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It's the "Good" Cancer, So Who Cares? Perceived Lack of Support Among Young Thyroid Cancer Survivors

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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.

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, Ferrell, & 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

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al. (2003) found that thyroid cancer survivors reported more memory loss and psychological complications than other cancer survivors, and more migraine headaches than other cancer survivors as well as the general population. Singer et al. (2012) found that even after the study results were adjusted for age and gender, thyroid cancer survivors suffered from significantly more physical (e.g., fatigue, sleep disturbances), emotional, cognitive, and social functioning symptoms than the general population (Singer et al., 2012). Other studies measuring health-related quality-of-life (HRQOL) scores also found that thyroid cancer survivors had significantly reduced scores compared to healthy controls or other cancer survivors (Dagan et al., 2004; Hoftijzer et al., 2008; Husson et al., 2011; Tagay et al., 2006). One study found a pronounced decline in psychosocial HRQOL scores in thyroid cancer survivors who suffered symptoms of hypothyroidism following the removal of the thyroid gland (Tagay et al., 2006). However, Husson et al. (2011) found improved HRQOL scores with longer time since surgery.

Although studies exist that show the long-term impact of thyroid cancer treatments, few studies have examined psychological adjustment in thyroid cancer survivors (Costa & Pakenham, 2012) or the experiences of those patients using a qualitative approach. The original purpose of the current study was to assess the follow-up care needs of young adult survivors of all types of cancer across Canada using a constructivist grounded theory approach (Miedema, Easley, & Robinson, 2013). However, within the larger study, a prominent theme emerged from participants diagnosed with thyroid cancer, and this article focuses on the experiences of those participants.

Methods

For the current study, participants were recruited via social networking Web sites (e.g., Facebook), classified advertisement Web sites (e.g., Kijiji), newsletters, online message boards at cancer advocacy groups (e.g., Young Adult Cancer Canada), posters in various oncology clinics, newspaper and media articles. Young adults who were diagnosed with cancer, aged 18–39 years and were 1–5 years post-treatment were invited to participate. Participants were required to be able to speak English or French and provide informed consent. Once a potential participant indicated willingness by phone, e-mail, or through Facebook, the participant was screened to ensure eligibility. A consent form was forwarded to the potential participant and a telephone interview date was set. Before the telephone interview, the consent form was discussed to make sure that the participant was fully aware of the study procedures, risks, and benefits. Verbal consent was obtained prior to starting the interview. The study was reviewed by Dalhousie University and Memorial University research ethics boards.

Qualitative interviews were conducted using 11 open-ended questions. The first two questions were designed to help the participants feel comfortable and tell their stories. The interview also included questions about current cancer follow-up care (CFC), broad CFC issues (i.e., physical, psychological, relationship, and social), and recommendations for improvement. After the interview, sociodemographic information was collected to create a participant profile. Two research assistants conducted interviews with gender-paired participants. All interviews were transcribed verbatim and proofed for accuracy.

For analysis, the authors used a constructivist, grounded theory approach, which often is used in health research when the voice of a participant is important (Busby & Witucki-Brown, 2011; Hubbard, Kidd, & Kearney, 2010). Constructivism is a research paradigm that rejects the notion of an objective reality but views realities as social constructs; data are narrative constructions and may have multiple meanings. Using that theory,

Table 1. Sample Characteristics (N = 12)

Characteristic	$\bar{X}$	SD	Range
Age at diagnosis (years)	32	3.94	24–37
Age at interview (years)	34	3.26	28–38

Characteristic	n
Gender	
Female	11
Male	1
Area of residence	
Urban	9
Rural[a]	3
Marital status	
Single	3
Married or common-law marriage	8
Divorced	1
Family status	
Have children	6
No children	6
Employment status	
Full- or part-time	8
Full-time homemaker	2
Social or government assistance	1
Student	1
Education	
Junior high or high school diploma	2
Community college degree	5
College degree	4
Graduate degree	1
Insurance	
Supplemental private health insurance	9
No private health insurance	3
Annual family income ($)	
30,001–50,000	2
50,001–70,000	1
70,001–80,000	1
80,001 or greater	6
No answer	2

[a] Population of less than 10,000

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researchers must go beyond the surface of the data to find meaning and values (Mills, Bonner, & Francis, 2006). Two coinvestigators and two research assistants read the same three transcripts independently and developed a coding scheme during a two-day meeting. The rest of the transcripts were coded line by line by one researcher to ensure consistency using the constant comparison method, and coding was refined through continued discussion among team members. The coding process was facilitated by the qualitative data analysis program NVivo 9, and the sociodemographic information was analyzed with SPSS®, version 15.0.

