



## PATIENT EDUCATION

# *Providing Information to Patients With a Rare Cancer:* Using Internet Discussion Forums to Address the Needs of Patients With Medullary Thyroid Carcinoma

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Nurses always have been responsive to patients' informational needs and spent much of their direct patient care time answering questions, giving nursing advice, and teaching patients about procedures, diseases, and medications. The purpose of this article is to describe the use of the Internet as a means of addressing the informational needs of patients with medullary thyroid carcinoma (MTC).

## Background

A Harris poll conducted by Sigma Theta Tau International Honor Society of Nursing in 1999 revealed that the public requested advice from nurses about health issues in only four areas: self-care or the care of others in the immediate postsurgical period, over-the-counter health-care products, medication administration and side effects, and interpreting information from physicians (Floyd, 2000). This poll suggested that the public is unaware that nurses possess expert healthcare knowledge in areas other than those listed.

Patient information and communication is a concern for all healthcare providers. At an interactive session during the Annual Meeting of the American Society of Clinical

Medullary thyroid carcinoma (MTC) is a rare disease, and specific experience with the condition is not commonly found outside of major cancer centers. Because of the rarity and slow-growing natural history of the disease, patients with MTC frequently have many questions concerning prognosis, treatment, and follow-up care. Many of these patients have joined an e-mail group on the Internet through which they share information and concerns. The author has joined this group and shares her expert clinical knowledge about the disease. When individuals are armed with accurate and expert information, they can make informed decisions. The source of this information can be diverse. Nurses with expert knowledge can use opportunities such as e-mail groups to answer questions and respond openly about subjects about which they have unique perspectives.

Oncology in 2000, participants were asked what they thought was the number one reason for less than optimal physician-patient communication. Forty-seven percent of respondents indicated that a lack of time was the greatest hindrance (Miller, 2000).

In a study of the supportive care needs of patients with cancer, 1,492 patients were surveyed. Almost 900 patients returned surveys that indicated that they experienced the highest levels of unmet needs in the psychological domain, though this was followed closely by the communication and informa-

tion domain (Sanson-Fisher, Girgis, & Boyes, 2000).

We live in the "information age," and many people seek information on a variety of topics. That patients with cancer seek information about cancer is not surprising. Patients with cancer are consumers who frequently use the Internet to access health information and support (Clark & Gomez, 2000). Online support groups are being created for patients with a variety of health issues (Finfgeld, 2000; Han & Belcher, 2001; Johnson, Ravert, & Everton, 2001). Little is known about the efficacy of online support groups (Finfgeld). Some studies have shown that these groups are helpful. The benefits of Internet group participation include obtaining information, sharing experiences, receiving support, venting feelings, and gaining empowerment as a result of interacting with people with similar life and health issues (Bacon, Condon, & Fernsler, 2000; Han & Belcher; Johnson et al.; Reeves, 2000).

Healthcare providers have important roles in assisting patients in locating helpful, cor-

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