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Patients' Need for Information About Cancer Therapy

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Purpose/Objectives: To obtain detailed information about the preferences of patients with cancer and their need for information about side effects of cancer treatment to design an interactive multimedia educational program.

Design: Qualitative.

Setting: Regional rural academic medical center.

Sample: 51 patients and 14 spouses of patients who either currently were undergoing or recently had completed chemotherapy or radiation therapy for cancer.

Methods: Focus groups.

Main Research Variables: Information needs and common and distressing symptoms.

Findings: Patients wanted information about the process of getting treatment, specific side effects that might occur, and the impact of treatment on their lives. Patients sought information from a variety of sources, but many found that other patients were the most helpful source. Although most patients wanted as much information as possible so they would be prepared for whatever happened, some patients preferred to avoid information about possible side effects. Several obstacles related to information were reported, including access to providers, communication difficulties with providers, informational overload, and problems with retention.

Conclusions: Several aspects regarding information needs confirmed previous findings, and new aspects were illuminated. This led to a conclusion that multimedia technology offered many advantages to meet these informational needs.

Implications for Nursing: New approaches to patient education that will meet the needs of patients as well as clinicians and educators need to be developed.

Key Points . . .

- ▶ Patients wanted timely information, in a format that they could understand, based on their individual needs.
- ▶ Patients needed information to be prepared and know what to expect ahead of time.
- ▶ Patients identified other patients as being the most helpful source of information.
- ▶ Traditional approaches to patient education are not adequate in the current healthcare system. Interactive multimedia technology offers an innovative approach to patient education that has many advantages over traditional instructional media and overcomes many informational barriers.

Research has shown that the informational needs of patients with cancer reflect a combination of personal and situational factors (Mills & Sullivan, 1999), as does their ability to learn. Needs change over the course of the illness as patients attempt to cope with their diagnosis, make treatment decisions, undergo treatment, and adjust to survivorship (Adams, 1991; Luker, Beaver, Leinster, & Owens, 1996; Mills & Sullivan). This requires a dynamic assessment and delivery process for information. Personal factors, particularly coping style, influence patients' preferences for information, as well. Many patients, referred to by Miller and Mangan (1983) as "monitors," actively seek information as a way of reducing anxiety and gaining control over their lives. Other patients, called "blunters," assume a passive role and avoid any information about their disease. One study suggested that patients' coping styles reflect patients' views of themselves as people with cancer (Van der Molen, 2000). Patients who view themselves as "dying from cancer" frequently avoid information, whereas patients who

Cancer treatment is a difficult and potentially distressing experience for many patients. During the course of treatment, patients may experience physical and psychological symptoms; disruption of normal activities, including work and social activities; and significant financial burden. Over the years, research consistently has shown that most patients with cancer want information about treatment (Ali, Khalil, & Yousef, 1993; Cassileth, Zupkis, Sutton-Smith, & March, 1980; Fallowfield, 1995; Suominen, Leino-Kilpi, & Laippala, 1994). Interventions designed to educate patients about treatment and treatment-related side effects have been effective at increasing self-care behaviors (Dodd, 1988; Hagoian, 1996) and reducing symptom severity (Devine & Westlake, 1995; McQuellon et al., 1998; Meyer & Mark, 1995; Smith, Scammon, & Beck, 1995) and disruption of daily activities (Johnson, Lauver, & Nail, 1989; Johnson, Nail, & Lauver, 1988). Yet, anecdotally, many patients with cancer continue to report that they are not receiving the information that they need to cope successfully with treatment.

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Digital Object Identifier: 10.1188/04.ONF.313-319

view themselves as “living with cancer” actively seek out information. According to Van der Molen, patients change from information avoiders to seekers as they transition back and forth between viewing themselves as dying from cancer to living with cancer. These differences in coping style and resulting informational style must be considered when examining and addressing informational needs. Additionally, patients’ ability to meet their individual learning needs varies with literacy, coping style, emotions, motivation, stress and anxiety, fatigue, and culture (Treacy & Mayer, 2000). Treacy and Mayer identified factors in meeting these needs that could be influenced directly by healthcare providers. They include knowledge and skill of the educator, educational media, environmental factors, and timing of instruction.

