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The Role of Online Support for Anaplastic Thyroid Cancer Patients and Survivors

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Walden University
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Abstract

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MSW, Monmouth University, 2000

BS, Rutgers University, 1997

Dissertation Submitted in Partial Fulfillment
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Doctor of Philosophy
Human Services—Clinical Social Work

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Abstract

The rate of thyroid cancer diagnosis has risen, and researchers point to improved diagnostic testing, overdiagnosis, and increases in actual incidences as reasons behind this rise. With improved treatments and testing methods, the number of thyroid cancer survivors has increased. Thyroid cancer presents challenges to coping and can cause significant stress in an individual's life. More specifically, anaplastic thyroid cancer (ATC) creates complicated challenges for patients and survivors. Patients need support during diagnosis and treatment when adjusting to their "new normal" and may be reaching to Internet based social support groups to gain health information. Lazarus's transactional theory of stress and coping formed a framework for this generic qualitative exploration of the types of support ATC patients and survivors receive from an online Facebook support group. Thematic content analysis was conducted on archival data collected from the group over 4 months, namely 2,384 posts created by 166 group members. From this analysis, a picture relevant to all group participants was developed to include themes found among the data. Themes of emotional, informational and spiritual support emerged as well as the significance of using emojis as symbolic expressions of support. Implications for social change include expanding the theoretical knowledge of the ATC patient and survivor experience and the types of support available in online environments. This knowledge can lead to positive social change in terms of improving support resources, which may help in recovery from ATC; lessening the burden on patients, families, providers, insurance, the healthcare system, and our society as a whole.

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Dedication

I would like to dedicate this paper to my late mother, Doris Clare Morgan, M.S. (Biology), who passed in July 2018 following her own struggles with cancer. During her academic career, she completed enough credits to obtain a Ph.D. but had been unable to complete a dissertation project. She held a M.S. in Biology and enjoyed teaching as a college professor for over 30 years.

Mom, it was because of you that I was encouraged to even consider the challenge of a dissertation and doctoral degree. And it was because of you that I believed I might be smart enough and determined enough to get to the finish line. I am only sorry you were not still here in person to enjoy this with me, but I know you are here in spirit.

And to my son, Bryce, may you learn that you are capable of more than you know; don't quit trying at whatever your dreams may be, you might surprise yourself.

Acknowledgments

I would like to thank all my loved ones who stood by me and supported me along the journey of completing my dissertation; my father, my siblings, my best friends, and my colleagues. Your encouraging words allowed me to keep going when completing this degree felt insurmountable. My husband, Jeff Nixon, thank you for never letting me give up; you wouldn’t let me give in to all the many road blocks along the way and you made yourself available in so many ways as my biggest supporter; I love you for that.

To my professors who pushed me and guided me along the way, including Dr. Stout, my second committee member, and Dr. Scotten, my URR. And especially to Dean Dixon-Saxon and Dr. Benoliel, my committee chair, without the support and hard work from you both, I likely would have stopped this journey and not reached the finish line. Thank you so much for all your efforts.

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Chapter 1: Introduction to the Study

Introduction

Cancer is a fear-filled diagnosis, and despite the progress in treatments today, many still fear that cancer equals death (Harkin, Beaver, Dey, & Choong, 2017). Digesting information about the diagnosis, making decisions about treatment plans, and processing the impact of the diagnosis on their life and quality of life is challenging for most cancer patients (American Cancer Society, 2018a). As a result of these challenges, patients may begin to struggle with posttraumatic stress symptoms (Stanton, Rowland, & Gamz, 2015). Getting a physical exam or having medical testing done once was routine; however, these experiences now are associated with a lethal diagnosis. Some people report a trauma-like experience, and their fear of recurrence is triggered every time they feel pain or experience some new physical change (Stanton et al., 2015).

When a patient's prognosis is positive and the patient presents as stable, provider involvement may slow down, but chronic issues related to treatment can remain (Hoffman, Lent, & Raque-Bogden, 2013). Frequent provider involvement at this stage may seem unnecessary from a medical perspective and survivors have many unmet needs as a result. A cancer diagnosis of any type can be frightening for patients and their support systems. Family and friends will have many fears about the diagnosis their loved one has received. Thyroid cancer, and especially anaplastic thyroid cancer (ATC), not being as well-known or well-publicized as other forms of cancer, may cause even greater fear for patients and loved ones (Harkin et al., 2017). People tend to fear the worst when they hear the word cancer, and with an ATC diagnosis there is much to fear (Harkin et al., 2017).

Patients and survivors can have many emotional struggles to contend with as they experience required tests and treatments. Thyroid cancer patients often struggle with feeling dismissed, feeling they get mixed messages about treatments, and feeling lonely throughout the treatment process (Sawka et al., 2009). Patients and survivors may not feel properly informed or supported. A lack of knowledge about what the diagnosis means or what treatment will look like can cause additional stress to patients and their support systems (Wiener, Cassisi, Paulson, Husson, & Gupta, 2017).

Lack of connection to resources and support is a contributing factor to distress in patients (Wiener et al., 2017). They may not have the capacity for finding available resources in the community on their own: They may not know how to search for resources, be overwhelmed by the process, or even fear reaching out. The diagnosis has changed their lives, and there are many unknowns. Roberts, Lepore, and Urken (2008) discussed survivors’ needs for ongoing information and experiencing unmet emotional and social needs. Without support and guidance from others, adjusting to changes can be overwhelming and distressing. Providers may be satisfied with giving survivors reports of a favorable prognosis; however, this alone does not translate into positive health-related quality of life (Gamper et al., 2015).

Of specific interest to me in this study were individuals with ATC, a very rare and aggressive type of thyroid cancer that develops from papillary or follicular thyroid cancer (American Cancer Society, 2018g). It is considered the most lethal type of thyroid cancer, even with positive prognosis or treatment success (Molinaro et al., 2017). Because of the lethal and aggressive nature of the disease, ATC patients and survivors present with particular needs, and research into this diagnosis has proven beneficial for supporting these individuals. The focus of this study was on identifying the types of support that ATC patients and survivors receive through participating in an ATC support group on Facebook. These support types were expected to be informational, social, and emotional. An additional focus was on investigating the online support group's role in helping patients and survivors adjust to a "new normal," or way of life that patients and survivors of ATC live following diagnosis and treatment (see Katz, 2011). It is said to be a new normal because life has been altered in physical, psychological, and perhaps even spiritual ways by the diagnosis and treatments (Katz, 2011). Life continues, but not in the same way.

This study has several implications for social change. Extending the theoretical knowledge of ATC patients' and survivors' adjustment to a new normal impacts social change by offering insight to providers on how patients and survivors experience ATC. Providers having a more in-depth understanding of patients' experiences allows them to have greater empathy for their patients. This also gives providers the ability to provide resources and recommendations that are better fit to the true experience and needs of those individuals. Having gained insights into the types of support patients and survivors receive in online environments and the related impact on their well-being through this research informs providers about how this support might reduce stress for patients, survivors, and those who support them. According to the study results, the stress experienced by patients and their families as well as the burden on providers, human service agencies, and society can be reduced through greater use of online support, such as with the social media group in this study.

In Chapter 1, I first discuss ATC and the issues that patients and survivors face. Sections on the study purpose, research questions, and the nature of the study follow. The transactional theory of stress and coping is identified as the theoretical framework of the study, then discussed. The study assumptions, limitations, strengths, and significance are then presented, followed by a summary.

Background of the Problem

Thyroid cancer, the most common endocrine malignancy, is increasing in worldwide prevalence (Wu et al., 2016). Vigneri, Malandrino, and Vigneri (2015) noted that thyroid cancer incidence remained fairly stable until the 1990s, at which time numbers started to rise. Thyroid cancer has demonstrated a greater increase in frequency than any other cancer type (Vigneri et al., 2015). The American Cancer Society's (2019) estimates for 2019 projected about 52,070 new cases of thyroid cancer in the United States, with 37,810 being women and 14,260 being men. Deaths from thyroid cancer for 2019 are projected at 2,170 (American Cancer Society, 2019). These projections show a slight decrease in the number of new cases and yet a slight increase in the projected deaths since 2018 (American Cancer Society, 2019). Thyroid cancer accounts for more deaths than all other endocrine cancers; yet, improvements in detection and treatment result in more people living as survivors (Wu et al., 2016).

