

AN EXPLORATORY STUDY OF HEAD AND NECK
CANCER QUALITY OF LIFE IN SURVIVORSHIP

by

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CANCER QUALITY OF LIFE IN SURVIVORSHIP

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ABSTRACT

The purpose of this study was to explore the quality of life experiences of head and neck cancer (HNC) survivors. Researchers recruited survivors from an HNC support group at UT Southwestern Moncreif Cancer Institute. Each of the survivors was then interviewed using a set of four interview questions designed to investigate each of the survivor's experiences with HNC. Transcripts of these interviews were then analyzed using qualitative methods to create a list of themes, categories, and phrases. Five themes emerged from this analysis: gastrointestinal symptoms, importance of information, the need to support the caregiver, feelings of isolation, and changing with the diagnosis. The survivors' also provided advice for healthcare professionals, caregivers, and other HNC survivors. This information illustrates the experiences and emotions of the survivors, which can both help survivors anticipate how their diagnosis will affect their lives and guide future research and nursing practice to better support HNC survivors and their caregivers.

Key words: head and neck cancer; survivor; quality of life; qualitative research

Background

Head and neck cancer (HNC) typically involves the squamous cells located in the oral cavity (includes cheeks, lips, hard palate, gums, and the first two-thirds of the tongue) pharynx (includes nasopharynx, oropharynx, and hypopharynx), larynx (includes vocal cords and epiglottis), paranasal sinuses, nasal cavity, or salivary glands (National Cancer Institute [NCI], 2013). In the United States, HNCs account for about three percent of all malignancies; it is estimated that in 2016, 61,760 people will be diagnosed with a type of HNC in the United States, and 13,190 people will die because of the malignancy. Males, especially those aged 50-70 years, are two times as likely to develop HNCs than females. Common risk factors for developing HNC include tobacco use (including smokeless tobacco), alcohol usage, ultra-violet light exposure, previous radiation exposure, and human papilloma virus (American Academy of Otolaryngology—Head and Neck Surgery, 2015; Ridge, Mehra, Lango & Galloway, 2016).

The Centers for Disease Control and Prevention (CDC, 2016) defines a cancer survivor as anyone diagnosed with cancer from the time of diagnosis to the remainder of their lives. Treatment modalities, including chemotherapies, radiation treatments, and surgical procedures, are selected based on the cancer's location, type, and staging. Side effects can be different with each of the treatment types, however, many patients with HCN report issues with chewing, swallowing, dry mouth, mucositis, and nausea (NCI, 2013). As the different treatment modalities have similar success rates and survivors are living for longer periods of time, health care professionals have the responsibility to ensure that preserving quality of life is prioritized (CDC, 2016).

Research Approach and Methods

Ethical Considerations

The Institutional Review Board at Texas Christian University approved this project, and each informant provided written informed consent prior to participating in the study. Each interview was de-identified prior to transcription and interviewees were given an assigned code number to use on forms.

There was minimal risk for participating in the study; however, researchers did identify a potential for psychological harm as the interview could remind the survivors of bad memories or unresolved issues related to their cancer experience. Researchers instructed the participants that they were permitted to request a break, and if necessary, end the interview prior to its completion. None of the participants chose to take a break or leave the study.

Sample and Setting

A convenience sample of four participants was accessed through the HNC support group at UT Southwestern Moncrief Cancer Institute. Once identified and recruited, interviewees were given the ability to choose to have their interview held at either UT Southwestern Moncrief Cancer Institute or Texas Christian University, both of which are located in Fort Worth, Texas. All participants had completed treatment at the time of his or her interview and were over 18 years of age. In an effort to maintain participant anonymity, researchers refrained from gathering demographic information, but participants did offer some personal information throughout their interviews. Of the four, three informants were male, and all identified as being married (n=4). Each participant had a different type of HNC, but all stated that they had some type chemotherapy and an amount of radiation as part of their treatment (n=4). One of the informants had a previous history of cancer.

Data Collection

Data was collected in the form of interviews using four basic open-ended questions (Figure 1). In general, study participants were asked to share any information about how their cancer diagnosis, treatment, or survivorship has been affected. Interviewers had the freedom to ask additional clarification or follow-up questions, but all of the guiding questions were asked during each interview to maintain consistency. Each interview was recorded and all identifying information was removed prior to having the audio transcribed using a transcription service. After receiving transcripts of each interview for further analysis, researchers deleted the original audio interview recording, but did keep any field notes taken during interviews to be used during analysis.