Although most research has focused on the informational needs of patients newly diagnosed with cancer, a few studies have examined the needs of patients at other points in the disease trajectory. Studies that have examined patients’ informational needs during treatment indicate that most patients want as much information as possible about treatment and treatment-related side effects (Ali et al., 1993; Graydon et al., 1997). Only one study provided details about the specific kinds of information that patients want. This study examined the informational needs of patients with cancer receiving treatment at an outpatient clinic in Ireland (McCaughan & Thompson, 2000). In this study, the overwhelming majority of patients indicated that they wanted information about how treatment works, the effectiveness of treatment, how treatment is given, possible side effects, preventive and self-care strategies, and the impact of treatment on their families. Most patients were satisfied with the information they received, yet many indicated that they would have liked more information about the effectiveness of treatment and the impact of treatment on their families. The literature provided little additional information about patient preferences in regard to the specific kinds of information that would be helpful or the format in which that information should be presented.

Sitzia and Wood (1998) offered several explanations for inadequate information about cancer treatment. First, although specific interventions have been developed for some symptoms (e.g., nausea and vomiting, mucositis), education regarding other common symptoms is just beginning to be studied. For example, a body of research relating to patient education for fatigue currently is lacking (Chelf et al., 2001). Second, chemotherapeutic agents elicit different responses in different people. At this point, predicting who is at risk for a particular side effect or how severe a side effect might be in a particular patient is difficult. Additionally, the way that patients currently perceive the side effects of chemotherapy has changed. Researchers in Europe have reported that fatigue and quality-of-life issues currently predominate (Carelle et al., 2002) as compared to two previous studies that documented concerns regarding emesis, nausea, fatigue, and negative reactions to the treatment visits (Coates, Abraham, & Kaye, 1983; Griffin, Butow, & Coates, 1996). Finally, “enhanced” interventions, that is, interventions that combine pharmacologic and psychoeducational strategies, are not used routinely because they tend to cost more and require more staff time than standard care consisting of a prescription and a quick suggestion from a provider. Employing these “enhanced” interventions in a healthcare climate that stresses cost-containment and places

pressure on healthcare providers to see more patients in less time is difficult. Chelf et al., in a comprehensive review of the current literature of cancer-related patient education, also provided continuing evidence that literacy and readability are still issues in most patient educational materials that currently are offered.

One potential solution to these problems is to develop computer-based educational programs for patients that can be used to supplement standard care. The literature has shown that computers are easy and informative tools (Bulmer et al., 2001; Chelf et al., 2001; Jones, Nyhof-Young, Friedman, & Catton, 2001; McDerby, John, Brunt, & Kacparek, 2001; Wilkie et al., 2001). One of the principle advantages of interactive multimedia technology is that it offers a range of options for presenting information in a variety of formats (e.g., lectures, interactive exercises, patient testimonials) using text, audio, video, or graphics. One of the challenges of designing an interactive multimedia program for patients is to make informed decisions about the amount and type of information that should be presented, the format(s) in which it should be presented, and the amount of control that patients should have over the form and content of the information that they see. These design decisions should reflect the informational needs and preferences of patients as well as the educational objectives of clinicians and educators to ensure development of a program that will be useful to patients.

The purpose of this study was to obtain detailed information about the preferences and needs of patients with cancer regarding side effects of cancer treatment. The data were gathered through a series of focus groups conducted with patients and family members who currently were receiving or recently had completed cancer treatment. The purpose of these focus groups was to provide detailed information about patients’ needs and preferences that would inform decisions about the design of an interactive multimedia educational program.