Thyroid cancer diagnosis involves different types and stages. The different types of thyroid cancer are follicular (FTC), papillary (PTC), medullary (MTC), and anaplastic (American Cancer Society, 2018g). PTC, FTC, and MTC are types of thyroid cancer which are considered differentiated, meaning that the cancer cells mimic the look of regular thyroid cells under a microscope (American Cancer Society, 2018g). ATC cells do not look or function like typical thyroid cells, which makes ATC treatment much harder (American Cancer Society, 2018h). PTC tends to occur in only one lobe of the thyroid gland, grows slowly, is rarely fatal, and can spread to the lymph nodes (American Cancer Society, 2018h). FTC does not spread to the lymph nodes but can spread to other sites in the body (American Cancer Society, 2018g). FTC treatment is harder than PTC and prognosis is more negative but still can be treated easily (American Cancer Society, 2018g). MTC is a more aggressive type of thyroid cancer that occurs in the C cells of the thyroid (American Cancer Society, 2018g). MTC can spread to the lymph nodes, the lungs, or to the liver, at times even before a nodule in the thyroid is detected (American Cancer Society, 2018g).

As previously stated, ATC is a very rare and aggressive type of thyroid cancer that develops from PTC or FTC (American Cancer Society, 2018g). It is considered deadly despite prognosis or treatment success (Molinaro et al., 2017). Successful treatment merely prolongs the patient's life (Molinaro et al., 2017). Although ATC incidence is low, it accounts for about 40% to 50% of all thyroid cancer deaths (Paunovic et al., 2015; Pezzi et al., 2017). The American Thyroid Association (2018b) stated that the overall length of survival for ATC is poor, citing 6 to 12 months, but also noted that there are long-term survivors.

ATC treatment tends to be complicated and involves several different methods. A mixture of treatments is used to reduce tumor size and prolong survival (Molinaro et al., 2017). The combination of surgery, external beam radiation, and chemotherapy maximizes outcomes (American Thyroid Association, 2018b). Not only do ATC symptoms impact patients' quality of life, but each of these treatment methods comes with its own set of side effects (Molinaro et al., 2017). It seems reasonable that the aggressive and lethal nature of the disease can result in intense focus on the medical and physical aspects of the disease by patients and providers. However, I believe that the psychosocial impacts deserve attention as well because psychological stress has been noted to impact coping abilities and the healing process (see Lazarus, 1966).

Thyroid cancer can be divided into Stages I through IV, depending on the size and location of the tumor (American Cancer Society, 2018e). In Stage 1, the tumor is determined to be small and the cells have not spread to the lymph nodes or other sites (American Cancer Society, 2018e). In Stage II, the tumor is larger and has typically spread to the lymph nodes but not to other sites (American Cancer Society, 2018e). Stage III is assigned when the tumor has grown significantly and has affected areas of the neck, larynx, and esophagus (American Cancer Society, 2018e). With a Stage III diagnosis, the cancerous cells may or may not have spread to the lymph nodes but have not spread to other sites (American Cancer Society, 2018e). Stage IV is assigned when the cancer is more advanced, has grown in size, is affecting the spine or blood, and has metastasized to other sites (American Cancer Society, 2018e). ATC is always considered Stage IV due to its aggressive nature, but there are three subcategories for this stage: Stage IVA is when ATC is confined to the thyroid gland, IVB is when it has spread to the lymph nodes, and IVC is when it has spread to other sites (American Cancer Society, 2018e). Stage IVC is the most serious diagnosis (American Cancer Society, 2018e).

There are reasons that patient care tends to focus on physical issues rather than emotional or psychosocial ones. Patients may have questions about psychosocial symptoms but put off asking them, assuming that the physical issues are what are really important to medical providers (Kim, Shah, Namkoong, McTavish, & Gustafson, 2013). Physicians might have time constraints that limit sharing information other than concrete physical symptoms (Stringer, 2014). Patients may not want to be seen as problems or they may assume that providers would ask about emotional aspects if they were relevant (Stringer, 2014). Additionally, physicians may only focus on offering the most positive prognosis possible and avoid looking deeper into patients' quality of life issues (Duan, Gamper, Becherer, & Hoffmann, 2015). Stringer (2014) noted that emotional challenges patients face may not be addressed if they assume that these challenges are inevitable with a cancer diagnosis. These individuals may avoid talking about emotional difficulties when they feel that nothing can be done to relieve them. Patients may also think that discussing emotional challenges may distract from treatment planning (Stringer, 2014).

When patients do not feel they can burden medical providers with the emotional and psychosocial impacts of their diagnoses, they may seek this information elsewhere (Kim et al., 2013). Locating valid information about the emotional and psychosocial side of an ATC diagnosis can be overwhelming and frustrating, especially due to the rarity of the disease and the limited number of long-term survivors (Carter, 2017). As a result, patients and survivors may feel isolated and alone in their experience. This is especially problematic for survivors after completing treatment because this might be the first time since diagnosis that constant support has not been present (Morley & Goldfarb, 2015). Getting to the point of being a cancer survivor is a positive achievement, but it can still be a time when individuals continue to experience emotional or psychosocial effects of the disease and its treatment (Morley & Goldfarb, 2015).

Medical professionals who work with ATC patients can marginalize the emotional effects of the disease by taking a primarily physiological approach (Absolom et al., 2011). Merckaert et al. (2010) noted that despite the many negative impacts of psychological distress on treatment and healing, medical providers rarely offer psychological intervention; however, the absence of this type of intervention may negatively impact progress. Wu et al. (2016) found that patients who received attention to psychosocial and emotional needs in addition to medical care showed greater health-related quality of life and reductions in depression and anxiety. It can be deduced that people feel more supported if they sense their providers care about them and their quality of life, not just their symptoms.

Having cancer can increase a person's stress levels, and increased stress levels can negatively impact their coping and healing abilities (American Cancer Society, 2018a). Seok et al. (2013) discussed how stress can negatively impact patients' psychological and emotional well-being. Experiencing negative emotional reactions to stress, such as depression and anxiety, can negatively impact physical health and healing (Tagay et al., 2006). Chronic depression can negatively impact healing (Stringer, 2014). Having any illness can cause distress and stretch an individual’s resources to the limits. Hearing a cancer diagnosis and further, diagnosis of a rare form of thyroid cancer that is aggressive and lethal can be even more taxing. All of cancer’s aspects are stressful (American Cancer Society, 2018a). When people’s resources are exhausted, their ability to cope with stressors is diminished (Lazarus & Folkman, 1984). The stress negatively impacts every part of a patient’s life (American Cancer Society, 2018a).

Thyroid cancer in general is not connected to high death rates, and providers often refer to it as “the good cancer” to have (B.C. James et al., 2016). The problem, however, is that people do still die from thyroid cancer and have significant challenges to face, and these facts can be more impactful with an ATC diagnosis. During initial testing and screenings, providers may maintain optimism by minimizing the potential for a negative prognosis, but this approach can result in patients feeling let down, fearful, and disappointed when they learn the reality of their diagnosis (Sawka et al., 2009).

ATC patients and survivors must adjust to the changes in their lives created by their diagnosis and treatment; in other words, their new normal. What this new normal might be can vary (Baker et al., 2016). Cancer patients and survivors demonstrate a significant need for information and support as they adjust to their new reality; those diagnosed with ATC are no different (Morley & Goldfarb, 2015). They may seek information about what to expect and want connection with others who have been down the same road or who are going through similar experiences.

Even when treatment has ceased, patients and survivors may feel the need for information and connection to those who understand their diagnosis. Lee et al. (2010) found that thyroid cancer survivors continue to struggle with decreased quality of life in the form of fatigue, depression, and disease-related fears even after treatment had ended. While it is understandable that medical providers' attention tends to be on patients during diagnosis and treatment, a continued focus is beneficial as patients transition out of the treatment phase. Morley and Goldfarb (2015) found that patients close to initial diagnosis received more information and support from providers than patients further out from treatment and survivors. Patients and survivors can benefit from continued information from medical providers after treatment ends, including practical information for dealing with the next steps (Morley & Goldfarb, 2015). It could be surmised that providers who are cognizant of this adjustment, the potential differences between patients' experiences, and the continued needs of patients and survivors may be better able to support them, which in turn can improve care, reduce stress on patients and families, and reduce the burden of medical care.

Looking beyond support from medical professionals, social media and the Internet connect people to health information, supportive peers, and other resources. Social media are avenues for people to connect emotionally and informationally about all health issues (Garlapow, 2016) and can play a role in shaping ATC patients' adjustment to a new normal (Cohen, 2011; Lepore et al., 2014; Shim, Cappella, & Han, 2011; Vlahovic, Wang, Kraut, & Levine, 2014). Using the Internet and social media sites can give patients greater access to health care and health care information than in the past

(Garlapow, 2016). People can access information and support right at home, which offers a sense of security and ease of access. The Internet can be a useful tool for patients and survivors that can be more easily accessed than other avenues.

