PATIENT EDUCATION

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

Pamela N. Schultz, PhD, RN

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 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 information 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-

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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rect, and appropriate information on various health-related Web sites (Houston & Ehrenberger, 2001). For patients with rare cancers, dependence on this type of resource may be even more profound.

**Medullary Thyroid Carcinoma**

MTC is a rare condition, and specific experience in treating the condition often is not found outside of major cancer centers. MTC accounts for 5%–10% of all thyroid malignancies, and thyroid malignancies account for about 1% of all cancers (Fuchshuber, Loree, Hicks, Cheney, & Shedd, 1998; Giuffrida & Gharib, 1998). MTC is a malignant tumor of the parafollicular c-cells in the thyroid gland that secrete the hormone calcitonin. This neoplasm occurs in sporadic or familial forms. When familial, MTC is inherited as an autosomal dominant trait. Mutations of the RET proto-oncogene have been found in germline DNA of patients with familial MTC, and evidence indicates that these mutations result in MTC. Familial MTC accounts for approximately 25% of all MTC cases (Gagel et al., 1995). Familial MTC can be found in one of three forms: as part of the multiple endocrine neoplasia (MEN) type 2A, as part of the MEN type 2B, and as non-MEN familial MTC (Samaan, Ordonez, & Hickey, 1993). MEN 2A is characterized by MTC with one or more of the following neoplasms: pheochromocytoma (i.e., benign tumor of the adrenal medulla), primary hyperparathyroidism as evidenced by parathyroid hyperplasia, or multiple parathyroid adenomas. MEN 2B is characterized by MTC with one or more of the following: pheochromocytoma, mucosal neuromas, intestinal ganglioneuromatosis, marfanoid habitus, and skeletal deformities (Samaan et al.).

**Genetic Concerns**

Because familial MTC is autosomal dominant, each offspring has a 50% chance of inheriting the mutation. The penetrance is close to 100%; therefore, affected individuals probably will express the malignancy at some point in their lifetime (Gagel et al., 1995). Often, this cancer is not diagnosed until the fourth or fifth decade, and affected individuals usually have begun their families. Genetic testing is commercially available and reliable, and genetic susceptibility is yet another informational concern for these patients.

Freyer et al. (1999) examined the psychosocial impact of genetic testing in familial thyroid carcinoma. Seventy-seven patients with MTC who had received genetic counseling and treatment completed a quality-of-life profile and psychometric measurements of anxiety and depression. None of the patients had active MTC at the time of the study. The researchers found that knowledge of the genetic information was associated with a substantial decrease in overall quality of life. They also found that the patients had high levels of frustration and dissatisfaction related to either the management of the genetic information or, simply, the knowledge of the genetic risk of cancer.

Treatment for MTC includes surgery consisting of a near total thyroidectomy and central node dissection of the neck. Surgery is the best treatment for this disease, and some patients may require additional surgery following their initial surgery at community cancer centers (Fleming et al., 1999). Patients are informed that MTC frequently recurs locally, and a diligent follow-up schedule is planned and discussed. Although the plans are individualized, certain procedures are performed standardly. These include ultrasound of the neck, chest x-ray, thyroid function studies, serum calcitonin, and serum carcino-embryonic antigen measurements.

**Prognosis**

Patients with MTC may be cured with the initial surgery. However, “cure” refers to a biochemical cure. MTC produces the hormone calcitonin, and the assay used to measure this hormone is extremely sensitive. In a patient who has undergone thyroidectomy, the calcitonin level should be unmeasurable (i.e., less than 0.7 pg/ml). Calcitonin levels may be in the multiple hundreds before any radiological evidence of disease exists. Patients may have a steadily rising calcitonin level for several years before any macroscopic tumor is found (Fleming et al., 1999). Because this tumor usually is slow growing, biochemical evidence of disease may exist long before any radiological evidence (van Heerden, Grant, Gharib, Hay, & Ilstrup, 1990). Patients often have difficulty understanding the concept that biochemical markers indicate tumor activity and that this pattern can continue for years without radiological or clinical evidence of disease recurrence. Modigliani et al. (1998) found that the five-year survival rate of 899 patients with MTC was 86%, and the 10-year survival rate was 78%. Biochemical cure at 10 years was 98%. Prediction of biochemical cure was dependent solely on stage of the disease at diagnosis. Other factors influencing survival of patients not experiencing biochemical cure were gender, type of surgery, and familial forms (Modigliani et al.).

