomy that would not require revision in future versions of the programs. Final written sign-off, a process that formalizes responsibility for content, is the standard procedure for all patient-education materials used at MSKCC. Senior members of each team reviewed the final script. Five patients from each team then read the scripts, all said they wished they had had it before beginning their own treatment, and all said it was excellent. None had any suggestions for changes or additions.

Program Organization

The first step in the instructional design process was to determine the navigational structure. The author identified several drawbacks to otherwise excellent CD-ROM programs. These drawbacks included inability to escape from a page until all of the media has played, confusing navigational systems, inability to return to sections quickly, giving a program a “personality” that might alienate some users, and slow-loading movies. A major concern was ensuring that the programs would be easy to navigate. They needed to be intuitive to new computer users who likely were experiencing high anxiety based on their upcoming cancer treatment. For these first two prototypes, the developers elected to provide three different navigational aids: a top left corner pull-down menu showing main menu and subsections; bottom, left, forward, and back arrows for linear movement (see Figure 1); and an overview menu page from which the user could go directly to any listed section. Red text was linked to the glossary. Blue text was linked to more information else-

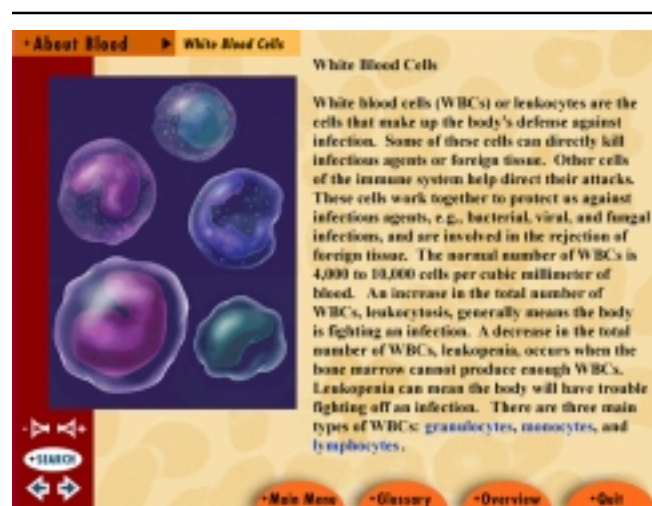


Figure 1. Screen Shot Showing Navigational Aids in the “About Blood” Section of the Bone Marrow Transplantation CD-ROM

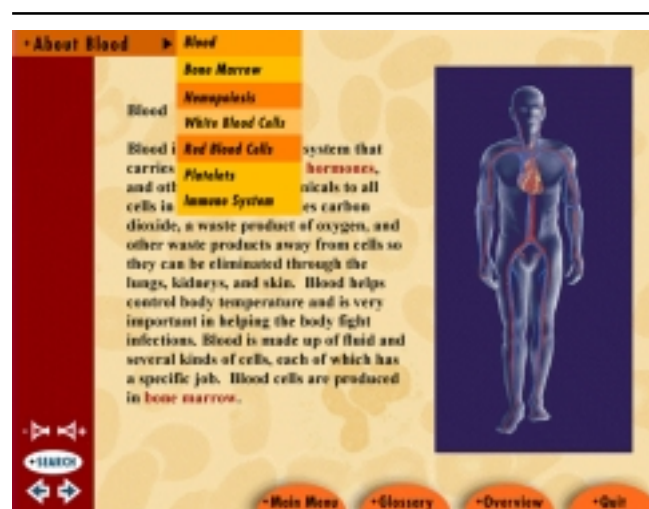


Figure 2. Screen Shot Showing Seven Submenu Sections in the “About Blood” Section of the Bone Marrow Transplantation CD-ROM

where in the program. Audio buttons allowed users who prefer reading to turn off the narration.

The graphic design of the MSKCC programs is limited to six or seven major topic areas, each of which is divided further into two to seven subsections (see Figure 2). A section on the involved organ describes both the anatomy and function. This provides a framework for understanding local and systemic symptoms and any side effects of treatment. “About Cancer” describes cell biology and the genetic basis for cancer, as well as any known genetic changes that lead to the particular cancer. A cancer-specific section deals with signs and symptoms, risk factors, and in general terms, prognosis. Diagnosis, staging, and grading are all explained in another section. Each program has one or two treatment sections. Two sections may be necessary either because two major types of cancer exist in the organ (e.g., small cell and non-small cell lung cancer) or very large categories of treatments exist depending on whether the cancer is diagnosed at an early or advanced stage (e.g., prostate cancer). Remaining sections depend on the total number of major topics for the program. For example, if a program needs six topics to cover the cancer and treatment-related areas, survivorship, patient stories, and resources are covered under a broad category called “Resources.” If a program only needs five topics to cover these areas, survivorship and resources are treated separately as major topic areas.