Data Analysis

Two researchers performed a qualitative analysis on the four interviews, using Sandelowski's (1995, 2000, 2002, & 2009) approach on qualitative research as a guide; one of these researchers was one of the interviewers for this study. Independently, each researcher immersed themselves in the transcriptions by reading each interview several times. After this, each researcher made note of ideas or phrases from each interview. The researchers then collaborated using the interview questions to create a list of categories, themes, and phrases each had identified during the transcript immersion.

Results

After qualitative analysis, five illustrating themes were selected to describe the prominent experiences and ideas the survivors described during their interviews. These themes (Figure 2) illustrate the physical and mental side effects of their diagnosis treatment and how these experiences have affected their caregivers, friends, and family. In addition to the themes,

researchers isolated specific advice from the survivors for health care professionals, future caregivers and support systems, and future HNC survivors.

“My body got beat up so much”: Gastrointestinal Symptoms

All of the survivors had side effects of their HNC or treatment, most of which were related to the gastrointestinal (GI) tract. All of the interviewees identified the following symptoms during their interviews: dry mouth, choking and swallowing difficulties, and increased need for chewing. These side effects lead to others, such as muscle and weight loss, “physical pain,” dehydration, nausea, and vomiting. One participant accounts most of the GI symptoms to the radiation that is “burning your throat up,” which prevents eating and “drinking liquids because it hurts so bad.” These symptoms have a severe impact on the survivors’ life as they frequently have to “get two full IVs pumped into me,” and “watch your water.” One participant noted that certain brands of bottled water caused nausea and vomiting.

Oral impairment is especially severe in HNC survivors; one participant, who paused frequently during the interview to drink water, stated his speech was affected if his mouth got too dry and discussed his altered sleep patterns as “an hour and a half to two hours [of sleep], drink, restroom, go back to sleep.” Another survivor, now 10 years post-radiation treatment to the neck region, does not “have saliva to kiss [her husband].” These symptoms also can affect the caregivers of the survivors, because they are often “afraid I would [aspirate] in the middle of the night.”

“Knowledge is power”: The Importance of Information

Many of the survivors felt as though they needed additional information, mainly relating to treatment and life as a survivor. They stated they felt “powerless” and as though they were “walking blindly throughout the treatment” that doctors had determined for them. Many

participants pointed to their “big time” weight loss as a specific incidence where doctors failed to provide the patients with realistic expectations of treatment. One survivor told his doctor, “Yeah, I need you to save my life, but I also need to know what’s going to happen to me as a result of this treatment.” Another survivor stated that “I think if I had known more, I might have made different choices” in relation to her radiation treatment.

Informants also stated many times that their family members, significant others, and caregivers needed additional information as well, primarily relating to supporting the survivor. Several of the informants’ caregivers did not understand the “food issue” and “you’re sitting there and you’re starving...not able to join in” because of the pain of swallowing. Additionally, some of the interviewees stated that those around them did not know how to interact with the survivors and often avoided discussing the cancer, even avoiding saying the word altogether, even though survivors discussed “want[ing] somebody to ask how we are doing.”

“I’ll take being the patient any day over being the caregiver”: The Need to Support the Caregiver

Survivors continuously elaborated on the importance of the caregiver and support systems, because “you can go through this by yourself, but it will be a thousand times worse.” One participant noted that his wife, his primary caregiver, “saved [his] life,” but “it was a major, major impact on her life,” implying a negative, stressful effect. Another participant discussed that any outside support “doesn’t benefit the cancer patient. It benefits the caregiver, which secondarily affects the patient.” Adding to that idea, another survivor stated that he wanted those who offered help to do “something to make [his wife] feel like she’s a human, living a normal life again.”

“Who wants to sit in public with this stuff going on”: Feelings of Isolation

While each survivor has different experiences, all of the participants described feeling isolated from others around them. Many discussed being deprived of the social nature of eating because of their oral impairments and their struggle to participate. Survivors touched on changes in “the way you drink water or you can’t eat in restaurants. Or you’re eating with friends and you’d choke”; these things create a divide between those with normal eating habits and the survivors. Caregivers would occasionally become frustrated and tell the survivors “well you just need to stop whining and eat,” which multiplies the social isolation felt from not being able to fully participate in eating.

Physical symptoms continued to isolate the survivors from support group meetings, because “we are too sick...to get out of the house and go” to support group meetings, despite the fact that most found these meeting to be “important” and “enhance” their lives. One informant discussed the “human experience” found during the support group, in addition to the desire for “any wisdom [from] people that have been through it.” Unfortunately, the “physical pain” that survivors experienced prevented them from connecting with others “who actually lived [through] this.”