Problem Statement

The medical and physical aspects of thyroid cancer have been identified by researchers including Cho et al. (2015); Davies and Welch (2014); Leboulleux et al. (2013); and Polotsky, Brokhin, Omry, Polotsky, and Tuttle (2012). Research on the emotional and psychological effects of thyroid cancer has increased in recent years, as seen in studies by Absolom et al. (2011); Gallop, Kerr, Simmons, McIver, and Cohen (2015); and Rogers, Mepani, Jackson, and Lowe (2017); however, far less is known about ATC patients' and survivors' needs, particularly from their personal perspectives. Gamper et al. (2015), Husson et al. (2013), Tamminga et al. (2016), and Wu et al. (2016) focused on thyroid cancer and the emotional aspects but relied on standardized questionnaires and quantitative measures for data collection and analysis. While these studies made substantial contributions to what is known about the emotional aspects of thyroid cancer and treatment, they did not describe the experiences from the points of view of patients and survivors.

The problem is that the lack of more detailed information means that providers treating ATC patients and survivors may not have a full understanding of what these individuals are going through, which can result in less effective treatment. In other words, providers may only be targeting a part of the experience. Targeting only a part of the experience may result in ongoing and increasing stress in patients and survivors that can negatively impact the healing process. Addressing these aspects of the disease can improve coping and therefore, improve chances for positive healing, recovery, extended life expectancy, and improved quality of life as survivors (Applewhite et al. 2016).

With treatment advances, more people are living as thyroid cancer survivors than before (American Cancer Society, 2019). Long-term ATC survivors do exist, although low in numbers (Carter, 2017). ATC impacts survivors physically and emotionally, making a return to what was previously the norm impossible. Survivors must instead adjust to a new normal. Specific to the focus of this study, the role that social media might play in providing a source of support for making this adjustment and the kinds of supports available from online social media are understudied to date.

Purpose of the Study

The purpose of this study was to explore how ATC patients and survivors cope with their new normal through participating in an online support group. Access to posts in a Facebook support group allowed me to document and analyze individuals' narratives about their experiences. Narrative accounts of an experience are a way to report about a phenomenon in a human way that readers can connect with (Dahlstrom, 2014). Learning about experiences and reporting them from the participants' perspectives is a key component of qualitative research (Merriam & Tisdell, 2016).

My goals in conducting this study included identifying themes in participants' experiences with ATC, gaining a better understanding of the emotional effects of the disease from their perspectives, gaining insight into the lives of patients and survivors as they adjust to a new normal, and categorizing the types of support that individuals receive from the Facebook ATC support group. The results from these inquiries may benefit medical and mental health professionals by offering a better understanding of the experiences of ATC patients and survivors, the types of support they need, and ways to better meet these needs. By providing professionals with new ideas on how to support patients and survivors, the relationships between patients, survivors, and providers may be enhanced and the burden of medical care on the health care system and society may be reduced.

With more knowledge about these aspects of the disease and the support that patients can receive, future patients may feel more connected to other patients and survivors. Improved connection to these supports may result in patients and survivors feeling less stressed, less anxious, and less emotionally overwhelmed. Providers reading the results of this study and studies that may follow may gain a better understanding of their patients' experiences. Providers who have a better understanding of their patients can provide more personalized and patient-centered care.

Improved connections and understanding between patients and providers allow for better working relationships. Patients who are more at ease with their providers and believe that the providers understand their experiences can heal more effectively (Bitton, Onega, Tosteson, & Haas, 2014). The healing process may be improved because patients feel more comfortable asking questions of and collaborating with their providers, and, as a result, patients may have better access to the information they need to improve coping. These improvements can be true with any patient–doctor relationship, but in this study, the focus was on ATC patients and providers.

The purpose of conducting a qualitative study is to report the lived experiences of participants from their points of view (Meltens, 2014). Information evolves as the study progresses because the participants' experiences guide the direction of the study, which is expected in qualitative research (Merriam & Tisdell, 2016). Additionally, in qualitative research, it is assumed that the researcher's values are a part of the research and do not need to be separated from the work (Meltens, 2014). I was the primary researcher in this study, and I am a thyroid cancer survivor. As a result, my experiences and personal values undoubtedly impacted this research. However, in qualitative research, this impact is viewed as beneficial to the study rather than a problem (Merriam & Tisdell, 2016). What is important is noting how these aspects impact the study.

The results from a basic qualitative study are not generalizable to a larger population (Melton, 2014). It is not possible to take the results from this study and generalize them to a larger population. Instead, the goal was to increase the knowledge base about the experiences of a specific group of individuals. Future studies on potential similarities in other samples can be developed from the results of this study.

Research Questions

The following research questions guided the study:

Research Question 1 (RQ1): How do ATC patients and survivors express support in the Facebook ATC support group?

Research Question 2 (RQ2): What types of support do ATC patients and survivors receive through participating in the Facebook ATC support group?

Theoretical Framework for the Study

People face many challenges that can cause stress in their lives. Different stressors as well as individual characteristics, environment, and social influences impact coping abilities (Lazarus, 1999). Lazarus's (1999) transactional theory of stress and coping focuses on how people assess and cope with the events, life transitions, and social changes in their lives. The focus in this study was on how people diagnosed with ATC assess and cope with this diagnosis and how they use online support group participation in their coping processes. The close connection between the focus of this study and the focus of Lazarus's theory was why I chose this theory as the theoretical framework of the study.

According to Lazarus's (1999) theory, stress is a reaction to various stimuli that people encounter; stimuli cause different reactions in people, and stress is one reaction. Lazarus and Folkman (1984) defined these stimuli as "events impinging upon a person, conditions arising within the person, and major environmental changes a person's experiences" (p. 12). Stress levels can be subjective, and people experience varying degrees of stress to different situations (Lazarus & Folkman, 1984). Individuals assess stressors differently and cope differently, and this theory is used to explore the process of appraisal and coping with stress (Lazarus & Folkman, 1984).

In this study, the diagnosis and experience of having ATC was the identified stressor or stimuli. Patients and survivors have different reactions to being diagnosed with ATC. They experience treatments differently because people have different tolerance levels and physical differences that create variations in treatment impact

(American Cancer Society, 2018h). Some patients have an easier time coping with how treatment impacts their lives than others. Members of the Facebook support group post about their experiences and provide information about how they cope with the disease and treatment. Differences that patients and survivors expressed have been noted.

Patients and survivors who participate in the Facebook group have faced a significant stressor and significant challenges to their resources for coping with stress. These participants also come to the experience of ATC with different coping abilities and different resources available to them. Studying the impact of stress on these individuals, exploring their coping abilities, determining the needs of group members, and exploring the types of support they receive from the group aligned with the focus of stress and coping theory.

Other theories that I considered for this study included self-determination theory, cognitive theory, and psychodynamic theory. Deci and Ryan (2002) identified three basic needs in self-determination theory: competence, relatedness, and autonomy. Although the need for relatedness may align with what a patient or survivor may need, I did not feel that competence and autonomy accurately described their experiences. I also did not feel that self-determination theory would accurately summarize what a cancer patient might be experiencing. I do not think that patients feel their situation is completely within their control or can be fully impacted by their own self-determination. Cognitive theory looks at how people construct their view of the world (McLeod, 2018). The study of people coping with cancer can involve how they construct their view of the world, but this theory also involves stages of life development (McLeod, 2018). The focus of coping with cancer, adjusting to a new normal, and using the Internet as a coping tool did not seem to match this discussion of developmental stages. Lastly, psychodynamic theory focuses on people's unconscious desires and beliefs (Deal, 2007). In exploring what needs are met for patients and survivors through online participation in a support group, participants' unconscious drives would not be studied; therefore, this theory was not a good fit.

Thyroid cancer, and specifically ATC, is a significant life event and can cause various types and levels of stress in patients and survivors. Applewhite et al. (2016); Buchmann, Ashby, Cannon, and Hunt (2015); Rogers et al. (2017); and Seok et al. (2013) all described the experience of thyroid cancer as being significantly distressing to patients despite the specific cancer stage or prognosis. Feelings of distress can be amplified when people lack knowledge about what lies ahead. Many people do not know much about thyroid cancer, which can leave patients feeling very alone in their experience (Shey, 2001). Seok et al. noted that the highest distress levels for thyroid cancer patients develop when first diagnosed and when awaiting surgery; both can be times of great ambiguity.

People diagnosed with thyroid cancer experience a permanent life change that comes with great unknowns and that can be a source of great stress. An ATC diagnosis is accompanied with significant threats to a patient's life, uncertainty, and a great deal of stress. Because of the rarity of this diagnosis, patients may feel even more isolated than in the case of other types of thyroid cancer. ATC is a personal challenge and life stressor that requires many personal and external resources for positive coping.

Online support groups can be valuable resources for accessing help and support during times of stress (Koball et al., 2017). People often reach out through online forums as a coping strategy (Harkin et al., 2017). Investigating how people participate in online support groups and identifying the types of support they receive from their participation, as I did in the present study, are ways to explore how people cope with stress.