Building the Library

Extremely positive feedback from early users was encouraging in the initial phase. However, extensive direct evaluations were not possible because computers were not available widely for patients to use in ambulatory care areas. Nevertheless, with two prototypes, MSKCC began an ambitious effort at attracting funding to cover CD-ROMs for more cancers and improve technical development. Having the two prototypes made this effort relatively easy. The prototypes demonstrated that the institution could produce quality programs.

Lung cancer survivors attending a one-day course about developments in the treatment of lung cancer completed a sur-

Table 1. Results of Lung Cancer Survivor Survey

Very Important/Important Topics	n	%
Treatments	59	98
Lung cancer	57	95
Recurrence	57	95
Side effects	55	92
Survival statistics	53	88
Diagnosis	52	87
Follow-up	51	85
Cancer and the cell	50	83
Prevention	49	82
Staging	48	80
Screening	48	80
How the lungs work	46	77
Cancer biology	45	75
Causes	45	75
Common questions	44	73
Glossary	38	63
Lung anatomy	38	63
Internet sites	36	57
Patient stories	33	55
Smoking cessation	29	48

N = 60

vey on topics that might be included in new programs. Most responders wanted comprehensive discussions on everything from cell biology to resources (see Table 1). These results greatly expanded the depth of the information in current programs.

Two new treatment programs were targeted at large patient populations. *Chemotherapy* covers all agents approved by the U.S. Food and Drug Administration and incorporates the topics identified in the survey of lung cancer survivors. The *Pre-operative Teaching* program describes the 118 operations most commonly performed at MSKCC. Users can learn about their operation and recovery period; see animated explanations of why coughing, deep breathing, and early ambulation are important; meet patient-to-patient volunteers; view video clips of the admitting process and the operating and recovery rooms; and even be talked through a relaxation exercise. With the addition of more topics and information, and with two years of experience watching people use the programs, the original interface and navigational design were revised to reflect a hospital chart tab metaphor. This was intuitively a winning approach, and testing has shown it to be very user-friendly (see Figure 3).

Specific cancers then were addressed. In addition to those previously mentioned, completed programs include *Soft Tissue Sarcoma*, *Colorectal Cancer*, *Ovarian Cancer*, *Breast Cancer*, and *Lung Cancer*. Two symptom-management programs, *Pain Management* and *Management of Nausea and Vomiting*, also were completed. Programs on leukemia and chemopre-vention of breast cancer are in progress.

Barriers and Progress

Two major barriers, lack of access to computers and lack of staff support, hindered initial widespread use of the programs. For the first three years, though new titles were produced, patients had limited access to them. Nurses were enthusiastic about the programs when they saw them, but routinely forgot to direct their patients to the few computers in the waiting rooms.

In the summer of 1999, MSKCC opened a 200,000-square-foot ambulatory facility servicing about 75% of MSKCC's ambulatory-care population. Each floor in the Laurance W. Rockefeller Outpatient Clinic is devoted to a specific disease-management team, and each has several computers for patient use in both common and private waiting areas. On each computer, either *Chemotherapy* or *Preoperative Teaching* are available in addition to any programs specific to the patient population served on that floor. For example, the genitourinary cancer floor has *Prostate Cancer* and *Pain Management*.

Even these changes have not eliminated barriers. Difficulty informing patients about the programs persisted. One solution was to assign a part-time training instructor to visit the waiting areas, chat with patients about the programs, and help them get started. This instructor has met systematically with groups of nurses, session assistants, and nursing and administrative managers to show them the programs and discuss ways to make them more available to patients. He also distributes a trifold flyer describing the programs in every waiting room.

The program directors initially thought waiting rooms would be the best place for patients to access the programs. The rationale was that wait times are often a half-hour or more, the patient's attention already is focused on the diagnosis, and the computers are easily accessible. However, recent experience has shown this thinking to be faulty. In fact, few patients seem willing to view the programs in the waiting areas. Comments ranged from "I don't really feel well right now" to "I've had this disease for a long time and already feel educated" to "I'm really not interested." Patients also may be too distracted and unsettled to want to do any learning or research on their own in the waiting rooms. However, they respond differently when nurses ask them to review specific sections of a CD-ROM program in a consult room before the doctor comes in. Possibly, this request makes it appear that the program is part of the consultation and patients are happy to comply.

