Thyroid cancer survivorship: the patient experience

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Abstract: There are increasing numbers of thyroid cancer survivors due in part to the rising incidence of thyroid cancer and its generally favorable prognosis. Though thyroid cancer is often labeled by providers as a "good cancer", the diagnosis can be life-altering and for many patients, thyroid cancer survivorship is marked by increased worry and decreased quality of life (QoL) compared with other cancer types. While this paradox merits further study, a paucity of disease-specific validated instruments limits our current understanding and ability to develop appropriate interventions. Understanding the unmet needs of thyroid cancer survivors is critical to this effort. Early study has identified particular groups, including Hispanic and low-income populations, that may be more vulnerable at diagnosis and throughout treatment and survivorship and may therefore benefit from additional support. Thyroid cancer survivors often experience unmet informational needs and search online where the quality of information available is highly variable and often not personalized. Though not well studied, support groups may help meet the informational, emotional and psychological needs of thyroid cancer survivors. Defining the specific roles of different providers in the long-term management of thyroid cancer in individualized survivorship care plans (SCPs) may help to ensure these various needs are better fulfilled in survivorship.

Keywords: Thyroid cancer; survivorship; survivors; worry; quality of life (QoL)

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Introduction

The incidence of thyroid cancer is increasing, and given the generally favorable prognosis, there are increasing numbers of thyroid cancer survivors (1-4). Differentiated thyroid cancer affects women four times more often than men; globally it is the fifth most common cancer in women aged 20–84 years. Among young adults aged 20–44 years, it is the third most common cancer and carries an excellent prognosis, with a five-year survival rate exceeding 99% (5-7). In spite of its excellent prognosis, the impact of cancer diagnosis can have significant bearing on patient worry and quality of life (QoL) (8). With increasing numbers of thyroid cancer survivors living for decades beyond treatment, the survivorship experience merits special consideration.

Thyroid cancer worry

Receiving a cancer diagnosis can be life-altering; even those with favorable prognosis report experiencing worry at all

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stages of care from diagnosis through survivorship. Worry may begin in the perioperative setting with perioperative distress impacting recovery from surgery (9). Over years of surveillance, anxiety may increase in association with follow-up visits as patients worry about recurrence and exhausting potential treatment options (10). In a study of 2,215 disease-free thyroid cancer survivors, patients expressed worry about death (41%), treatment harms (44%), impaired QoL (55%), family at risk (58%), and recurrence (63%) (11). Worry also extends to broader concerns about long-term financial burden (12), fear of developing another cancer (10), and the impact of treatment on cognitive function, especially for patients requiring life-long thyroid hormone replacement (13,14).

Worry is not experienced uniformly across all patient groups; decreased worry has been reported by men and older patients (11) while increased worry has been reported by patients with more advanced disease (11) and/or younger age at diagnosis (11,15,16), lower education and being Hispanic or Asian (11,16,17). Women—and in particular mothers—report increased worry compared to men (15). It has been suggested that increased worry in younger patients and women may reflect differences in coping styles and in the expression of worry, rather than any true underlying differences in worry itself (9). Nonetheless, the experiences of these groups remain valid in their own right.

A disconnect between actual mortality risk and patient perception of cancer risk has been described for differentiated thyroid cancer (15). Fear of recurrence has been shown to have the same negative impact on QoL as actual recurrence (18), and actual recurrence may be more traumatic for patients than the initial diagnosis of cancer (19). Overestimation of risk and worry about recurrence and death has been shown to be associated with lower educational level and Hispanic ethnicity, and contributes to decreased QoL (16,17). In contrast, patients with more accurate risk estimation report decreased worry about recurrence and death (17). How patient worry is addressed varies by practice setting and geographic region. Patient worry is associated with increased healthcare utilization, including increased treatment intensity and increased frequency and duration of office visits (20). Tailoring patient communication about diagnosis, treatment and survivorship to account for education level and cultural influences may mitigate the impact of patient worry on QoL, especially for vulnerable groups that include younger patients, women, those with lower education and certain ethnic/racial minorities (11,17). Ensuring that patients feel adequately informed may also lessen patient worry, which may be otherwise heightened by a perceived lack of information (10). Effective communication between providers and patients improves patient's functional and physiologic status and emotional well-being (21). It is important to have a high index of suspicion for patient worry which may not be evident during short encounters, especially if minimizing is used as a coping strategy by patients (10). Some areas of worry may be proactively addressed by providers. For example, although familial differentiated thyroid cancer is relatively rare, failure to address concerns about familial risk may result in a lost opportunity to assuage this aspect of patient worry (11).