Nature of the Study

Because the focus of this study was on describing a human experience using archival data, I identified a generic qualitative approach as being the most appropriate (see Merriam & Tisdell, 2016). Qualitative research is descriptive or interpretive rather than statistical and allows for in-depth and accurate descriptions of people's subjective experiences (Merriam & Tisdell, 2016). Furthermore, qualitative studies are appropriate for delving into the deeper meanings of experiences and the perceptions individuals might have about their own experiences (Merriam & Tisdell, 2016). By focusing on participants' emotional and subjective experiences, the goal in this study was to gain a more comprehensive picture of the experience of ATC and the support needs that might be met through online support group participation. Findings from this study may help providers better connect with their patients' emotional needs.

Quantitative research is a valuable part of the literature in science and social science. Quantitative researchers have access to statistics about the cause and effect or correlation of a situation or will use numerical equations for predicting a potential outcome (Merriam & Tisdell, 2016). Qualitative research is more a process for the researcher of uncovering the meaning behind an event or situation (Merriam & Tisdell, 2016). More details on the contributing factors to experiences, different impacts on events, and nuances about these can be described in qualitative studies (Merriam & Tisdell, 2016). The impact of societal factors on individuals' experiences may become more evident through qualitative data. As Dulmus (2012) stated, more can be gained from a story told directly by a person experiencing the phenomenon, such as aspects about the society he or she lives in, cultural factors, and social norms of the time. Understanding a phenomenon works best when the described experience includes all related factors, which tends to be expressed through individual's personal accounts. Dulmus also stated that personal narratives allow for greater understanding of the complexities involved in individual's lives and how these impact a given experience. Although quantitative research is useful for gaining information about situations, it cannot portray how people define their own experiences (Keen, Murray, & Payne, 2013).

By reading qualitative research results, medical and support personnel are presented with information that is closer to their patients' actual experiences (Rubin & Rubin, 2012). In the current study, relying on qualitative methods for data collection and analysis allowed for the development of more thorough knowledge and an emotionally connected understanding of the study population's experiences. With the results, providers may then have access to first-hand information from the points of view of ATC patients and survivors.

ATC patients and survivors were the specific focus in this study. The study sample was members of a Facebook support group, and the data collected were in the form of posts on the group page. ATC impacts both men and women, and group membership included both males and females; therefore, both genders were represented in the study sample. Although women tend to show higher numbers in diagnosis, mortality statistics on all types of thyroid cancer are more similar between men and women, so looking at both genders is necessary (Glaser et al., 2016).

Study participants were a minimum of 18 years of age. This age limit was a result of the Facebook group's requirement for the group members to be of adult age and also was helpful in avoiding ethical issues related to including minors in a research study. No upper age limit was set for study participants because there was no such limitation for membership in the Facebook group.

I collected posts from August 1, 2018 through November 30, 2018. No posts outside of this 4-month period were used. The reason for this time frame was to avoid sifting through an exorbitant amount of data for analysis. Not limiting the number of posts would have been unrealistic in terms of the logistics for completing this study.

The data collected and analyzed were archival, which had benefits and weaknesses. Benefits of using archival data include being able to collect more data than if collecting raw data, data collection being less time consuming, and having the data readily available (University of Virginia, 2018). Using archival data also allows for relationships in the data to emerge, which may not have occurred if the study was based on predetermined questions in interviews or on questionnaires (University of Virginia, 2018). Limitations of using archival data are that casual conclusions cannot be made, and correlating data into emergent themes is the best result possible (University of Virginia, 2018).

Definition of Terms

The following terms were used in this study:

Anaplastic thyroid cancer (ATC): An aggressive, undifferentiated form of thyroid cancer that is the most rapid growing type of thyroid cancer. It spreads quickly to other organs and does not respond to radioiodine therapy or thyroid stimulating hormone suppression like other types of thyroid cancer (American Thyroid Association, 2018b).

Follicular (FTC) and *papillary thyroid cancer (PTC)*: FTC and PTC are referred to as differentiated, which means that the cancer cells look and act like normal thyroid cells in some respects. PTC grows very slowly but can spread to lymph nodes and other parts of the body. FTC usually does not spread to the lymph nodes but can spread to the lungs or bones (American Thyroid Association, 2018b).

Hyperthyroidism: Having an excessive amount of thyroid hormone resulting from an overactive thyroid gland or from taking too much thyroid hormone. Symptoms can include increased heart rate, weight loss, anxiety, and cognitive slowing (“Hyperthyroidism,” 2005).

Hypothyroidism: A deficiency of thyroid hormone that is characterized by abnormally low thyroid hormone production. Symptoms can include fatigue, slowed metabolism, and depressed mood (“Hypothyroidism,” 2005).

Medullary thyroid cancer (MTC): This cancer develops in the C cells of the thyroid glands and is easier to treat and control if found before it spreads to other parts of the body. There are two types of MTC: sporadic and familial. MTC treatment is surgery, and long-term prognosis is not as positive as for differentiated thyroid cancer (American Thyroid Association, 2018b).

Radioactive ablation (RAI): In RAI, radioactive iodine, or I-131, is taken into the body in liquid or capsule form and concentrates in thyroid cells. The radiation from the I-131 destroys the thyroid gland and any other thyroid cells (including cancer cells) that take up iodine, with little effect on the rest of the body. However, permanent hypothyroidism results (American Thyroid Association, 2018b).

Thyroidectomy: Surgery to remove part of or the entire thyroid gland. Complications of the surgery can include vocal cord paralysis and accidental removal of the parathyroid glands, which are located behind the thyroid gland ("Thyroidectomy," 2005).

Assumptions

Assumptions in research reflect what the researchers believe to be true; these assumptions are necessary as a foundation to the research but cannot be proven (Simon & Goes, 2013). I identified several assumptions at the start of this study. I assumed that members of the identified support group had posted genuine and honest statements, questions, and answers. I also assumed that group members struggled with their experiences of ATC and were hoping to find ways to improve coping and adjust to a new normal. Another assumption was that group members were participating in the group to seek support from other ATC patients and survivors. My final assumption was that the group members' posts would demonstrate a pattern of different types of support that they were both seeking and receiving. All of these points were the groundwork for the research questions and goals of this study.

Scope and Delimitations

As previously stated, my focus in this study was on ATC patients and survivors and on exploring their participation in an online support group to determine the types of support they receive from the group. The study sample included posts from members of an ATC support group on Facebook. Using the identified group was possible after receiving consent from the group administrators; I did not obtain consent from other groups that I contacted. Some administrators were unsure about how their group members' confidentiality would be protected and if the members needed to provide consent and were therefore unwilling to provide access. Some administrators were unfamiliar with the ethical requirements for consent, and some administrators were simply unresponsive. One group was a more general thyroid support group, and I determined that the scope of issues addressed in their group would be too varied for the purpose of this study. One group's administrator gave verbal permission, but the group then had a change in administration. The new administration stated that as a result of this change, consent for participation could no longer be given.

Limitations

This study also had several limitations. First, using only one Facebook group and a specific date range for data collection limited generalizability outside of the target population. The results relate only to ATC patients and survivors, not those with other cancer types. When using case studies in research, generality is always unclear (Merriam, 1988). Case studies involve only one group or certain people; this type of exploration involves the goal of having a deeper understanding of a phenomenon (Merriam, 1988). The study results can then help to inform future studies for expanding this knowledge. Further research would be needed to explore similar issues among people with different thyroid cancer types and the types of support that might be available in social media forums other than Facebook.

Qualitative research of a phenomenon can create some credibility and validity issues. The burden of showing that findings are based on critical investigation lies with the researcher (Merriam & Tisdell, 2016). Although there are methods for increasing credibility and validity levels, such as triangulation, member checking, and checking the researcher’s bias, there are no specific tests to ensure these aspects (Merriam & Tisdell, 2016). I am a thyroid cancer survivor. This was another limitation because there was some subjective bias in this study. Focusing specifically on ATC patients and survivors helped to minimize this because I was diagnosed with differentiated PTC (i.e., Stage 1). My experience was quite different from those of the study population as a result of having a different diagnosis and having experienced thyroid cancer in 2007. Qualitative research also takes into consideration the researcher’s values and subjective biases, and these are accepted as an integral part of the process rather than a hinderance (Merriam, 1988). Qualitative research is both strengthened and weakened by human subjectivity, but the benefits are thought to outweigh the drawbacks (Merriam & Tisdell, 2016).

I managed my personal bias through reflective journaling, consulting with an objective colleague who was not involved in the study and participating in a monthly peer supervision group to discuss aspects of the research and my findings. The reflective journal included thoughts and feelings that emerged while obtaining and analyzing data. Discussing my notes with a colleague and the supervision group then helped with processing my reactions throughout the study and addressing any bias.

Lastly, it is important to keep in mind that study participants were both ATC patients and survivors. Survivors are more removed from the experience of being a patient and going through treatments; therefore, their recollection of events and assessment of past events may not be exact. Collecting data about past experiences may have resulted in some variation of details, emotions experienced, and coping ability levels reported.