**Informational Needs of Patients With MTC**

When patients with MTC present to an outpatient clinic, oncology endocrine nurse specialists, endocrinologists, surgeons, and oncologists spend considerable time discussing the care involved in treating this unique cancer. Because MTC may involve MEN 2A or 2B, the conditions of primary hyperparathyroidism and pheochromocytoma are discussed, along with other manifestations of this syndrome. Because hyperparathyroidism or pheochromocytoma may not present at the same time as the MTC, surveillance of these conditions over the patients’ lifetime is needed.

Hyperparathyroidism occurs as a result of parathyroid hyperplasia or adenoma, which produce excessive amounts of parathyroid hormone and result in hypercalcemia. Treatment for this condition is surgical excision of the abnormal parathyroid tissue. Pheochromocytoma is a benign tumor of the adrenal medulla that secretes excessive catecholamines and results in hypertension. This type of hypertension can become increasingly severe and lead to premature death. Treatment usually consists of adrenalectomy of the affected adrenal (Samaan et al., 1993). In addition, about 25% of patients with MTC have a germline mutation of the RET proto-oncogene; therefore, genetic counseling also is initiated (Gagel et al., 1995).

Genetic counseling includes information about indications for testing, the implications of testing, when to test, who to test, and management of the care of individuals who test positive for the disease. For patients with MTC, genetic counseling is viewed as a long-term project. Efforts are made to establish a stable interaction with family members. A clear screening and treatment strategy, which has evolved with the understanding of MTC, is provided (Gagel, 1993).

**E-Mail Groups**

Some patients with MTC are not able to travel to cancer centers where expertise in MTC treatment and support is available. Local support groups may meet patients’ emotional needs but may not meet patients’ informational needs, as support groups often are organized by facilitators not familiar with this unusual cancer and its treatment. Yahoo!® Groups (http://groups.yahoo.com)
is a Web site that allows individuals to create and join e-mail groups. This site has a subgroup for patients with MTC and their families and friends (http://groups.yahoo.com/group/Medullary). While investigating the group, the author saw a need for expert healthcare knowledge about MTC. For example, patients had posted questions about treatment, genetic screening, biochemical markers, and the rationale for the interpretation of test results. Some questions about how they had coped with the disease were directed at members of the group. Some individuals requested advice about where to go for treatment and what type of treatment was best. The author joined the group and began to read and respond to all the entries posted to the forum. Reading all of the postings takes about 15–20 minutes per day, and writing responses averages an additional five minutes. Sometimes, investigating a new drug or treatment is necessary to answer a question, but the time involved usually is less than an hour.

**Nursing Interventions**

When the author joined the MTC e-mail group, she identified herself, explained her experience, and wrote that she would respond to specific questions about MTC, its treatment, and natural history of the disease and address concerns and questions. Occasionally, patients ask for feedback on coping with cancer-related issues. The author refrains from giving nursing advice in these instances because she believes that allowing other affected individuals to respond is more appropriate. Patients find this "patient-to-patient" advice helpful. Some of the discussions are directed to specific individuals that regularly participate in the group. Sometimes the author is addressed specifically. For instance, a posting might read, “[Nurse], could you respond to my question about where to get genetic testing done?,” and the author always responds to these postings in some way. Postings to the forum are sent automatically to all who subscribe to the forum. Therefore, even though participants may respond to a specific question from a specific individual, all participants receive their responses. This is a very efficient way to disseminate information.

Because many of the same questions continue to surface, participants frequently comment on how ongoing discussions answer many questions already posed. The author has written the same information several times but altered the language or style because the message may not have been clear or new subscribers may be reading. Figure 1 lists some of the common questions posed by patients with MTC.

My calcitonin is higher, and my doctor wants to see me again in three months and repeat the test. Does this sound reasonable?

I have medullary thyroid carcinoma (MTC), and my son tested positive for the genetic mutation. He is 8 years old. The doctor wants to take out his thyroid right away. Isn't that too young?