Another barrier to widespread use of the programs has been staff. Some nurses have been concerned that the programs would usurp their role as patient educators. Some have been

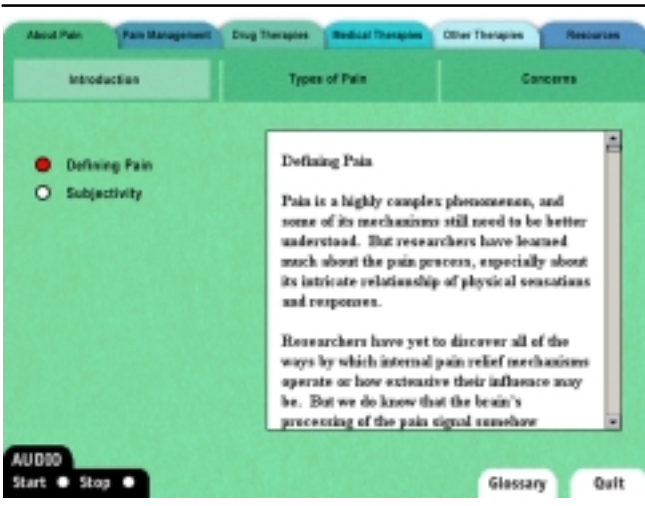


Figure 3. Screen Shot Showing Tab Format Navigation in the *Chemotherapy* CD-ROM

Table 2. Program Evaluation Survey: Demographics

Characteristic	n	%
User information		
Patient	249	82
Family member	45	15
Friend	6	2
No answer	2	< 1
Race		
Caucasian	269	89
African American	3	< 1
Asian	7	2
Hispanic	7	2
Question deleted from survey	16	5
Experience with computers		
New	103	34
Intermediate	160	53
Expert	35	12
No answer	4	1
Sex		
Male	108	36
Female	191	63
No answer	3	< 1
Age (years)		
< 30	16	5
31–50	119	39
51–65	114	38
≥ 66	43	14
No answer	10	3
Time spent on program		
Less than 10 minutes	79	26
10–30 minutes	152	50
30–60 minutes	41	14
More than one hour	12	4
No answer	18	6

N = 302

Note. Because of rounding, not all percentages total 100.

uncomfortable with computers themselves and felt they could not assist patients who had technical questions. Some have insisted that they would have to sit with the patient at the computer to explain everything and it would take too much of their time. All of these barriers can be explained based on Rogers's (1983) *Diffusion of Innovations*. A continuum begins when a new program is introduced. It flows from knowledge (the program exists), to persuasion (I like it), to decision (I will use it), to implementation (I am using it), and, finally, confirmation (it works). Some individuals traverse the stages very quickly (innovators) whereas some hold out until the program becomes a standard part of care (laggards).

MSKCC has adopted a multipronged approach to overcoming barriers. Nurses who are members of a disease-management team have the opportunity to be involved at the beginning of each new program by suggesting topics to be covered and reviewing content. This hopefully will result in some ownership and pride and will help nurses to want their patients to use the programs. New programs are demonstrated to individual nurses and groups.

Evaluation

Although CD-ROMs are well established and successful in many areas, cancer-related, patient-education CD-ROM pro-

grams are newcomers to the field. The tools used to evaluate video or print materials may not work with this much more comprehensive approach to educating patients. Because knowledge gain is the primary goal, this seems to be the starting point. However, the reality is that few patients look at an entire program at one time. Rather, the programs are designed to be viewed over the course of a cancer diagnosis and treatment. Most people retain only what they need at any given time, so assessing knowledge at one time point would be unlikely to provide a satisfactory snapshot of a program's value. MSKCC has selected four evaluation approaches: observations, user surveys, telephone interviews to probe survey answers, and, finally, a randomized trial.