Significance of the Study

Studying the experiences of ATC patients and survivors is an important part of thyroid research. Wu et al. (2016) demonstrated how findings from studies on thyroid cancer patients help to inform improved interventions, which in turn improve patient quality of life. Morley and Goldfarb (2015) stated that researching thyroid cancer patients increases insights into patient needs and that greater understanding of their needs results in better patient support. Understanding a situation in better detail allows medical providers and other professionals to effectively address the needs that exist. As previously stated, less is known about ATC patients and survivors; therefore, findings from this study were an important contribution.

The numbers of people diagnosed with ATC and living as survivors continue to increase (American Thyroid Association, 2018a). Having a thorough knowledge of the experience directly from patients and survivors will help future patients understand what may lie ahead, help inform providers on how to best treat their patients and allow for the greater availability of improved resources. Knowledge of the existence of a new normal for survivors can help direct care for patients, inform the providers treating these people on a long-term basis, and ease the transition to a new normal.

Online support groups have become helpful resources for many people, including cancer patients and survivors. More and more studies on using the Internet for cancer support have been published, including those by Garlapow (2016); Lepore et al. (2014); Portier et al. (2013) and Zhao, Greer, Yen, Mitra, and Portier (2015). Adding to the knowledge base of how participating in online support groups benefits cancer patients and survivors could give providers greater insight to their patients' experience, their needs, and the types of resources that are beneficial. More specifically, looking at the types of support that online group participation offers ATC patients and survivors can improve the functionality of these groups and inform providers regarding what patients and survivors most need.

The data used in this study were the actual narratives of group members in posts to the group. Using participants' own narratives allowed me to stay as true to the participants' perspectives and meanings as possible. Bennett, von Wagner, and Robb (2015) stated that using narratives in their research is what afforded them the vivid picture of their participants' experiences, which they were seeking. Using narratives from patients and survivors allowed for genuine and specific descriptions of how they were impacted by the disease and its treatments, what a new normal might be for them, and the types of support that are helpful to patients and survivors in the online support group format.

Summary

I conducted this study of ATC patients and survivors to gain insights into patient experiences and ways they coped with the stress of an ATC diagnosis. Treatment and support for patients can be improved by having more thorough knowledge of their experiences and the types of support they receive from participating in online support groups. In this chapter, I presented an overview of the problem addressed in this study and its purpose. The research questions and the nature of the study were also presented. Transactional stress and coping theory was identified as the theoretical framework for the study. A basic qualitative approach was identified and discussed. Study assumptions, limitations, strengths, and significance were then presented. In Chapter 2, I present a review of the literature conducted for this study.

Chapter 2: Literature Review

Introduction

Thyroid cancer can be a difficult and emotional experience for patients and survivors. Almendrala (2015), Buchmann et al. (2015), Gamper et al. (2015), and B. C. James et al. (2016) have described the psychosocial and emotional impact that thyroid cancer can have on quality of life. The emotional impact can be even more devastating when a patient is diagnosed with ATC, the more aggressive and lethal version of thyroid disease. Patients and survivors hope to someday return to normal; however, treatment effects and the lethality of the diagnosis tend to make this hope unrealistic. The concept of adjusting to a new normal for ATC patients and survivors as well as identifying the types of support they receive in online groups, the focus of this study, had not been previously researched. In this chapter, I review the literature, compare my findings to the purpose of the present study, and discuss the theoretical framework.

Literature Search Strategy

I used numerous databases to find relevant literature for this review, including ProQuest, MedLine, Google Scholar, PsycINFO, PsycBOOKS, PsycEXTRA, PsycARTICLES, PsycCRITIQUES, EBSCOhost, Thoreau, and CINAL. The following keywords and keyword combinations were used in the search: *thyroid cancer and diagnosis*, *ATC*, *thyroid cancer treatment*, *emotional*, *pain*, *fatigue*, *loss of control*, *fear*, *anxiety*, *depression*, *psychosocial*, *psychosocial impact*, *psychosocial reactions*, *psychosocial experience*, *social impact*, *behavioral interventions*, *remission*, *survivors*, *survivorship*, *life after*, *cultural impact*, *cultural*, *negative reactions*, *stress*, *coping*, *quality of life*, *health-related quality of life*, *mental health*, *isolation*, *distress*, *trauma*, *sexual activity*, *fertility*, *qualitative study*, *thyroid cancer diagnosis*, *breast cancer*, *prostate cancer*, *the best cancer and thyroid cancer*, *quality of life and thyroid cancer*, *health-related quality of life and thyroid cancer*, *new normal and cancer*, *new normal and thyroid cancer*, *online support and thyroid cancer*, *online support groups and thyroid cancer*, *Facebook and thyroid cancer*, and *support groups and thyroid cancer*.

Research on the emotional experiences of thyroid cancer patients and survivors has significantly progressed in recent years. I found articles discussing the needs of thyroid cancer survivors, the risk factors for decreased quality of life, and the psychological and behavioral interventions that exist, such as those by Gamper et al. (2015), Husson et al. (2013), and James et al. (2016). I also found several articles in which the authors discussed the emotional experiences of those diagnosed with other cancer types, such as breast cancer and prostate cancer, as well as research regarding the psychosocial aspects of living with cancer, as seen in studies by Absolom et al. (2011) and Brunet, Sabiston, and Burke (2013).

In searching for studies regarding the idea of a new normal, I found none on the idea of a new normal specific to thyroid cancer or ATC. The articles I found on a new normal all concerned other types of cancer or cancer in general, such as those by Baker et al. (2016), Mendes (2015), and Shannonhouse et al. (2014). During my search for articles discussing the types of support that online support groups offer survivors in coping with their new normal, I again only found studies related to other cancer types, which can be seen in studies by Batenburg (2014); Shim et al., (2011); and Yli-Uotila, Rantanen, and Suominen (2013).

Theoretical Foundation

Transactional Stress and Coping Theory

Transactional stress and coping theory explores how people assess and cope with life events (Lazarus & Folkman, 1984). The main theorist behind the theory, Lazarus, first proposed ideas about stress and coping in *Psychological Stress and the Coping Process* (1966). In 1984, Lazarus collaborated with Folkman on *Stress, Appraisal, and Coping*. Lazarus (1999) released an updated version to include the dynamic of emotions in *Stress and Emotion: A New Synthesis*. Lazarus and Folkman (1984) discussed how the theory developed from earlier behavioral and cognitive theories. As individuals were living longer and facing more challenges in adulthood, psychologists began to look more at how adults cope with life transitions and social changes (Lazarus & Folkman, 1984). Coping with ATC, its treatment, and living as a survivor can be considered a major life transition. There are many different situations that most people would identify as being stressful, such as job loss, death of a loved one, or change in health status (Lazarus, 1999). Being diagnosed with ATC is a significant change in health status and can be considered a stressful event.

Stress is caused by a stimulus or life event (Lazarus & Folkman, 1984). The level of stress experienced by a given event and a person’s ability to cope with that stress is determined by a combination of factors. The combination of the event itself, the person’s assessment of that event, and the person’s personal characteristics all work together to determine the individual’s reaction or coping with stress (Lazarus, 1999). Certain situations can be seen as universally stressful, and these events “are much more likely than others to be psychologically noxious; they represent harms or threats to most people, so we tend to think of them as stressors” (Lazarus, 1999, p. 54).

Lazarus (1999) explained that the process of assessing stressful events and coping ability involves an interaction between an individual’s personal characteristics and environmental changes. This interaction is what defines whether a situation is stressful or how stressful the situation is to the individual; appraisal of a situation as stressful is considered to be subjective due to the interplay of these factors (Lazarus, 1999). Lazarus identified events as being seen by people as a harm, a challenge, or a threat. Depending on a person’s determination of the intensity of a situation, along with the assessment of their own abilities and resources to cope with the situation, a person will react as if he or she is completely anxious and overwhelmed or will remain calm and confident about his or her ability to cope (Lazarus, 1999). People may possess certain personality characteristics that result in their being more or less resistant to the effects of stress; examples of these are hardiness, learned resourcefulness, and a sense of self-efficacy (Lazarus, 1999). Individuals who doubt their ability to cope with the world effectively will have a more difficult time coping with stress (Lazarus, 1999).

Neirinckx, Morton, Herman, and Hinze (2015) stated that high stress levels can impact people’s abilities to effectively process information and learn. People who are naturally more anxious may have a more difficult time coping with stressors as a result of the impact of anxiety on thought processing and decision-making (Neirinckx et al., 2015). Neirinckx et al. also stated that when people are anxious, their ability to process information, make appropriate decisions, and carry out skills can be diminished; these types of impairments negatively affect coping ability.

My focus in this study was on the psychological stress experienced from ATC diagnosis and treatment, its impact on quality of life, and the experience of stress during adjustment to a new normal. Psychological stress can be defined as the emotional and mental impact of dealing with a challenging situation (Hollar & Piotrowski, 2018). Lazarus and Folkman (1984) described psychological stress as “a relationship between the person and the environment; it is appraised by the person as taxing or exceeding his resources and endangering his well-being” (p. 19). Events that people perceive as being threatening and beyond their own coping abilities will be viewed as extremely stressful.