I had surgery for MTC five years ago, and they recently found out I had liver metastases. Is there any effective treatment out there?

My diarrhea is getting worse. Any suggestions?

I just completed radiation treatments. Should I see an endocrinologist or stick with my surgeon?

**FIGURE 1. EXAMPLE QUESTIONS AND COMMENTS MADE TO THE MEDULLARY THYROID CARCINOMA E-MAIL GROUP**

Communicating via the Internet often is challenging. E-mail group subscribers do not know who they are talking to and cannot receive feedback beyond what other subscribers choose to type back. Many times, individuals on the forum refer to and discuss the author’s comments in a previous message. Postings addressed to the author always have been polite, considerate, and gracious. Occasionally, she receives e-mails addressed to her privately. These usually are in the form of thank-you.

Three major concerns about participating in the MTC e-mail group are the issue of sharing correct information, the author’s role as patient advocate, and patient confidentiality. Nurses have a moral duty to provide accurate information. In the rapidly advancing oncology field, nurses must remain current. Different practices are used in the treatment of MTC; not all physicians treat this malignancy the same way. The author’s experience with the e-mail group has revealed that patients want as much information as they can get to help direct their own care. This trend reflects a shift from paternalistic health care.

Unfortunately, the Internet provides no way to validate or authenticate the information that individuals choose to share with the group. Group members know the author’s credentials and name; no participant ever has disputed this information. Sometimes patients apparently misunderstand information that has been provided to them. Occasionally, medical misinformation is given. In these instances, the author posts a response that usually begins with, “In my experience . . .” and may suggest that individuals ask their physicians about the issue. Because so much variation exists in the treatment of MTC, these issues can be difficult.

Patient advocacy also goes beyond individual patients and encompasses patients as a group; in this instance, advocacy involves a group of patients with MTC. The author fulfills her role as advocate by providing expert knowledge of this rare disease process.

Patient confidentiality is a potential problem because some of the e-mail group participants are patients that the author has cared for. She has been diligent in keeping remarks general and not patient-specific and has posted that she will not compromise patient confidentiality in any way. The author has been criticized on the forum for not being more personable; for example, one complaint was that she was too factual. This comment indicated that patients are in need of more than factual information. The author has chosen not to become involved in addressing emotional support in this group except when furnishing information.

Well-informed patients make better decisions, which can lead to a better quality of life. Time is a precious commodity for patients as well as healthcare providers. When individuals are armed with accurate and expert information, they can make informed decisions. The source of this information can be diverse. Nurses can use e-mail groups to answer questions and respond openly about subjects about which they have expert knowledge and unique perspectives.

**Implications for the Future**

Nurses must be willing to expand their thinking about how to care for patients. The delivery of healthcare has changed dramatically in the past few years and probably will continue to do so. Nurses must retain their traditional values of caring, compassion, empathy, diligence, and loyalty but also must be prepared to be creative in the use of new technology in the nursing care of patients. Using the Internet is one way to integrate information technology into patient care. However, incorporating this type of activity into practice may not be a role for the novice clinician.

Involvement in the Internet e-mail group is not a part of the author’s job description; therefore, she is legally and solely responsible for the information she provides. The author carries individual liability malpractice insurance coverage and encourages other nurses practicing outside the traditional arena of nursing to do the same.

The world is hungry for information. It has been said that “If the experts don’t put it out there, then someone else will.” Although e-mail groups are not the traditional way to inform patients about their diseases and
nurses should not abandon those methods, nurses should work to incorporate new ways of patient education and support that are technologically appropriate and easily accessible to patients.

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Author Contact: Pamela N. Schultz, PhD, RN, can be reached at pschultz@mdanderson.org.

References


For more information on this topic, visit the following Web sites:

Rare Cancers: Where to Start
http://cancer.about.com/library/weekly/aa012601a.htm

National Institutes of Health: Office of Rare Diseases
http://rarediseases.info.nih.gov

RARE-CANCER: The Rare Cancers Discussion Group
http://listserv.acor.org

These Web site are provided for information only. Hosts are responsible for their own content and availability. Links can be found using ONS Online at www.ons.org.