Methods

Sample

Focus group participants were patients who had received, or were in the midst of receiving, chemotherapy, radiation therapy, or a combination of chemotherapy and radiation therapy within the prior 12 months and who lived within a 100-mile radius of the rural regional academic medical center in New England. The participant selection process was started by computer-generated lists of patients who had received chemotherapy ($n = 145$), radiation therapy ($n = 177$), or combination therapy ($n = 87$) produced by the office of clinical quality resources in the medical center. The lists were reviewed by providers to screen out patients who were too ill, experiencing cognitive difficulties, or hearing impaired. One hundred patients from each of the chemotherapy and radiation therapy lists were selected randomly and invited to participate along with all 87 patients from the combination therapy list. Although they were not specifically invited, spouses and caregivers were encouraged to attend if they wished. This strategy was supported by Hinds, Streater, and Mood (1995), who reported that family members, as well as patients, benefited from information regarding their family members’ disease. The choice of 100 for the random sample was based on a historical response rate of 10% to invitations to focus groups at the authors’ institution.

Instruments

In preparation for the focus groups, six advanced practice nurses from the hematology/oncology section were assembled to provide content for the development of focus group facilitator guidelines that reflected relevant questions about informational needs of patients undergoing treatment for cancer. Various themes were generated from the discussion of therapy and symptom management: transfer of information, meaning of information, perception of information, type of information presented, and information resources. A list of questions was generated and formatted to encourage a semistructured discussion. The questions addressed (a) the symptom experience of patients during therapy, including descriptions of the symptoms and their effect on function and on those around them, and (b) the content and process of information transfer between providers and patients related to symptoms and symptom management. Discussion focused on the type of information to be conveyed, the format(s) in which information might be presented, patients' perception and interpretation of information, and use of other sources of information. Based on this discussion, a set of facilitator guidelines was developed by the authors and a trained facilitator. The guidelines consisted of 13 questions that were designed to encourage discussion about the nature of the symptom experience and patients' informational needs about cancer treatment and management of treatment-related side effects (see Figure 1).

Procedures

After the study was reviewed successfully by the hospital's institutional review board, focus group sessions were held in small conference rooms at the medical center. Invitations were sent to 287 patients to attend a focus group two to three weeks from the date of the invitation. Patients were allowed to bring a significant other if they wished, but they were asked not to bring young children.

Group 1 (radiation therapy only) was split into two groups: one with 9 patients and 1 spouse, and the other with 8 patients and 1 spouse. Group 2 (chemotherapy only) consisted of 16

patients and 3 spouses. Group 3 (combination therapy) was split into two groups: one group with 10 patients and 4 spouses, and the other with 8 patients and 5 spouses. Nine patients, who could not attend, sent written comments based on the topic described in the invitation. Each session lasted approximately two hours and was led by a trained facilitator from the human resources department who was instructed to facilitate the group to prevent any one member from dominating the discussion and encouraged each member to respond. One member of the research team was present but did not interact during the group and was introduced to the group as a silent observer, present only to take notes. The facilitator guideline was followed for each group. Each group was audiotaped for transcription of comments after the sessions.

Data Analysis

Audiotapes were transcribed using a participant number to protect confidentiality. Three of the authors reviewed each transcript, independently highlighted focus group participants' comments, and created thematic categories as the comments were reviewed. The group then met to discuss their results, reach a consensus about the categories that had been created, and decide how each comment fit into a category. The comments and categories were entered as data into a qualitative analysis software program, HyperQual (HyperQual, Boerne, TX), to organize the analysis. The program consists of special stacks designed to hold and organize data. Coding consists of highlighting relevant text chunks and sending them to a pre-specified stack. Codes can be attached by browsing through the stacks, and multiple codes can be attached to each chunk of information. Codes can be added, changed, or deleted. HyperQual offers special stacks for narrative responses from questionnaires for example, so that these responses can be sorted easily according to the various questions even before any coding is done. Any card containing the data coding created can be printed out. Available as a stand-alone application or as a HyperQual stack, this software allows users to input direct quotes from transcripts and then assists in organizing the material so that reviewers can identify themes. Exemplars from the comments were chosen to illustrate each of the themes.

