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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Background

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).

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.

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