Findings

Sixty-seven young adult cancer survivors from across Canada expressed interest in the study, and 55 of those participated in telephone interviews (Miedema et al., 2013). The remaining 12 could not be reached or declined to participate after initial contact. Of the 55 who participated, 12 had been diagnosed with thyroid cancer and are the focus of the current analysis (see Table 1). All 12 participants were Caucasian.

Impact of Having the "Good" Cancer

The most prominent theme that emerged from the interviews was the reference to having the "good" cancer. Every participant mentioned that having the good cancer was a paradox. They knew that the classification was meant to reassure and emphasize the excellent chance of survival, but participants also noted that it downplayed the diagnosis and experience. Standard treatment for thyroid cancer does not include chemotherapy, so participants did not have the typical outward signs of having cancer (e.g., baldness). They described feeling that they were perceived as not needing support and often felt unworthy of accessing available support programs. However, participants still acknowledged that their cancer was a life-altering illness even if it was not seen as life threatening, and the illness physically and psychologically affected them. Patients with thyroid cancer often face long-term health complications because of treatment and have to take medication for thyroid glands with limited or no function (Husson et al., 2011; Roberts et al., 2008; Ying et al., 2009). Health-related consequences of treatment for thyroid cancer may not be immediately visible, but they are present in many survivors (see Figure 1).

Isolation

Isolation was strongly connected to the theme of being told that thyroid cancer is the good cancer. Isolation was discussed in relation to three different areas: isolation from other patients with cancer and support programs, mandatory physical isolation periods following radioactive iodine treatments, and isolation from their peers without cancer. Many participants said that they could not relate to patients and survivors with other types of cancer, and they felt that other patients did not want to hear about their experiences because thyroid cancer treatments typically are well tolerated. As young adults with cancer, participants also expressed difficulty identifying with older adult patients with cancer because of differences based on life stages. In addition, participants discussed the psychological effects of being physically isolated from family, friends, and healthcare providers during the radioactive iodine treatment. Radioactive iodine treatments require a period of complete isolation until the radioactivity has worn off, sometimes for several days depending on treatment dosage. Human contact is kept to a bare minimum during this time. One participant compared the experience to that of a zoo animal or having the plague at a time when she needed contact and support the most. Thyroid cancer survivors described being isolated from their peers who did not have cancer because they could not relate to or understand the experience of having a serious illness. Although peers may recognize the physical symptoms

Psychological Impact

"I don't think it is fair to keep saying that it's the best cancer to have. Like, that's frustrating to people who are trying to deal with it. Yeah, it might be the best one, but it's downplaying it, and it's not helping people deal with the fact that they have been diagnosed with cancer."

"Thyroid cancer is a unique cancer in that, you know, most people say, 'Oh well, it's the good cancer to have. . . . You're okay.' . . . And you know, yes, it's just thyroid cancer, but it still puts your life perspective in a whole new thing."

Lack of Support

"They call it the 'good' cancer. And I'm like, how can it be the good cancer? . . . I didn't lose my hair . . . and we don't look like we have cancer. And that's why it's very hard for us to find support because we haven't gone through chemotherapy. We don't have scars from radiation. You know? People forget."

"So for me to go to [the Cancer Support Centre] . . . I didn't feel like I belonged there. I didn't feel like I had cancer because no one recognized it like that. I would go in and then I was like, this isn't for me because . . . I could walk in there and they'd be like, 'Yeah, right.' Because that's the reputation that thyroid cancer has. . . . It's not that no one believes you, it's just that it's the good cancer, so who cares?"

"I think as soon as the radiation stuff was done, I was done to [healthcare providers]. To the medical profession, I was finished, and I was so not finished. I felt like I have a minor cancer, so . . . I feel like there's a class of patients that's like the real cancer patient [laughs]. And they would get, you know, different kind of care."

Figure 1. Participant Quotes for the Theme of Having the "Good" Cancer

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of illness, they may not understand the psychological impact of a cancer diagnosis. Participants could not relate to the carefree attitude of their peers (see Figure 2).

Discussion

The current analysis existed within a study that examined CFC issues of young adult patients with cancer (Miedema et al., 2013). However, when analyzing the data, the researchers found that patients with thyroid cancer have different experiences than patients with other forms of cancer. A diagnosis of thyroid cancer can have a serious impact on psychological well-being and quality of life. Several studies have concluded that psychological well-being is worse in patients with thyroid cancer when compared to other patients with cancer and healthy controls (Husson et al., 2011; Schultz et al., 2003; Ying et al., 2009). The participants in the current study knew that the survival rate for thyroid cancer is good, but as a result, they felt that negative psychological effects often were overlooked. Sawka et al. (2009) similarly found that telling patients they have the good cancer is not reassuring and can be perceived as dismissive of the issues they may experience.