“This is What Happened to Me. This is What My Journey is About”: Changing With the Diagnosis

Many informants described their time since diagnosis as a “journey” or a “lifestyle change” with many positive and negative effects. A HNC diagnosis “isn’t just a 30 day ordeal. It’s a lifestyle change” and “there’s no end to it.” Despite this, survivors noted how they learned “to adapt no matter what” and “don’t ever ask ‘why me?’” The informants talked about how their HCN cancer was a “gift” or a “blessing” that gave them the “freedom to feel.” Several discussed

how they have reprioritized since the diagnosis and “make every day count” without attending to what others expect of them; men specifically noted that they are “becoming more emotional.” One was “grateful [he] lived through it, while another said it gave him “purpose in life,” in addition to “heightened” empathy and more mental strength.

Despite all the positive perceptions of the “gift of cancer,” informants also shed light into the difficulties it can bring after treatment when “you really start going through hell because it builds up in your body. It’s another two or three months even of suffering.” While some side effects do fade or improve, one of the survivors still has oral impairment 10 years post-treatment and another had to sell his boat two years post-treatment due to persistent increased fatigue. The survivors “worry more” about “all kinds of things that can go wrong,” including threat of metastasis or recurrence and the effects it has on his or her family. One survivor illustrated the frustrations associated with their “journey” saying:

Living with cancer is like living with a third person in our house. It was a family member and it was obnoxious, rude, cruelest person you’ve ever met, but you can’t kick him out...you don’t get to do anything without them being a part of your decision, not for a month or two months- maybe six months or a year even- and that’s the way you should look at it. You can’t kick them out of your house. They’re there to stay and they’re the most brutally cruel person you’ve ever met, but they’re like family. They’re stuck on your back and there’s nothing you can do.

Advice from Survivors

Several of the survivors expressed a desire to give back to those now beginning their survivorship; one expressed the idea of increasing his “psychic paycheck.” The interviews were

rich with advice they wished to give to health care professionals, caregivers, and future HNC survivors.

For healthcare professionals. Most of the advice for healthcare professionals revolves around providing more information to the patient and improving communication between inter-professional teams. One survivor emphasized having “rapport so that [the patients] feel comfortable talking to you, really what to expect from one to ten.” Other informants discussed that “basically you have five or six people in this team... I think that it’s important that... they’re willing to communicate with each other to see what’s going on,” while another one stated that the doctor or someone on the team needs to have “better human relations.”

Participants also offered concrete changes for healthcare practice; one suggested a mentorship program between the newly diagnosed and someone that had already been through treatment, and another recommended having one person on the treatment team that is “the focal point” or “tip of the spear” to contact first if any issues arise from treatment. Due to the physical inability to attend support groups during treatment, one survivor suggested implementing technology so that those in the middle of treatment and who “physically cannot” go could “stay in touch...during treatment.” Finally, one survivor observed, “They seem to talk a lot about chemo,” and hoped that there would be increased education for radiation treatments. Multiple survivors wished they knew what to expect from the claustrophobia of getting a radiation mask created; one survivor hoped that health care providers could learn to “equate education with removing fear.”

For caregivers and support systems. Aside from being more understanding about the survivors’ physical limitations, the interviewees offered practical advice for helping the survivor and his or her caregiver. One survivor suggested having one or two people that will “be the main

contact” and a phone chain to spread any messages of need throughout the extended support system. Another survivor stated the importance of practical help for the caregiver, such as “pick up her package, grocery shopping, take care of plumbing,” rather than receiving meals, which the survivor often could not actually eat themselves.

For future HNC survivors. The survivors had a large amount of information they hoped to relay to those who face a HNC diagnosis, many of which focused on surviving the treatment phase. One survivor stressed “how important hope is” and that one needs to “find something bigger than yourself to believe in and then trust that.” Another hoped that other HNC survivors would “be able to ask more questions and be open to understand that it’s going to be difficult no matter what.” One survivor advises people, “don’t set dates,” but “you need to set goals...not timeline goals but achievement type goals...it’s more realistic.”

On a more practical level, one survivor suggested having a binder filled with medication orders, business cards, and copies of any tests or scans. Another stated the importance of either being good at organization or finding someone to help stay organized. One survivor also stated, “you have the right to ask for help, and people have the responsibility to help,” even though one survivor stated, “Guys don’t ask for help.” One concluded by saying, “so you can live through this, and yes, it’s going to change you, and yes, you may have problems.”