Health problems, especially cancer, are threatening to a person’s well-being and are considered taxing to functioning. Chyi, Lu, Wang, Hsu, and Chang (2017) and Pryce and Fuchs (2016) identified health problems as being considered stressful by most individuals. Roerink et al. (2013), Rogers et al. (2017), Seok et al. (2013), and Zebrack et al. (2014) all noted cancer and thyroid cancer as causing significant distress. Diagnosis of ATC and the detrimental impact of required treatment can certainly be considered stressful.

Appraisal. When people face a situation, they will typically consider different aspects of it and evaluate what it might mean for them. Lazarus and Folkman (1984) identified that evaluation of the situation and an individual’s ability to cope with it as the process of appraisal. Some factors that may be considered during appraisal include how close a person is to the situation, how long the situation will last, whether the timing involved is known, and if the individual is coping with other challenges at the same time (Lazarus & Folkman, 1984). People base their appraisals of situations on all the factors they are experiencing.

Cognitive appraisal refers to the intellectual conceptualization of a situation (i.e., what people think their reaction will be or what their coping ability might be; Lazarus & Folkman, 1984). People continually assess situations that arise, using their emotional and cognitive resources to make decisions and problem solve (Lazarus & Folkman, 1984). People's evaluations of situations reflect their personal characteristics and their knowledge of the situation, based on past experience (Lazarus & Folkman, 1984).

Lazarus and Folkman (1984) identified two types of appraisal in stress theory: primary and secondary. Primary appraisal refers to an individual's assessment of the situation in terms of the significance of the situation to the individual and can be identified as threatening or benign (Lazarus & Folkman, 1984). When faced with a situation, people will consider both what they know about the event and their abilities and resources; together, these aspects will lead to determining just how stressful the situation is for them (Lazarus & Folkman, 1984).

During the appraisal phase, some situations may require immediate reaction, whereas others may require steps to be taken later. Secondary appraisal deals with the options for coping with the situation in the future (Folkman, 2008). Receiving a thyroid cancer diagnosis requires deciding a plan of action rather than taking immediate action (American Thyroid Association, 2018a). The treatment plan will be mapped out, and the plan steps will be carried out along a certain timeline. Determining this plan and the timeline occurs during secondary appraisal. People with this diagnosis must consider all the options at their disposal and their ability to effectively follow through with the available options.

Personal and situational factors. Personal and situational factors can affect the appraisal process. Personal factors can include peoples' beliefs, their assessment of the level of importance of the situation, their sense of personal control, and even their existential beliefs (Lazarus & Folkman, 1984). Situational factors refer to certain aspects of the challenging event a person is facing, such as the timing of the event, how long it will be endured, and the context in which it is occurring (Lazarus & Folkman, 1984). These factors also influence how people perceive a situation, their appraisal of it, and their decisions or actions related to coping with it (Lazarus & Folkman, 1984).

Personal factors give meaning to the situation that is being appraised and determine coping strategies. Folkman (2008) mentioned meaning-focused coping and likened it to appraisal-focused coping. The author stated that people rely on their personal beliefs, values, life goals, and spiritual meanings to cope through difficult times. People face a given situation with their own set of contributing factors that impact their appraisal and coping abilities (Folkman, 2008).

Each person has a finite amount of resources for coping with stress. Like filling up a container, once these resources have been maximized, the stress will overflow and become too much for the person to effectively cope with. The inability to properly cope with stress can have many detrimental physical and emotional effects (Pryce & Fuchs, 2016). People whose physical and psychological abilities have been maxed out will struggle to cope with stressors.

Coping abilities are also affected by health status and the amount of energy one has to expend toward coping (Lazarus & Folkman, 1984). If people are already unhealthy and experiencing compromised energy levels, they will often not have the physical resources to fight additional stressors (Hollar & Piotrowski, 2018). They are already using a significant amount energy to fight the illness. Coping with an emotional challenge at the same time can tax the system (Hollar & Piotrowski, 2018).

Other challenges a person may be facing at the same time can affect appraisal and coping abilities (Lazarus & Folkman, 1984). A person experiencing multiple challenging events at once or in succession can easily become overwhelmed. This results in having limited resources available for coping with stress, emotionally as well as physically. The flight or fight response involves a physiological and hormonal response that the body needs time to recover from (Hollar & Piotrowski, 2018). A lack of time between stressful events will keep the system from returning to baseline. When the body is unable to recuperate and return to baseline, the physical, emotional, and psychological resources people have at their disposal will be stretched to the limit (Hollar & Piotrowski, 2018).

A person's outlook on life is another factor related to coping ability (Lazarus & Folkman, 1984). A positive outlook can assist a positive response during stressful situations. Feeling negative, fearful, and hopeless about a situation reduces resistance to stress (Lazarus & Folkman, 1984). There is substantial evidence that positive emotions can help restore physical and mental coping resources during times of stress (Folkman, 2008). Emotions that result from people's perceptions of a situation, in conjunction with their general outlook on life, can affect their ability to cope positively or negatively (Folkman, 2008).

Problem-solving skills and self-confidence levels also impact coping abilities (Lazarus & Folkman, 1984). Problem-solving skills related to coping include being able to research a problem, learn about available options, weigh these options, determine a plan, and follow through with the plan (Lazarus & Folkman, 1984). Whether or not people believe they have the ability to cope effectively in life can impact their coping ability (Lazarus, 1999). What they believe about themselves can have just as much impact as their actual abilities (Lazarus, 1999).

Social skills can also impact coping abilities (Lazarus & Folkman, 1984). People with good social skills are better able to access social resources in times of stress and therefore will also have greater confidence in their ability to cope (Lazarus & Folkman, 1984). Positive social skills result in having good connections with others and feeling supported by others in times of stress. In a health care scenario, patients with positive social skills will also feel confident that they can effectively communicate with providers and increase their knowledge of the situation and their options. Lazarus and Folkman (1984) also pointed to being able to elicit help from others as empowering and beneficial in coping. Accessing help from others is a part of good social ability.

Support networks are another factor affecting appraisal and coping (Lazarus & Folkman, 1984). Having others around can be comforting and help people feel they are not alone. Social supports can be in the form of emotional support, informational support, help with task accomplishment, and general social interactions (Lazarus & Folkman, 1984). Each of these support types can improve coping abilities, and the more assistance people have, the more improved their coping abilities will be.

Society itself impacts people and their coping abilities. The social climate and cultural environment impact how people perceive, assess, and cope with stressful situations. A mismatch between people and their expected societal roles can create stress (Lazarus & Folkman, 1984). For example, divorce is a stressful situation. Society viewed divorce as unacceptable and unrespectable in the 1950s; it was not until the 1960s and 1970s that this began to shift (Fine & Harvey, 2006). Therefore, it can be assumed that in the 1950s a woman getting divorced could experience higher levels of stress related to the divorce than a woman going through divorce in 2018.

Material resources affect appraisal and coping. People who have better access to financial support, legal advice, or medical care will feel more secure about their coping abilities (Lazarus & Folkman, 1984). In this sense, people with greater resources at their disposal are less vulnerable, which can reduce stress.

As previously noted, the timing of a situation can impact appraisal and coping. Facing challenges when they are particularly unexpected can cause greater stress and more difficulty coping (Lazarus & Folkman, 1984). As it relates to the current study, most people do not expect to be diagnosed with cancer at a young age as it is often thought of as something more common as people grow older (American Cancer Society, 2018c). Therefore, a cancer diagnosis at a young age can increase the amount of stress experienced.

Uncertainty. Ambiguity around a situation can also affect stress levels and coping. Knowledge tends to give people a greater sense of control, which in turn affects their assessment of a situation and their coping abilities (Lazarus & Folkman, 1984). The more control individuals feel they have, the better they tend to cope. This point relates well to focus in the current study, which was on how types of support and the amount of information about ATC interact to impact coping and adjustment.

In contrast, uncertainty often increases stress; people tend to fear the unknown. As Lazarus and Folkman (1984) stated, "In real-life events, anecdotal observations suggest that maximum uncertainty is often extremely stressful; it can have an immobilizing effect on anticipatory coping processes and cause mental confusion" (p. 115). People make assumptions about situations based on earlier knowledge or previous experiences (Lazarus & Folkman, 1984). When people have some knowledge or past experiences to base their appraisals on, they can better assess the situation and cope in a more confident manner.

Coping plays a significant role in how individuals feel emotionally and physically, especially when dealing with a stressor like cancer. Lazarus and Folkman's (1984) view of coping and cognitive appraisal aligns with my interest in how individuals experience stress such as being diagnosed with ATC. The experience involves appraising the situation and assessing one's coping ability. Researchers such as Morley and Goldfarb (2015) have suggested that coping with thyroid cancer could be improved through better availability of information, support, and resources. As such, my goal in the present study was to investigate ways to improve support and resources for ATC patients and survivors.