Results

Demographic information about the sample is provided in Table 1. The response rate was double what was expected. In all, 51 patients and 14 spouses participated in the groups. The radiation therapy-only group consisted of 17 patients and 2 spouses, the chemotherapy-only group consisted of 16 patients and 3 spouses, and the combination therapy group consisted of 18 patients and 9 spouses. As a result of the size of the rooms reserved, the radiation therapy-only and combination therapy groups were each randomly split into two groups. Thus, five focus groups of mixed patients and spouses were held.

Participants ranged in age from 31–85 years with a mean of 59 years. Demographic data were abstracted from the patients' charts and not available for all participants. The sample was nearly evenly divided between men and women and was entirely Caucasian, largely Protestant and married, and 26% had at least a high school education. The ethnic distribution is largely reflective of the population in this area of the United States where very little diversity exists. No specific effort toward obtaining a diverse population was made. The

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1. What would you tell a friend about symptoms and how to manage them?
 2. What information about symptoms would have been helpful to you?
 3. When would it have been most useful to receive that information?
 4. Do you have an opinion about the best format to learn about symptoms and how to manage them (e.g., in person, in writing)?
 5. Who gave you the best information about symptoms?
 6. Continue to think about the symptoms you experienced. . . . Which one was the most distressing or upsetting and why?
 7. What symptom was most difficult to manage and why?
 8. How did these symptoms impact your life, work, or family?
 9. Did you get any additional help from other treatment modalities such as
 - a. Medical treatments
 - b. Psychological or behavioral
 - c. Emotional
 - d. Spiritual
 - e. Other treatment modalities (e.g., herbal, acupuncture)?
 10. Where did you find information about them?
 11. How did you decide whether they were safe? Or didn't safety make any difference?
 12. Identify the symptom that is the most important to you. How did you manage it and what information was helpful or not helpful?
 13. Have you ever used a computer at home or work?
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Figure 1. Facilitator Guideline Questions

Table 1. Patient Demographics

Characteristic	n	%
Age (years)		
\bar{X} = 59	–	–
Range = 31–85	–	–
Gender		
Female	26	51
Male	25	49
Marital status		
Married	36	71
Divorced	5	10
Single	7	14
Widowed	3	6
Religious background (n = 28)		
Protestant	18	64
Catholic	7	25
Jewish	1	4
Other	2	7
Educational level (n = 27)		
High school	7	26
Some college	6	22
Four-year college	7	26
Postgraduate degree	7	26
Cancer diagnosis		
Breast	13	25
Lung	7	14
Lymphoma	7	14
Genitourinary	7	14
Gastrointestinal	6	12
Gynecologic	4	8
Brain	3	6
Head and neck	3	6
Multiple myeloma	1	2
Treatment status		
Currently receiving treatment	12	24
Completed treatment within prior 6 months	25	49
Completed treatment within prior 7–12 months	14	27

N = 51

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

distribution of diagnoses (N = 51) was representative of the population of outpatients treated at the cancer center. It included 13 patients with breast cancer, 7 with lung cancer, 7 with lymphoma, 7 with genitourinary cancers, 6 with gastrointestinal cancers, 4 with gynecologic cancers, 3 with brain cancer, 3 with head and neck cancers, and 1 with multiple myeloma. Twenty-four percent of the patients were currently receiving treatment, 49% had completed treatment within the preceding 6 months, and 27% had completed treatment within the preceding 7–12 months. Of the patients who directly answered the question (n = 12), 66% had a computer or knew how to use one. Of patients who directly answered the question (n = 26), 67% stated that they would like to use a computer for information relating to cancer treatment, 25% stated they would not like it, and 8% were unsure.

Informational Themes

Many of the patients who participated in these focus groups reported that they had not received adequate information about treatment and treatment-related side effects. Some had not received any information at all. Some reported receiving what one patient described as “those cheesy little handouts.”

Others reported being overwhelmed by information from a variety of sources and having difficulty determining what was accurate and what was relevant to them. The major informational themes derived from the analysis of the transcripts are presented in Table 2.

