It’s the “Good” Cancer, So Who Cares? Perceived Lack of Support Among Young Thyroid Cancer Survivors

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Thyroid cancer is the third most common cancer in young adults aged 20–44 years and is more prominent in this age group (7% of all cancers) than in all ages combined (2% of all cancers) (Canadian Cancer Society’s Advisory Committee on Cancer Statistics, 2013; Cancer Care Ontario, 2006). Four principal types of thyroid cancer exist: papillary, follicular, medullary, and anaplastic (Public Health Agency of Canada, 2013). Most young adults with thyroid cancer are diagnosed with well-differentiated papillary carcinoma (83% of cases), which has excellent outcomes and a high survival rate (Banach, 2013; Cancer Care Ontario, 2006; Ying, Huh, Bottomley, Evans, & Waguespack, 2009). The overall five-year survival rate for patients with thyroid cancer younger than age 40 years is greater than 99% (Ying et al., 2009).

Standard treatment for thyroid cancer includes surgical removal of the thyroid gland followed by radioactive iodine treatment, depending on the severity of the disease (Costa & Pakenham, 2012). Patients generally tolerate treatment well; however, aggressive surgical and postoperative treatments often are associated with many physical and psychological late effects, such as voice difficulties (e.g., hoarseness, vocal cord paralysis), migraine headaches, anxiety, body image issues because of scarring, and symptoms of thyroid disregulation (e.g., fatigue, sleep disturbances, temperature sensitivity, weight gain, depression, skin dryness, loss of libido) (Husson et al., 2011; Schultz, Stava, & Vassilopoulou-Sellin, 2003; Ying et al., 2009). With the removal of the thyroid gland, patients become dependent on thyroid replacement therapy for the remainder of their lives, which can affect overall quality of life (Banach, 2013; Roberts, Lepore, & Urken, 2008; Ying et al., 2009). Difficulties with thyroid replacement therapy include dealing with hormone imbalances, struggling to find the proper dosage, and dealing with side effects of medications.

Thyroid cancer survivors often have been referred to as the neglected segment of the cancer population because of the relatively low mortality and morbidity rates and the perceived dismissal of the diagnosis as not serious (Costa & Pakenham, 2012; Dagan et al., 2004; Dow, Ferrrell, & Anello, 1997; Husson et al., 2011; Sawka et al., 2009; Schultz et al., 2003; Tagay et al., 2006). However, previous studies that focused on thyroid cancer survivors suggested significant reductions in quality of life and impaired affective and cognitive functioning compared to other cancer survivors as well as healthy controls (Costa & Pakenham, 2012; Hoftijzer et al., 2008; Husson et al., 2011; Sawka et al., 2009; Schultz et al., 2003; Singer et al., 2012; Tagay et al., 2006; Ying et al., 2009). Schultz et

Purpose/Objectives: To describe the survivorship experience of young adult patients with thyroid cancer.

Research Approach: A qualitative, descriptive study.

Setting: Four Canadian provinces, with most participants from Ontario.

Participants: 12 young adult thyroid cancer survivors who participated in a larger study on follow-up care needs consisting of 55 young adult cancer survivors.

Methodologic Approach: Telephone interviews were conducted with cancer survivors who were diagnosed from age 18–39 years and were 1–5 years post-treatment.

Findings: All 12 thyroid cancer survivors discussed the feeling that their cancer experiences often were downplayed because thyroid cancer is labeled as the “good” cancer. Many said that they were not considered real patients with cancer by healthcare providers and other patients with cancer, and they were unable or unwilling to access support programs or assistance from healthcare providers.

Conclusions: Cancer can have an impact on a person’s life regardless of the prognosis. Being diagnosed with thyroid cancer at a young age can pose additional challenges because of the lack of available support to address needs specific to young adults.

Interpretation: Healthcare providers must recognize the needs of thyroid cancer survivors and encourage them to access supportive services.

Knowledge Translation: Patients with thyroid cancer believe that their needs often are overlooked because of high survival rates, and they have difficulty accessing support resources and finding help. Young adults with cancer often have unique support needs. Support needs may not be the same for all young adult patients with cancer, and those needs should be recognized and addressed.