Discussion

The four survivors interviewed shared personal narratives of their experiences since receiving their HNC diagnosis; the researchers used these accounts to identify five emergent themes and a compilation of the survivors’ advice. The physical and GI symptoms that the survivors have experienced have been well documented in the literature, especially pain, fatigue, dysphagia, and xerostomia (Bornbaum et al., 2012; Bower, Vlantis, Chung, & Van Hasselt, 2010;

Verdonck-de Leeuw et al., 2007; Verdonck-de Leeuw, van Nieuwenhuizen, & Leemans, 2012). Many of the issues that survivors experience can relate back to the functional problems caused by their physical symptoms; just as the survivors often indicated, these side effects are present beyond the treatment periods (Davies, Rhodes, Grossman, Rosenberg, & Stevens, 2010; Suzuki, 2012). Research has also connected some of the oral impairments experienced to the malnutrition and weight loss that were discussed by the survivors in this study's interviews (Languis et al., 2013).

The survivors often indicated that they were not properly informed of what to expect of their treatment. This has also been shown in previous research as caregivers have stated that they did not anticipate the duration and severity of their survivors' side effects of treatment (Nund et al., 2014). This lack of information is troublesome, as research has shown that survivors have better outcomes if they have trust and confidence in their physician, which can be harder to obtain if the patient believes information has been withheld (Davies et al., 2010). One particular study applied Mishel's Theory of Uncertainty to HNC patients and determined that uncertainty was negatively correlated with the patient's reported quality of life according to surveys (Suzuki, 2012). The survivors stated that they wished their providers would provide more complete education for radiation therapy; these feelings have been supported in the literature (Richardson, Lee, & Birchall, 2002).

While the survivors indicated they often became more self-centered and dependent on others during treatment, they did not fail to acknowledge the tremendous role their caregivers and support systems played during their treatment. Research shows that social support increases the patient's well being during treatment, and that the role of the caregiver is instrumental in patient outcomes (Iconomou, Viha, Kalofonos, & Kardamkis, 2001; Verdonck-de Leeuw et al.,

2007). Some caregivers have stated that they did not know what resources were available, specifically that speech pathologists could aid a patient with swallowing difficulties (Nund et al., 2014). Because HNC more commonly affects males, it is often the wife that becomes the survivor's primary caregiver; however, females are more prone to the negative side effects that caregiving can bring, such as depression and anxiety (Iconomou et al., 2001; Ridge et al., 2016). This makes it important for health care professionals to support both the survivor and the caregivers to ensure everyone is prepared for what to expect. As the interviews indicated, many caregivers change their whole lives to support the survivor; this notion is supported in the research. For example, some caregivers even gave up certain foods and social interactions to decrease negative experiences for the survivors (Nund et al., 2014). Additional research has stated that survivors and their caregivers often wish they had more practical support during their treatment, which reiterates the feelings expressed in this study's interviews (Bottomley et al., 2014).

The survivors' HNC diagnosis often leads to feelings of isolation, primarily as a result of their symptoms. Dry mouth and dysphagia can create embarrassing choking incidents, in addition to the fact that they may prevent the survivor from engaging in the normal social activity of preparing and eating food (Bower et al., 2010; Nund et al., 2014; Richardson et al., 2002; Verdonck-de Leeuw et al., 2007). This embarrassment often causes the survivors to abstain from eating outside of their homes, decreasing social interactions and relationships with those who do not understand (Nund et al., 2014). As the survivors stated during their interviews, the oral impairment can even create isolation from their caregivers and family members that do not fully comprehend or grow frustrated with the survivors' new eating habits (Bornbaum et al., 2012; Nund et al., 2014). The survivors also felt isolated when they became too ill from their

treatments to attend support group meetings, assuming that they even know how to get into contact with those groups (Richardson et al., 2002).

Survivors repeatedly discussed the life-style changes they had to make due to their cancer diagnosis. Literature has supported the idea that survivors often feel “profoundly changed” in a variety of both positive and negative ways after their diagnosis (Richardson et al., 2001). The survivors indicated that they are often more grateful for their life and attempt to live their lives with a more positive outlook. Despite the positive mental changes, the negative physical side effects often force life style changes as well. The literature supports the fact that the HNC survivors often have extreme long-term side effects because of their treatment (Bower et al., 2010). Research has shown that HNC survivors, when compared to other cancer diagnoses, have higher rates of anxiety, depression, and suicides (Bornbaum et al., 2013).

The survivors were eager to share their wisdom and advice to others during their interviews. For health care professionals, they wished to share their beliefs that providers need to provide more information more readily, especially relating to radiation therapy (Richardson et al., 2002). They also indicated that communication could be improved between patient and provider and between the treatment team. Additionally, they wanted to create a method of using technology to help the patients maintain attendance at support groups. The survivors wanted to share with their caregivers and support systems some of the frustrations associated with their swallowing difficulties. A few survivors also provided practical solutions, which research shows survivors and caregivers often wish they had, for providing support to the patient and the (Richardson et al., 2001). Finally, they hoped to show future patients some of physical issues they may experience, in addition to providing advice for staying mentally positive and keeping medical information organized.