Observations

A beta version of a CD-ROM is a working disk that is ready for testing and final review. The beta version of *Chemotherapy* was included in the formative evaluation. Research assistants (RAs) took laptop computers to patients receiving chemotherapy in the Adult Day Hospital, oriented them to the program, and then sat with or watched them from a distance. Immediately after patients finished using the program, RAs recorded comments the patients made and noted observations of the ease or difficulty the patients had in navigating the program. Thirty-one patients and nine family members/friends, ranging in age from 30–70 years, viewed the program. Patients did not appear intimidated by the computer, and older, new users were as engaged as those who stated they were expert users. Even patients who had been on chemotherapy for many years said they found the program to be informative, although they often went to specific sections instead of reviewing the entire program. Some patients chose not to look at the program and offered the following reasons: they already had done extensive research, they felt comfortable with their knowledge and did not wish to learn more, they were tired or did not feel well, and they were almost finished with treatment and would be leaving shortly. The observations stopped when the RAs stated they were no longer seeing new behaviors or different comments. The majority of patients were very positive about the program. Nurses reported that the program made it easier for patients to participate in their care, helped increase their knowledge about their treatment, and allowed nurses to teach on a more advanced level. An unanticipated benefit also was identified. Using the program gave patients something constructive to do while waiting for treatments to be completed.

The tab format turned out to be so user-friendly that even new computer users mastered it within minutes and did not need additional assistance to move around the program. This format now is used in all new programs. A surprise was the number of people who looked at every screen in the cell biology sections. They commented that this was information they could not get elsewhere and it made the rationale for chemotherapy treatments easier to understand.

User Surveys

A total of 574 surveys, 302 hard copy and 272 online, have been completed. Except for the chemotherapy program, which has not had many survey responses, the online numbers reflect that the programs went live as they were converted over the course of one and one-half years.

Only the hard copy surveys asked for demographic and program quality information. Of these, 249 were from pa-

Table 3. Program Evaluation Survey: CD-ROM Assessment

Criteria	Scale Score ^a					Total
	1	2	3	4	5 (%)	
Is user friendly	4	10	19	64	198 (67)	295
Has valuable information for me	2	9	26	62	188 (66)	287
Has information I did not find elsewhere	6	30	41	88	127 (43)	292
Is easy to understand	2	6	24	77	188 (63)	297
Is graphically interesting	3	7	50	64	169 (58)	293
Is written at the right level for me	3	4	24	69	193 (66)	293
Is organized in a way that helps me learn	6	6	23	60	192 (67)	287

^aScale: 1 = completely disagree; 5 = completely agree

tients and the remainder (53) were from family members and friends. Seventy-four percent of responders were between the ages of 31 and 65, while 8% were under 30 years and 18% were older than 65 years. Fifty-four percent rated their computer experience as intermediate. Seventy percent spent 10–30 minutes on the program, and another 19% spent 30–60 minutes (see Table 2). Patients were asked to agree or disagree with statements about the program using a five-point scale ranging from 1 (completely disagree) to 5 (completely agree). Table 3 demonstrates the high levels of approval with aspects of the program.

Slight changes to these surveys have been made over time, and some have questions that do not apply to other programs. Both the hard copy and online surveys asked whether the program was “not as useful,” “about as useful,” “more useful,” or “much more useful” than other sources of information. Fifty-five respondents and 60% (148) of the online users said the program was “more useful” or “much more useful.” In an effort to maximize the number of users willing to complete the online survey, the program directors deliberately kept it short. In addition to the previous question, the online survey asked if the program gave users the information they were looking for, what the users wanted if they did not find it, and if the program content was “too basic,” “just right,” or “too technical.” Of the 254 who answered those questions, 66% said they got the information they were looking for and 67% said the program content was just right. Of particular note, 53% (82) said the content was too basic, perhaps reflecting the sophistication of the online information seeker. The information users did not find ranged from content that was in the program to detailed genetic mutation information to very personal prognostic factors. One hundred ten hard copy users who viewed the program onsite were asked if the program would be useful to have at home. Seventy-five percent said yes. Some reasons for giving a no answer were “already knew a lot,” “do not have a computer,” and “program has already answered my questions.”

Both the hard copy and online surveys asked users to rate each program section using a 1 (not useful) to 5 (very useful) scale. All of these answers averaged more than 3.2, and most were in the 3.8–4.2 range.

Most of the comments were complimentary (e.g., “This is a good thing,” “The CD-ROMs were very helpful to me. Thank you.”). Some made suggestions about when to give them to patients or “Give CD to Barnes and Noble.” Further examples are in Figure 4.

Telephone Interviews

A telephone evaluation of the *Colorectal Cancer* program was abandoned when it became apparent that speaking to each patient required multiple phone calls and many patients were never reached. The goal was to probe answers given to the standard survey questions. Patients seen in the surgical gastrointestinal clinics with a diagnosis of either colon or rectal cancer were given the CD and asked if they would respond to a telephone survey within the next several weeks.