The underpinnings of worry in the thyroid cancer population and methods to effectively address it require further study. Cultural differences and varying social support systems may play a role (22) in addition to language barriers and degree of acculturation (11). A lack of clarity about the responsibility of providers to address or offer psychosocial care in the setting of thyroid cancer (23) complicates progress in reducing patient worry.

Thyroid cancer's impact on patient QoL

Despite the excellent prognosis associated with most thyroid cancers, decreased QoL remains a concern. The rising prevalence of thyroid cancer along with increasing numbers of young survivors has led to a growing body of literature exploring QoL in this population. Notably, thyroid cancer survivorship is relatively unique to other cancer types because most survivors are of young age, are otherwise healthy and will carry the burden of survivorship for an extended period of time. It is important to capture these unique psychosocial elements as well as to understand the physical morbidities associated with thyroid cancer treatment. In this regard, the burden of thyroid cancer survivorship must be carefully and thoughtfully studied. In a systematic review of studies examining patient-reported QoL outcome measures, Roth *et al.* identified a lack of instruments validated in this specific population and highlighted the challenges this presents for accurately understanding patient perspectives and experiences (24). The development of disease-specific validated instruments will improve our ability to provide patient-centered care.

The North American Thyroid Cancer Survivorship Study (NATCSS) (25) recruited a large-scale survivorship cohort to assess QoL in this population. The study utilized a validated assessment tool to measure the domains of physical, psychological, social, and spiritual wellness along with open-ended questions to gather qualitative data. The authors unexpectedly found that overall QoL was worse in thyroid cancer survivors compared with reported results for survivors of more aggressive cancer types, including breast and colorectal cancer. And despite assumptions that older patients experience greater difficulty in recovering from treatment, better QoL was reported in older thyroid cancer survivors. Additionally, QoL showed no correlation with thyroid cancer stage. Taken together, these findings highlight an apparent paradox of increased survivorship burden in younger patients with a favorable prognosis.

It has been suggested that the overall favorable prognosis of differentiated thyroid cancer may lead some clinicians to downplay the physical or psychosocial concerns of thyroid cancer survivors (6,26). In a qualitative study examining the perceptions of differentiated thyroid cancer survivors, Sawka *et al.* found that the experience of being diagnosed with thyroid cancer was life-changing and was accompanied by feelings of fear and uncertainty that were not assuaged by reassurances of a favorable prognosis (27). Indeed, it may be that by labeling thyroid cancer as a "good cancer", providers are causing their patients unintentional harm by minimizing their concerns (25). A qualitative study conducted by Randle *et al.* (8) found that characterization of thyroid cancer as a "good cancer" invalidated patient's fears of having cancer. Patients may not feel worthy of supportive services when comparing themselves to other cancer patients and may struggle to make sense of their diagnosis and survivorship experience (6). In the NATCSS study, one third of patients reported feeling that their side effects of treatment were not taken seriously by their physician. Additionally, patient-reported rates of complications such as voice change, hypocalcemia and side effects from medications were markedly higher than rates typically expected or quoted by the medical community (25). This group of researchers conducted a study examining physician perceptions of the effects of thyroid cancer on QoL, comparing patient data to physician perception. Significant discrepancies were identified between patient-reported QoL measures and how physicians perceive QoL for thyroid cancer survivors. Notably, both surgeons and medical physicians underestimated physical symptoms experienced by patients, with surgeons estimating fewer symptoms than medical physicians (28).