Informational needs: Most patients and caregivers said that they wanted detailed information so that they would know what to expect and could plan accordingly. Specifically, they wanted to know about (a) the treatment process (e.g., where to go, what the room would be like, who else would be there, exactly what the treatment would involve, how long it would take), (b) side effects that they might experience (e.g., how severe they might be, how long they would last, how to deal with them), and (c) how the treatment would affect their lives (e.g., their work, family, social life, recreational activities and hobbies, financial situation). One spouse described her experience this way.

How long he would be in the infusion room, you know, the first time? We thought he would be gone, like, an hour. We have kids, and we got a baby-sitter for a couple of hours and then had to change because we called the doctor's nurse and she checked [and said,] “Oh no, it will be six, seven, eight hours.” We're, like, we had no idea, and I think that was a really important part. They should have told us for a few reasons. One was child care, one

Table 2. Informational Themes

Theme	Sample Supporting Comments
Informational needs	Nitty-gritty details of the treatment process
	Specific side effects to expect, including severity and duration
	Ways to deal with side effects
Being prepared; needing to know what to expect ahead of time	Impact on the rest of their life, including finances, work, family, and social life
	Relevant to a person in the situation
	As individualized and personalized as possible
	That a layperson can understand
Sources of information received	So they won't worry that something is wrong
	So they'll know how to deal with side effects that do occur
	So they can make appropriate plans
	To gain control over their lives
	Concerns about being unnecessarily frightened by side effects that might not occur
Obstacles	Written materials, including books, pamphlets, newspapers, and magazines
	Healthcare providers, including oncologists, radiologists, urologists, kidney specialists, nurse practitioners, nurses, technicians, pharmacists, naturopaths, and dietitians
	American Cancer Society
	Internet
	Peers including friends and support groups
Obstacles	Access to providers
	Provider reluctance to answer questions
	Concerns about liability, confidentiality
	Provider lack of knowledge of or sensitivity to special circumstances (e.g., age)
	Informational overload
Retention problems	

was just like, wow. . . . It was going to be, like, a really big part of what we had to plan and [get] psyched up for and everything.

Patients and caregivers also wanted information that was easy for a layperson to understand, accurate, and relevant to them. They wanted information to be as personalized and individualized as possible. They wanted to know what the experience was going to be like for them.

Being prepared: Many patients and caregivers expressed a desire to know about treatment and treatment-related side effects so that they could be prepared ahead of time for whatever happened. They wanted to know what side effects were likely to occur so that they could self-monitor for symptoms or side effects, would not worry that something was wrong when side effects did occur, would know how to deal with side effects that did occur, and could make appropriate plans. As one caregiver verbalized,

I mean, for, like, three or four days after the chemo he was . . . great. It was like, bang . . . when he came off, crash. They really . . . knew it was going to happen, because when I called, they said, "Oh, it's just because he came off the [steroid]." . . . It would have been real helpful if I had known so I knew how to deal with that. I could have said, "You're going to be okay." But I didn't know and thought maybe he isn't going to be okay. So, I think it would have been more helpful if they could explain . . . what to expect.

In many cases, being prepared allowed patients to feel that they had some control over what was happening in their lives. For these patients, information gathering became an important way of coping with treatment and with cancer more generally. One patient expressed his or her feelings this way.

I wanted [information] now, and I needed [it] to deal with my panic and my terror as well as my disease, as well as my life.

Although the majority of the patients and caregivers who participated in these groups were active information seekers, a small minority did not want to know about anything until it happened. They were concerned about things they had heard about treatment and did not want to worry about side effects that might not occur. These patients generally adopted a more relaxed attitude and did what they were told to do but did not seek out additional information or ask many questions.

Sources of information: Information had been obtained from a variety of sources, including physicians, nurse practitioners, nurses (especially infusion room nurses), books, pamphlets, newspapers, magazines, healthcare journals, television, the Internet, discussion groups, the American Cancer Society, and other healthcare providers (e.g., pharmacists, psychologists, dietitians). In many cases, family members, especially spouses, played an important role in gathering and managing information about treatment-related side effects.