A large portion of research relating to quality of life of HNC survivors attempts to quantitatively assess their quality of life through a variety of questionnaires; while these are not able to detect the slight nuances of each survivor's quality of life, they have been effective to determine that the physical symptoms and other experiences of the survivors lowers their quality of life (Bornaum et al., 2013; Bottomley et al., 2014). While HNC treatments have become more capable of saving lives, they also seem to cause more life-long morbidities (Verdonck-de Leeuw et al., 2012). A study assessing quality of life showed that most patients' quality of life decreased after treatment; studies suggest that radiation treatment in particular could have more negative impacts (Sawada, de Paula, Sonobe, Zago, Guerrero, Nicolussi, 2012; Suzuki, 2012). Some of the interview participants have echoed the feelings that the radiation caused more of their physical symptoms than the other treatment modalities. The literature supports the idea that since multiple treatments have similar success rates, quality of life needs to be considered while selecting treatments (Davies et al., 2010).

Limitations

There are several limitations in this study. The first would be the small sample size and the homogeneity of that sample. Though qualitative studies typically have a smaller sample size, there is a potential that the small number of participants does not adequately represent the target population (Brown, 2013). All participants live in the same geographical area of Texas and received similar therapy types, which could have caused similar experiences and beliefs that would not be evident in other parts of the country or with other treatments. Additionally, there is no demographic data to analyze aside from gender; this information might have been useful for comparisons between different age groups, socioeconomic statuses, and family structures.

Finally, the majority of the participants in this study were men, perhaps due to prevalence of HNC in men, which could have also skewed responses and experiences.

Implications for Society and Practice

Patients and Supporters

The researchers are hoping that this study will be made available to future patients so that they may have more of an understanding of what to expect during and after treatment. Even patients that are not diagnosed with HNC could potentially benefit from the advice and experiences of these informants. Those supporting the survivor can use this research to better understand what their survivor might experience so that they can provide the best possible help and care to them throughout survivorship before, during, and after his or her treatments.

Future Research

The interviews sparked many ideas for potential nursing research for this patient population. One of these would be the implementation of technology to connect survivors at all stages so that they can benefit from each other's experiences and encouragements. Though the HNC survivors are a very specific population, interventions that are applied to this group could potentially be applicable to patients facing other chronic and life-threatening illnesses. The information shared about the caregivers also could support additional research into the experience of caregivers during treatment of HNC and supporting their survivor.

Health Care Providers

The major implication for practice for health care providers is to provide more focused information about treatment (chemotherapy, radiation, and associated side effects) and the long-term aspects of HNC survivorship more consistently to the patients and their caregivers. Making an informed decision is important for survivors so that they can know exactly what to expect and

can be active in their health care. Veracity should guide health care professionals, as it is their responsibility to reveal all details of treatment, even if it might cause the patient to forgo treatment. HNC patients often have very complicated treatment plans and side effects, which creates an additional need for health care providers to work inter-professionally to ensure that the patient's are receiving the best possible holistic care. While it is important to save the patient's life, it is also important to ensure there is quality to that life afterward.

Conclusion

This qualitative study explores the impact that HNC has on the life of the cancer survivor and those providing support to him or her. The identified themes and supportive information helps to create a narrative that describes their experiences, rather than just quantifying them. Overall, the results of this study indicate that there is a tremendous amount of change, both positive and negative, associated with a HNC diagnosis; the information in this study can be used to guide understanding of survivors' experiences, in addition to creating potential for future research so that these survivors can be treated and supported in a way that preserves and improves their quality of life.

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1. How has your cancer affected you physically? Mentally? Spiritually? Your relationship with family? With Friends?
2. How has participating in the support group affected your life?
3. What advice would you give to health care providers about caring for and supporting head and neck cancer survivors?
4. What advice would you give to family and friends about caring for and supporting head and neck cancer survivors?

Figure 1: Interview questions used during each of the survivor interviews. Additional guiding or clarification questions may have been asked.

“My body got beat up so much”: Gastrointestinal Symptoms
“Knowledge is power”: The Importance of Information
“I’ll take being the patient over the caregiver any day”: The Need to Support the Caregiver
“Who wants to sit in public with all this stuff going on”: Feelings of Isolation
“This is what happened to me. This is what my journey is about”: Changing with the Diagnosis

Figure 2. The five emerging themes from the survivors’ interviews.