Theory Strengths and Weaknesses

Lazarus' transactional theory of stress and coping (1999) has several strengths when compared to other theories. One of these strengths is that the theory describes coping as a process rather than being trait oriented. Lazarus and Folkman (1984) saw people as individuals and noted many variables that come into play when facing stress. Another theory strength is that Lazarus and Folkman saw coping ability as constantly changing. People's knowledge levels, beliefs in themselves, number of supports, access to resources, etc., can change over time. Therefore, coping abilities can also change over time (Lazarus & Folkman, 1984).

Coping is seen from both problem-focused and emotion-focused perspectives in Lazarus and Folkman's theory, which is another strength. People interact with their environments cognitively and emotionally, so considering people's coping abilities from these two perspectives aligns with human functioning. Dalgleish and Power (1999) referred to the cognitive and emotional elements in how information is processed. They stated that although emotional states may exist independently of cognition, a person's awareness of these states is still impactful. Emotions and cognition tend to interact. Discussing appraisal and coping from only the emotional or the cognitive perspective would be missing part of the picture (Dalgleish & Power, 1999).

Other theories discuss coping as a series of stages (Lazarus & Folkman, 1984). The problem with this is that people are unique individuals, and not everyone experiences coping in the same way or in the same order of stages (Lazarus & Folkman, 1984). Many factors that influence appraisal and coping could be ignored if the process is narrowed down to specific stages.

Although this theory of stress and coping has several strengths, it also has weaknesses. If a person prefers clearly defined coping styles, a process approach may not be best. A process approach allows for constant changes and considers many influences on coping. Clearly defined coping styles reflect more rigid perspectives (Lazarus & Folkman, 1984). Clear and stable stages may prove beneficial in some situations.

The information used for exploring appraisal of stress and coping ability comes heavily from self-report, which may be seen as a theory weakness (Lazarus & Folkman, 1984). Self-report is subjective and can be harder to prove or define, which can result in less reliable results than more objective ways of obtaining data (Compas et al., 2014). How one person experiences a situation cannot always be generalized to all people. One individual's perspective can be slightly different than another's. Therefore, using self-report data can impair generalizability. Self-report use continues, however, because the advantages outweigh the disadvantages (Lazarus & Folkman, 1984).

Points of Controversy

One still-controversial point in stress theory is how coping abilities continue to change throughout adulthood. Coping abilities will change from childhood into adulthood as people gain knowledge, grow emotionally, and have more experiences (Dalgleish & Power, 1999). All the factors that can affect a person's coping ability—intellect, view of the world, problem-solving abilities, belief in self, etc.—continue to change as one grows and matures (Dalgleish & Power, 1999). Various theories reflect how this change occurs. Erikson presented a theory of stages that described changes that occur as a result of coping at certain periods of development (Lazarus & Folkman, 1984). Lazarus and Folkman (1984) noted that there is a move from active to passive mastery of situations. Previous work by Vaillant (1977) and Pfeiffer (1977) discussed coping as a skill that develops as people age because they develop more mature ways of coping throughout life. These theorists agree that coping changes as people grow but differ in how these changes occur.

Literature Review Related to Key Variables and Concepts

Cancer's Effects

Cancer can affect any part of the body. The American Cancer Society (2018f) defined cancer as the presence of abnormal cells that grow out of control and may invade other tissues. The presence of cancer cells tends to impair functioning in the invasion site and any other areas in which they may grow. Cancer can be deadly. It can sometimes be cured or maintained through treatment (American Cancer Society, 2018f). As people grow older, the potential for some form of cancer increases, although children and young people can also be diagnosed (American Cancer Society, 2018f). Diagnosis in young people can be more traumatic for them and for their loved ones because it is less expected in this age group.

Cancer has many causes. Some forms are a result of genetics, and many are from environmental factors. Cancer can result from changes in cellular DNA, which may be inherited from parents, or caused by exposure to certain environmental factors (American

Cancer Society, 2018f). Environmental factors listed by the American Cancer Society (2018f) include lifestyle factors, household exposures, workplace exposures, pollution, medical treatments, and naturally occurring exposures.

Cancer is a common disease, and many families have at least one member who will have had it in his or her lifetime (American Cancer Society, 2018f). Several agencies have studied the factors that may contribute to a cancer diagnosis (American Cancer Society, 2018f). Studies that expose animals to certain elements, along with studies on the statistics of human exposure, are continually conducted to better determine what may be carcinogens and how to address cancer incidents (American Cancer Society, 2018f). Through research, more knowledge about cancer is being gained every day in the hope of improving treatment options for patients and finding a cure. As a result of this research, more people are living as cancer survivors, and deaths from cancer are decreasing (American Cancer Society, 2018f).

Cancer's Emotional Impact

There is an emotional impact of being diagnosed with and treated for cancer. This impact continues even for someone living as a cancer survivor. Patients diagnosed with cancer and their loved ones often feel overwhelmed and distressed (American Cancer Society, 2018a). Being diagnosed with cancer can be traumatic and lead people to think about death and dying as soon as they hear the word (Stanton et al., 2015). Even though progress in cancer research and treatment has been positive, the old message about cancer being a death sentence continues to be conjured up for patients and family members (Stanton et al., 2015).

People diagnosed with cancer may experience many different emotions, some positive and some negative. Initially, a patient might feel vulnerable, depressed, anxious, worried, fearful, or shocked (American Cancer Society, 2018a). There may be a fear of inability to cope or feelings of guilt about potentially becoming a burden on loved ones (American Cancer Society, 2018h). Feeling a lack of power and control can surface as well as insecurity and worry about the potential of being stigmatized in some way (American Cancer Society, 2018a). Hewitt and Holland (2004) stated that studies on people with various types of cancer have shown psychological symptoms consistent with psychiatric diagnosis among half of these individuals. A cancer diagnosis is often distressing and is at least a stressful experience for patients and survivors.

People diagnosed with cancer react and cope in different ways. Some may isolate themselves and feel that family or peers will not understand what they are experiencing (Scheffold et al., 2014). There can be apprehension about seeking information or complete avoidance of information and resources. When individuals are unaccepting of the diagnosis, they may be preoccupied with intrusive or ruminating thoughts (Scheffold et al., 2014). Shutting down or completely denying to themselves and others that something serious is happening can be a reaction (Scheffold et al., 2014).

People may experience a wealth of emotions and even display different reactions at different points of their journey with the disease. They may look for someone or something to blame for the diagnosis, which can result in blaming themselves. Some feel an overwhelming sense of self-blame, which can then lead to feeling abandoned or punished by God or the universe (Scheffold et al., 2014). Intense anxiety and feelings of guilt can play a role in self-blame. Feelings of anxiety can lead patients to worry that they caused the disease through their own behaviors or life choices. They may fear being blamed by doctors or loved ones for the diagnosis. Guilt over past actions or life choices may result in feeling they brought the diagnosis upon themselves. Patients may feel their lifestyle choices are to blame and they might have been able to do something to prevent the diagnosis (Scheffold et al., 2014).

Depending on the type of cancer diagnosis, more specific emotional issues can result. Feeling unattractive, useless, or purposeless are examples of emotions connected to cancers affecting females and fertility (Hannum & Rubinstein, 2015). Cervical, breast, and ovarian cancers can alter an individual’s life plans and sense of purpose as they often impact fertility and family planning. Being thrown into early menopause can be an issue for women (Hannum & Rubinstein, 2015), causing them to feel unattractive and undesirable.

Men can have their own types of emotional struggles. Feeling emasculated can be a reaction from men when the diagnosis impacts their sexual functioning (Hannum & Rubinstein, 2015). They may feel stigmatized if diagnosed with breast cancer due to the lack of information about men also having this disease (Quincey, Williamson, & Winstanley, 2015). They may even feel like frauds for leaning on others for support because the belief is that men do not get breast cancer (Quincey et al., 2015). Lack of information about the disease feeds into these misconceptions.

More emotional changes can develop once treatment begins. Starting treatment may be when patients can no longer deny or minimize their diagnosis. Strong emotional struggles may begin even if patients previously presented as unaffected. Cancer treatment can be tiring, draining, and even traumatizing (American Cancer Society, 2018a). Patients trying to maintain a sense of normalcy in their lives may struggle with anxiety over how their treatment will impact their daily functioning, how hard treatment will be on them, or what treatment may mean for them. Lack of sleep, physical side effects, and cognitive side effects can cause significant emotional reactions (American Cancer Society, 2018a). Depression may develop if patients feel their thinking is less sharp or are anxious about people treating them differently if their appearance changes. Treatment and resultant symptoms can leave people feeling embarrassed and less than human (Mapes, 2015). The effects of treatment can become more noticeable to others and have a more obvious effect on functioning.