One of the most common and helpful sources of information that patients cited was other patients who had been through similar experiences. Patients shared their experiences with a wide range of practical strategies for managing symptoms, from using plastic silverware for taste changes to taking notes and tape-recording appointments to help with

memory problems. Patients reported receiving more than advice about symptoms from these exchanges. One spouse related, in reference to her husband,

Sometimes he thought he was alone and that he was the only one going through what he was going through. His friend would call, and then he would ask him all these questions. He would say, "I had that, and I did that, and I did that." Then he'd get off the phone and he'd be in a different frame of mind. He would feel better, deal better with this. [He'd say] "This isn't just happening to me."

Obstacles: Patients described many obstacles to getting the information they needed. Access to healthcare providers was often a problem. Once patients and caregivers had the opportunity to speak with providers, they found that the providers were reluctant to answer some of their questions. Some patients and caregivers believed that this was a result of the current climate of concern regarding liability. In addition, some patients felt that providers were not sensitive to special circumstances, such as age, that might affect treatment decisions or discussions related to those decisions.

I had made very sure the doctor understood that 85 is different from when you are 75. That 10 years makes a lot of difference. The doctor was young and didn't listen to me. . . . But you can't make a younger doctor understand. They don't have the experience.

Many patients talked about informational overload, about being "bombarded with such an enormous amount of information, most of it useless [and] some of it really destructive." They talked about needing someone (a spouse or a friend) to filter information for them. In addition, some patients described difficulties they had experienced with retaining information because they felt overwhelmed. For example, one patient said,

I think it is very hard to assimilate because you are being slapped in the face with, oh, I have cancer, the big "C" word. But there is a lot you are getting, and there is a lot to assimilate. Sometimes, like I said, it went through one ear and out the other.

Discussion

Focus group participants confirmed that many patients experienced distressing treatment side effects despite current efforts to minimize them and suggested that the most distressing side effects were the ones that patients were least prepared to handle. Although the authors believe that focus groups were an ideal method for obtaining input from patients about their information needs and preferences regarding cancer treatment, some limitations are apparent (Gulanick & Keough, 1997). First, focus group studies typically involve a relatively small number of participants. Thus, the results may not be generalizable beyond those groups. Second, the number of questions that can be answered in a typical one- to two-hour session is limited. Third, some patients may not be forthcoming because of a sense of social desirability, particularly if one member of the group dominates the discussion. Finally, some patients may come to the group with their own agendas, expecting more of a support group or educational program. The authors attempted to avoid some of these pitfalls by developing a set

of facilitator guidelines designed to structure discussion around a limited number of key issues and by using facilitators who had experience conducting focus groups with patients. Review of the transcripts indicated that facilitators were able to include all group members in the discussions and kept the discussions focused on the issues at hand. Review of the available demographic characteristics of the groups indicated that the sample was fairly representative of the general cancer population in terms of gender and diagnosis. However, all of the group participants were Caucasian. Thus, the results of these focus groups may have limited applicability to other populations. Despite these limitations, the authors believe that the focus groups were an appropriate method of gathering data to inform the design of the multimedia program for the target population.

Data indicated that many patients were not receiving the information that they wanted and needed to cope successfully with treatment. Either they did not receive any information or the information they received was not adequate. The data from these focus groups were consistent with another study of patients receiving treatment at an outpatient facility in Ireland (McCaughan & Thompson, 2000) that found that most patients wanted as much information as possible about treatment and treatment-related side effects; the process of getting treatment, possible side effects, and self-care strategies to manage them; and the impact of treatment on their lives, particularly their family relationships. Data from the focus groups also support findings by Carelle et al. (2002), who reported an increased concern for specific psychosocial issues such as impact on family and work. Findings were inconsistent with a review of the literature that found patients' needs for information currently were being met (Chelf et al., 2001). This might reflect that information is available but inadequate because of a lack of specificity. Specificity was one new finding identified by the current study. Patients described wanting very individualized, practical information that was concrete in nature about how treatment would affect their daily life. As cancer treatments grow in complexity and rely more on patients functioning on an outpatient basis, the practicality of information may become increasingly important.