It has been suggested that the lifelong time period over which thyroid cancer surveillance must be undertaken combined with the propensity for thyroid cancer to recur many years after initial treatment may contribute to increased survivorship burden in younger thyroid cancer patients (25). In a study of over 1,000 thyroid cancer survivors, young adult patients (aged 17–39 years) reported an overall worse psychological state and experienced headaches, anxiety and concerns about scar more frequently than older patients. Worse QoL scores correlated with female sex, higher level of education, unemployment and having another comorbidity (29).

In a population-based study from Europe, adolescent and young adult (aged 18–35 years) thyroid cancer survivors reported worse function of physical, role, cognitive and social domains compared with age-matched controls (30).

In a survey of over 2,400 patients from the Surveillance, Epidemiology, and End Results (SEER) database, Papaleontiou *et al.* (1) identified 4.1% with report of thyroid cancer recurrence and 5.8% with report of persistence. Patients with persistent disease were found to have worse QoL scores in the domains of physical and mental health compared with normative controls, whereas cured patients showed no meaningful difference compared with normative controls. Notably, the authors found that Hispanic ethnicity was associated with report of disease recurrence, raising concern for disparities in disease severity and management and the subsequent impact on QoL. In a separate study, the same author group examined perception of risk of recurrence and death amongst a subset of the SEER cohort determined to have an estimated risk of recurrence of 5% (17). The authors found that a quarter of patients overestimated their risk of recurrence and 12.5% overestimated their risk of mortality. Lower educational level was associated with overestimation of recurrence and mortality risk, and Hispanic ethnicity was associated with overestimating risk of recurrence. Not surprisingly, patients who overestimated their mortality risk had decreased QoL compared with the general population. These findings highlight the importance of identifying factors that may negatively impact QoL for thyroid cancer survivors (*Table 1*). Effective communication and patient education may help to mitigate these effects and interventions should be targeted at especially vulnerable groups (17).

The aggressiveness of treatment and side effects associated with treatment appear to correlate with worse QoL. In a study of 1,743 thyroid cancer survivors, Goswami *et al.* (31) found postoperative symptoms of dysphonia and dysphagia correlated with worse QoL scores across multiple domains. Similarly, side effects of treatment with radioactive iodine (RAI), including xerostomia, xerophthalmia, sialadenitis, decreased appetite and gastrointestinal

Table 1 Factors associated with decreased quality of life in thyroid cancer patients

Factors associated with decreased QoL	Groups at risk
Age (25,29,30)	Younger age
Sex (25,29)	Female sex
Patient overestimation of risk of recurrence (17)	Lower educational level (≤ high school diploma), Hispanic ethnicity
Patient overestimation of risk of mortality (17)	Lower educational level (≤ high school diploma)
Aggressive treatment (31,32)	Patients receiving RAI

QOL, quality of life; RAI, radioactive iodine.

disturbances were associated with worse QoL scores. In a matched-pair analysis of patients with low-risk thyroid cancer, this group of researchers found patients receiving RAI had worse QoL scores compared with their matched controls (32). These studies highlight the importance of balancing therapeutic goals with anticipated downstream effects on QoL.

