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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.

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.

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

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