The data from these focus groups present something of a paradox. On one hand, most patients indicated that they wanted more information about treatment. On the other hand, many patients reported that they had difficulty absorbing and retaining information that had been presented. This paradox supports theories relating to the complexity of how people learn as presented by Treacy and Mayer (2000). One explanation for this apparent paradox is that patients wanted detailed information about what was likely to happen to them and they wanted it presented in a format and at a time that maximized their chances of absorbing and retaining it. They desired timely information based on individual needs. Receiving and retaining information to be prepared gave patients a sense of knowing what to expect and control (Hinds et al., 1995). This suggested that current educational efforts were not specific or dynamic enough to keep pace with the rapidly changing informational needs of patients as they went through their cancer experience. Additionally, patients described many sources for obtaining this information (e.g., pamphlets) but expressed a desire for information to be in a lay format that they could understand, which supports the need for material of appropriate reading level. Patients frequently cited other patients as

sources of information, and this also may support the fact that using other patients in an interactive process can help to tailor and censor the information delivery and make it more specific.

The results suggest that traditional approaches to patient education are not adequate in the current healthcare environment. The shift from inpatient to outpatient care, combined with the increased pressure on clinicians to see more patients in less time, has placed greater demands on patients and caregivers to independently manage treatment-related side effects at home. New approaches need to be developed that will meet the current needs of patients, caregivers, and clinicians. The current study's data suggest that these approaches should

- Allow for individual differences in terms of the amount of information that is presented and the format in which it is presented. Patients should be able to slow the pace of information if they are feeling overwhelmed, have access to as much information as they need when they feel prepared to learn, and easily be able to review material that was forgotten or not understood.
- Include detailed information about the process of getting treatment, specific side effects of treatment, and strategies that can be employed to prevent or manage them.
- Include information about the impact of treatment on patients' families and lifestyle.
- Present information that is relevant to each patient (i.e., tailored to each patient based on individual characteristics).
- Contain testimonials from other patients about their experiences.

Interactive multimedia technology offers an innovative approach to patient education that has many advantages over traditional instructional media and overcomes many of the information barriers identified in the current study's data. Through the use of audio, text, graphics, and video, programs can present concrete objective information and model active coping strategies. Programs can engage patients in an active learning process that allows them to control the amount and type of information that is presented, the pace at which it is presented, and the format in which it is presented. Through the use of video, viewers can hear from patients who have been through similar treatments and go on "virtual tours" of the infusion room and radiation suites. Finally, programs can be tailored to patients based on individual situations. For example, the computer can be programmed to generate a profile of the most common side effects that a patient is likely to experience based on diagnosis, gender, and treatment regimen. This process reduces the burden placed on patients of sorting through a large body of information to try to determine what is relevant to them. Patients have the access they need at the level they want in a confidential manner. These features make interactive multimedia technology an ideal choice for a patient education program about the side effects of cancer treatment. The current study's results showed that most patients already are using computers to access information and would be able to use an interactive program.

The authors are currently in the process of developing and evaluating an interactive multimedia program for patients titled "Managing the Side Effects of Cancer Treatment." Decisions about the design and content of the program have been guided by the information obtained from the focus groups that have been described. The authors believe that the patients were a valuable source of information and that the design of the program has been improved as a result of the

information that was obtained. Future efforts should focus on the cost effectiveness and learning outcomes of such a program compared to traditional educational models.

The authors would like to acknowledge the contributions of the Office of Clinical Quality Resources at Dartmouth-Hitchcock Medical Center for identifying patients, the Department of Human Resources at Dartmouth-

Hitchcock Medical Center for moderating the focus groups, and Barbara Clark for organizing the groups and transcribing the audiotapes.

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