Current state of resources for thyroid cancer patients

Gaps in informational needs and online resources for thyroid cancer patients

Patients receiving a cancer diagnosis or treatment often turn to the internet for medical information and decision-making (33). Health-related internet use amongst cancer survivors has increased over the last decade; younger patients with higher educational attainment and socioeconomic status are more likely to use the internet for health-related purposes and are especially likely to do so when dissatisfied with their healthcare (34). As many thyroid cancer survivors are young, the informational needs and practices of this group are especially relevant. Several studies have demonstrated unmet informational needs amongst thyroid cancer survivors (26,35-37). In a study of 2,000 thyroid cancer patients who completed an online survey, Morley and Goldfarb (35) found that fewer than half of the respondents recalled receiving information about the long-term effects of their treatment, practical matters associated with treatment, or relevant emotional/psychological elements of care. Younger age and female sex correlated with worse recollection of having received information even though females placed greater importance on receiving information than males. Husson *et al.* (26) sought to examine the perceived level and usefulness of information given to thyroid cancer survivors; nearly half felt there was too little information and almost a third felt the information they had received was not helpful. More than a third of the patients wanted to receive more information, including information on the cause of their cancer, possible complications and long-term effects of treatment, and anticipated medication use. Dhillon *et al.* (38) surveyed 1,124 thyroid cancer survivors and found that over a third did not fully understand their treatment plan; nearly half reported their treatment plan did not play out as they had expected.

Unmet informational needs coupled with a desire for shared decision-making leads many thyroid cancer patients to search online for information (39). It is therefore prudent to examine the ways in which the internet is used, along with the quality of information that is available. Chang *et al.* (2) examined the internet-related practices of 39 patients with thyroid cancer and found that 84% routinely used the internet to search for information about thyroid cancer, with 94% utilizing Google to conduct their search. Patients looked most often for information about treatment and symptom management. The majority of patients selected websites identified at the top of their search and looked at only five or fewer websites. Budenz *et al.* (40) observed ten adult cancer survivors (breast and thyroid) perform an online search for information related to their specific cancer needs; most searched for information about their specific cancer type, including stage, treatment and prognosis. Participants reported having to perform excessive navigation to find information they deemed relevant.

Chang *et al.* (41) examined the quality of the top 100 thyroid cancer websites identified through Google and two meta search engines. All websites were evaluated using a validated structured tool to assess several domains including accountability, currency, content, and accuracy. The study found that the quality of information was highly variable, with some topic areas lacking complete or accurate information. Only 2 of the 100 studies provided information at or below an 8th-grade level of comprehension as recommended by the National Institutes of Health and American Medical Association (42,43). Much of the content was devoted to treatment, which the authors felt reflected a pattern of American healthcare institutions providing online information in order to recruit patients to their centers for treatment. The authors also noted a lack of disclosed authorship or citations for many websites, making it difficult for patients to determine their trustworthiness. The authors submitted two "patient" questions to 83 of the sites with interactive function; of these, 41 sites referred the "patient" to healthcare workers; 26 question responses were provided, 4 of which were deemed to be potentially harmful.

Doubleday *et al.* (44) systematically evaluated how well 22 websites provided information on topics identified by a group of stakeholders as critical to treatment decision-making for low-risk thyroid cancer. The authors found that none of the websites offered information regarding updates in the 2015 American Thyroid Association (ATA) guidelines; fewer than 20% referenced the ATA guidelines at all. A study evaluating the quality of German websites addressing thyroid cancer also found the information to be of highly variable quality (39).

The varied accuracy, completeness and ease of use of online content reflects a large gap in a resource critical to patient understanding and decision-making. As thyroid cancer patients will continue to seek and rely upon online information, medical professionals should be proactive in steering them toward appropriate resources (39). Importantly, patients may not be able to understand or interpret the information they find; clinicians should consider asking patients about the information they have found and provide appropriate context and explanation whenever there is confusion or apparent consumption of misinformation (2).

Role of support groups

Support groups play an important role in cancer survivorship, helping patients cope with the physical morbidity and emotional or psychological consequences of cancer treatment. These groups can take a variety of approaches, may be in-person or online, and may be led by a health professional or peer-run. Support group objectives may include delivery of information, teaching of coping techniques, or provision of emotional support, especially as it relates to the experiences of others who have been similarly afflicted (45).