The CD-ROMS were very helpful to me. Thank you.
 Add alternative medicine to choices (meditation, nutrition, etc.).
 I would like to try it again.
 Well done.
 Easy to use and all the information you could need.
 Add advice for patients with regard to constipation; tricks that people use to keep their bowels working.
 (Chemotherapy) could have more information on side effects and what to do about them.
 Easy to use and understand. Concentrated information in a compact form.
 Program is very informative and easy to research specific questions—well done!
 Good job—need to go one step deeper into information.
 The beginning parts on the cell, cell division were very dense with vocabulary and the graphics were flat.
 It's a good idea.
 I have always been afraid of reading or asking about cancer since I was a terrible smoker, so this is the first time I have this information.
 Give this CD program to patients when they are first diagnosed—schedule an appointment to watch computer program specifically on each illness.
 Give CD to Barnes and Noble.
 Great idea to have system available.
 This is a good thing.
 More in-depth information.
 Great idea and extremely informative. I found the moving video very useful and easy to understand.
 The program's content was slightly challenging.
 Add more videos of doctors and patients.
 Wonderful tool. Just needs to be more diversified, including more rare cancers. Nice to see such help available to patients while waiting during what can be an extremely stressful time.
 More information on other therapies.
 Great idea!

Figure 4. Program Evaluation Survey Comments

The program was given to 24 patients over two months. Twelve patients were contacted successfully. Of these, five patients loved the program and seven had not yet looked at it. One woman said the program made her realize that if she had had a colonoscopy, she might have caught the cancer at an earlier stage; she was very upset knowing this. One patient already shared the program with two other patients with colorectal cancer. Several commented that the patient stories section was particularly important because it boosted morale. One person suggested that the "How Colorectal Cancer Develops" section be lengthened because he found it very helpful. Finally, three patients said the program was much more useful than other sources, and two said it was about as useful as other sources. Four asked to be called back and one said he would call when he had looked at the program. Further attempts at contacting these five patients were unsuccessful. It was surprising that only five patients had looked at the CD. However, this was a patient group of individuals who already made a decision to have surgery. Informational needs tend to peak at particular time points during a cancer diagnosis. The time immediately after a treatment decision is made is probably not the time when people want to learn more. Rather, these patients may have been looking forward to being cured with surgery and may not have wanted to know more.

Randomized Trial

Perhaps the optimal test of any patient-education program is one of outcomes. Do these programs change behaviors that negatively affect health? Do they reduce side effects because of good risk management? Do they reduce anxiety as they improve knowledge? A prospective randomized trial of the *Bone Marrow and Stem Cell Transplantation* program was planned for 2001. This trial was to assign patients randomly to standard teaching or standard teaching plus the CD-ROM. After the protocol was reviewed and approved by the center's internal review board, the program directors began to test the reliability of four sets of quizzes that were to be administered respectively at the initial consultation, within two days of admission, within two days before discharge, and at the first post-discharge follow-up visit. Repeated attempts to make them more difficult still resulted in high scores with little variability in wrong answers. Because none of the patients had

seen the CD-ROM and all already had a good understanding of the issues, the protocol was closed before entering any patients.

The program directors currently are completing a program on chemoprevention of breast cancer. This program may allow MSKCC to conduct a randomized trial. At-risk women are offered participation in a national trial, or they can elect to receive five years of tamoxifen. Because the decision often is made during the course of a week or so, a CD-ROM intervention compared to a standard physician explanation should tell the program directors if the CD-ROM improves patient knowledge and whether it has an impact on the length and sophistication of the physician/patient discussion. Details of the protocol are in development.

Conclusion

Patients now are given a copy of the CD-ROM program highlighting their cancer during their first clinic visit. CD-ROM programs provide in-depth information for patients and their families. The 574 evaluations completed confirm that patients like the programs, the majority of those asked say they think the programs are better than other sources of information they have used, and they would like to have the programs at home. The Web also offers thousands of sites with comprehensive information. The more successful these media are in achieving their goals, the more likely that new programs will be produced, especially because no one program will meet every need, learning style, or taste. Oncology nurses who are experts in a field are well suited to create new programs. Just as hundreds of CD-ROMs on popular, nonmedical topics are available, the next several years likely will see a burgeoning of cancer-related CD-ROMs for patient education. Evaluations of the MSKCC programs and others will guide improvements in future programs and provide better road maps for determining how they should be used most effectively. As more and more homes have computers, patients will be able to select the medium that best meets their needs and most likely will use both CD-ROMs and the Web to learn more about their disease.

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