Young adults with thyroid cancer require as much support as young adult patients with other types of cancer, regardless of their prognoses. The diagnosis of a life-threatening or life-compromising disease can be traumatic for young adults. Unique challenges exist for young adults who have thyroid cancer, such as the physical changes from treatment (e.g., hormone imbalances, permanent damage to salivary glands, reduced taste) and the sense of isolation from peers and other cancer survivors. Isolation can be literal for patients who undergo radioactive iodine treatment. Challenges faced by patients with thyroid cancer require significant emotional and psychological support. Dow et al.'s (1997) study found that healthcare providers tend to stress the survivability of the disease, and patients stress the disease itself, so the two visions of illness and wellness are in conflict.

Limitations

Because the study results are based on a theoretical sample, they cannot be generalized to all thyroid cancer survivors. In addition, more women than men participated in the study, and more participants were from Ontario than other parts of Canada, which may have biased the results. As with other self-referral research studies, young adults who have experienced significant challenges may have been more inclined to participate than those who did not. However, the issues identified related to their experiences and survivors may be transferable to young adults with thyroid cancer across Canada, particularly because a large number of thyroid cancer survivors participated in the overall study compared to other types of cancer, which may constitute a higher percentage relative to the cancer incidence rates. The authors used the same recruitment strategies for all cancer-specific organizations, and the interest from thyroid cancer survivors may be related to the need to have their cancer experiences recognized as legitimate.

Isolation From Other Cancer Survivors

"I contacted [Cancer Support Centre] just recently to inquire about their exercise program that they have for cancer patients. But, I don't know, there's part of me that feels like . . . I'm not worthy. . . . I just have thyroid cancer and, you know, there's the whole big people out there who've been going through, you know, chemo after chemo treatment or whatever, so I wasn't sure if it would be okay for me to go. . . . I think, with thyroid cancer, there's always that little question like, 'Am I deserving of this [support]?' You know what I mean"?

"They have lots of group therapy [at the Health Care Centre], but again, it's people who have got serious cancer who are dying. They really don't want to hear about my little survival story when they are dying."

Isolation From Peers Without Cancer

"The physical thing is so easy to explain to my friends. I have low energy, whereas the psychological component is a little different. I guess for me, psychologically, I felt . . . I didn't have a lot of support at the time, and so that I felt very lonely. . . . I wouldn't say that I was depressed or anything, but definitely just lonely and just having to kind of deal with it all on my own at the time with no one that I could relate to."

"I feel a little bit . . . not hardened by life but . . . I guess you could put it that way, but sometimes it just seems like a lot of my friends just have it carefree and can do what they want when they want without this nagging, you know, cancer hanging over their head."

Isolation During Treatment

"First they're having the surgery, and then they're giving you the radioactive iodine, which to me was more traumatic than the actual surgery, the being in isolation. I mean, the nurse knocks on your door and looks through a window. They couldn't enter the room. . . . There were signs all over the door saying radioactive, radiation, and people would stand at the door and look at you like you were a zoo animal. . . . Even the doctors . . . he'd open the door a tiny crack and say, 'You okay?' [I'd say,] 'Yeah,' and [he'd] slam the door. . . . You know? It, it felt like you had a plague or something. You felt so isolated and alone to deal with this."

Figure 2. Participant Quotes for the Theme of Isolation

Implications for Nursing

Based on results from the current study, the authors stress the importance of recognizing the physical and psychological needs of patients with thyroid cancer and survivors to facilitate access to support resources that may reduce the psychological impact of cancer

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and its treatment. Patients with thyroid cancer are still patients with cancer, despite the high survival rate, and healthcare providers should acknowledge their support needs during treatment and the follow-up phase (Husson et al., 2011). Referring to thyroid cancer as the good cancer, although reassuring in relation to survival rates, does not help young adults make sense out of an unexpected diagnosis (Husson et al., 2011; Miedema, Hamilton, & Easley, 2007).

With increasing incidence rates and high survival rates for patients with thyroid cancer, a growing number of patients will experience the long-term effects of the diagnosis and treatment. An opportunity exists for oncology nurses and other healthcare professionals to help those patients get the support they need. Although the research was focused on young adults, the feelings of isolation and lack of support from healthcare professionals as well as the cancer community also may be issues that older adult patients with thyroid cancer experience. Additional research is needed to gain a better understanding of the specific needs of this population to help develop more appropriate and inclusive support resources.

Conclusion

Patients with thyroid cancer often are told by healthcare providers, family, friends, and other patients with cancer that they have the good cancer because of the high survival rate. Although grateful for the positive prognosis, patients with thyroid cancer who are told they have the good cancer have discussed not feeling worthy of supportive services as a result. Many patients and survivors struggle with psychological issues from the diagnosis of a life-altering illness. Cancer can have a negative impact on a person's life, regardless of a positive prognosis. Based on the results of the current study, the authors believe that healthcare providers can facilitate the healing process for patients with thyroid cancer throughout the cancer continuum by acknowledging their needs and reaching out and encouraging patients to access resources and available support.

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