Support groups have been well studied for many cancer types, including breast and prostate. By contrast, little investigation has been performed with respect to the role and potential benefit of support groups in thyroid cancer. Several studies have identified unmet psychosocial and informational needs amongst thyroid cancer survivors (26,37,38,46,47), circumstances for which support groups may have particular relevance. ThyCa: Thyroid Cancer Survivors' Association, Inc. is a non-profit organization that organizes support groups across the US and elsewhere, hosts online discussion groups for specific thyroid cancer types, and runs Person-to-Person Network, a peer-matching program that connects thyroid cancer survivors with similar circumstances (48). While this singular organization is well renowned amongst patients and professionals alike, no studies have directly measured the impact of its activities. Nonetheless, ThyCa provides a large cohort of thyroid cancer survivors who may serve as subjects in studies that illuminate the unique perspectives and experiences of this population (25,31,35,38).

Thyroid cancer survivorship care plans (SCPs)

National registries lack detailed data on recurrence versus persistence of thyroid cancer (1), but it is believed that up to a third of patients may recur in the decades following initial treatment (49). Life-long follow-up and treatment, including daily medication, is needed for many thyroid cancer survivors (50). The role of primary care providers (PCPs) and specialists, including endocrinologist and endocrine surgeons, in thyroid cancer survivorship care is variable; clearly defining these roles early in treatment benefits both patients and providers (3,51-53). While many thyroid cancer survivors prefer follow-up care by specialists (51), establishing team-based SCPs early in thyroid cancer care may ease patient concern and mitigate long-term healthcare costs (3).

A landmark report issued in 2006 by the US Institute of Medicine recommended transitioning survivorship care of all cancer types to PCPs and identified four domains of cancer survivorship care: (I) prevention and diagnosis of new or recurrent cancers; (II) cancer surveillance to identify malignant spread, recurrence, or new cancers; (III) intervention to address secondary effects of cancer and cancer treatment; and (IV) care coordination between PCPs and specialists to optimize survivorship care (54). The report also recommended that the principal oncology provider(s) create a treatment summary and SCP to facilitate quality of care in cancer survivorship (54).

In a survey of PCPs addressing thyroid cancer care, over half (53%) felt they should be responsible for survivorship care, although 76% reported involvement and fewer than 50% were highly confident doing so (51). Following dedicated thyroid cancer management guidelines may improve PCP confidence in caring for these patients (50,52,55) and some authors have called on future guidelines to explicitly define the role of PCPs and simplify SCPs as a means to support PCP involvement (51). Increased collaboration between thyroid cancer specialists and PCPs via SCPs which can be more seamlessly incorporated into PCP workflow has been proposed (52). This may be especially important with vulnerable groups for whom PCPs play an increased role in thyroid cancer care; such an arrangement may offer an avenue to address disparities in thyroid cancer care (53). Furthermore, delineating psychosocial support needs in SCPs may help to address patient worry (15).

Development of SCPs early in treatment may provide patients a better understanding of what to expect during treatment and surveillance. As described above, many thyroid cancer survivors experience unmet informational needs. While SCPs may improve PCP confidence managing survivorship care (52), awareness and utilization of SCPs remains inconsistent (56). Moreover, the influence of SCPs on patient satisfaction and patient outcomes in thyroid cancer is not well known and requires further study (57).

Future directions

As the cohort of thyroid cancer survivors grows, efforts should be directed at understanding the specific experiences and unmet needs of this group. Understanding worry is critical, especially given its seemingly paradoxical relationship to the overall favorable prognosis of thyroid cancer. Examining disparities in patient comprehension, worry and risk estimation is critical to providing informed and effective care. Defining and supporting the roles of various care providers, including PCPs, will bolster effective care delivery. Development of reliable online resources coupled by provider communication about unmet informational needs will help to streamline this process. There is a need for disease-specific validated instruments to assess the patient experience and augment provider understanding and ability to address this important aspect of thyroid cancer care.

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