Not only do cancer diagnoses impact people psychologically and emotionally, but psychosocial aspects of life such as employment, health insurance, financial standing, and social functioning are often impacted as well, additionally triggering feelings of anger, depression, and worthlessness (Hewitt & Holland, 2004). Where individuals were once determined and focused, their disease symptoms and treatments can lead to reliability, focus, and overall performance issues (Hewitt & Holland, 2004). Work performance can suffer, and social skills may be impaired. These effects can then lead to demotion, job loss, or loss of social connections with others.

Work and family life can be disrupted as a result of these changes (Hannum & Rubinstein, 2015). Pain, fatigue, weakness, immobility, cognitive impairment, sleep problems, sexual dysfunction, anxiety, and depression can all negatively affect performance and functioning (S. D. James, 2012). If treatment interrupts work schedules, patients may feel fragmented in their lives, unable to get securely grounded (Hannum & Rubinstein, 2015). Work disruptions can impact patients' identities. Where they were once considered hard-working and reliable employees, having cancer can change this; they may be less effective at work or frequently absent due to symptoms and treatment (Hannum & Rubinstein, 2015). Work can be linked to people's identities, social purpose, and financial security (Gordon et al., 2011). Inability to work can deprive people of their sense of independence, normalcy in life, and social stimulation (Gordon et al., 2011).

Patients may doubt their own abilities to cope and feel a sense of self-disappointment, which can also lead to depression (American Cancer Society, 2018a). When people experience loss of employment, changes in family dynamics, or changes in social connections as a result of something not in their control, they can feel depressed and hopeless. Patients can feel stigmatized and isolated by the disease. Buchmann et al. (2015) found that patients with head and neck cancer reported higher levels of distress than others due to location of the cancer and how visible it can be to others. The stigma that people feel can negatively impact their emotions. Women experiencing the effects of breast cancer express having visible changes that remained as proof of lingering effects of cancer (Brunet et al., 2013).

As treatment ends and people have a clearer sense of their prognosis, emotional changes can occur again. Patients must adjust to being cancer survivors rather than cancer patients. Because of poor cooperation between oncology and primary care settings, patients may feel an abrupt end to one service without a transition back to their primary care providers (Miller et al., 2016). When medically stable, cancer survivors can feel less supported by their providers. If there is not good transition of care and communication between the oncology team and a survivor’s primary care physician, patients may feel lost or as if their medical care is no longer important.

Patients with a poor prognosis or less positive results than they expected can experience many negative emotions (Liamputtong & Suwankhong, 2015). Feeling disappointed and abandoned by their bodies, by their physicians, and by God are reasonable emotional responses to news of poor prognosis (Liamputtong & Suwankhong, 2015). After months of the oncology team being supportive and optimistic, receiving less than positive news can be an emotional blow. Patients may feel betrayed and disillusioned or foolish for being hopeful. This is another time when depression can be an issue (American Cancer Society, 2018a).

The whirlwind of testing, treatment, consultations, and decisions to be made can leave patients incapable of fully absorbing their emotional reactions to the experience (Mapes, 2015). At the start of the journey, patients often find themselves in problem-solving mode, leaving little room for introspection and insight into emotions (Mapes, 2015). Once this period has passed, survivors can be surprised by the challenge of the emotional struggles that follow. They may now have more time to pay attention to feelings of anger, depression, or anxiety. They may be angry at their bodies for causing them such emotional pain. What patients’ bodies are capable of throughout a cancer experience and during treatments is amazing. However, emotional healing and coping with feelings of being betrayed by a person’s body can be hard to overcome (Mapes, 2015). Coping with emotional healing can be more overwhelming than coping with physical healing.

Survivors can experience negative feelings even if they receive positive news (Steger, 2012). Patients and survivors can experience multiple losses along the way and grieve many different facets of the experience (Steger, 2012). No matter how positively patients responded to treatments or how stable their physical condition, they are no longer the same. There can be a loss of physical functioning or changes to body image as well as the loss of feeling they were invincible (Steger, 2012). Others may feel a lack of security or certainty in life (Steger, 2012). Survivors can find it difficult to go forward without a constant reminder of the experience and the fact that negative things can happen at any time and without warning.

The fear of recurrence can be another effect of a cancer diagnosis (Rasmussen, 2012). Having lived through a traumatic, challenging, and unexpected experience can linger in the minds of survivors as something that could easily happen again. They did not expect to live through cancer, and yet it happened. A repeat diagnosis could happen again. A previously naïve sense of security in an individual's health and quality of life has been shaken. Thyroid cancer survivors, in particular, must frequently be monitored and tested, which can trigger fears of recurrence or feelings of reliving the initial diagnosis experience (Firmin, Pathammavong, Johnson, & Trudel, 2014). Revisiting where one was first diagnosed or going through similar testing can cause lingering fears of recurrence (Katz, 2011). Worrying about appointments can cause loss of sleep and intrusive thoughts (Katz, 2011). Survivors' lives have changed emotionally, along with their previous sense of security.

Cancer changes lives in many ways. Survivors may want life to return to what it was before they were diagnosed, but this is unrealistic. Life going forward is a new normal. How life is now different can vary depending on the diagnosis and treatment, but one commonality is that survivors' lives have been changed (Riter, 2016). Riter (2016) gave the following examples of what the new normal may mean for various patients:

> A man treated for oral cancer can no longer taste many foods. A woman treated for breast cancer whose arm is permanently swollen. A man treated for colorectal cancer needs to use the bathroom frequently because of the surgery on his gastrointestinal tract. In these situations, the cancers were cured, but their lives were changed. (para.1)

Cancer can also result in positive changes. Survivors may have an improved outlook on life or an improved focus on self-care. Emotional, psychosocial, and spiritual changes for the better are referred to as *posttraumatic growth* (Hewitt & Holland, 2004). Posttraumatic growth can be present regardless of prognosis. Survivors may feel a greater sense of meaning and acceptance in life (Scheffold et al., 2014). They may have taken stock of their lives, their accomplishments, and the goals they have not yet reached. They can feel a sense of being healed, physically or spiritually, as if they have been given a second chance at life (Scheffold et al., 2014). A greater appreciation for life and loved ones may surface. Some survivors may be newly motivated toward healthy living and have a renewed focus on the health of their relationships (Scheffold et al., 2014). The new normal can involve not only negative changes as a result of having cancer but also positive shifts in lifestyle.

Thyroid Cancer

Thyroid cancer is diagnosed when cancerous cells are found in the thyroid or parathyroid glands (American Thyroid Association, 2018b). The thyroid lies across the front of the vocal cords (American Thyroid Association, 2018b). Parathyroid glands are smaller glands behind and on either side of the primary thyroid gland (American Thyroid Association, 2018b). A tumor in the thyroid or the parathyroid glands will negatively impact their functioning and cause impairments.

Although new tests and treatments are available for thyroid cancer patients, and medical advances have improved survival rates for these patients, people do still die from thyroid cancer (American Thyroid Association, 2018b). The likelihood of dying from the disease depends on its type and stage. Until diagnosis and prognosis are made, the fear of dying can be prominent. Even if patients are not at immediate risk of dying, surviving thyroid cancer comes with other issues. Survivors will experience the lifelong impact of treatment and will be burdened with lifelong testing (Almendrala, 2015). Thyroid cancer survivors frequently report fairly severe psychological problems, memory loss, and migraines as results of their treatment, and these problems can last their entire life (Giusti et al., 2011). Significant recurrence potential is also an issue as this cancer can occur in 10% to 30% of survivors 10 to 20 years later (Almendrala, 2015). Becoming a thyroid cancer survivor is a great success, but it comes with an impact that never fully goes away.

Thyroid Cancer Statistics

Approximately 1.2% of men and women will be diagnosed with thyroid cancer in their lifetime (National Cancer Institute, 2018). Thyroid cancer detection and diagnosis have increased in the United States and other countries. The National Cancer Institute (2018) reported new thyroid cancer cases in the United States at 14.5 per 100,000 men and women per year, with deaths increasing by about 0.5 per 100,000 per year. The American Cancer Society (2018g) estimated 53,990 new cases of thyroid cancer in 2018. In 2013, 630,000 people were living with thyroid cancer in the United States, accounting for the highest increase over time among all cancer types (American Thyroid Association, 2018b). This increase is believed to reflect increases in the number of cases as well as improved tools for testing and detection (American Cancer Society, 2018d).

Anyone can get thyroid cancer, and its causes vary. Patients come from a variety of backgrounds, can be male or female, and vary in age. There are different types and stages of thyroid cancer. The most common diagnosis type is PTC, which has the best prognosis (American Thyroid Association, 2018b). Other types are FTC, MTC and ATC (American Thyroid Association, 2018b). PTC refers to a diagnosis of thyroid cancer through a mass found in the neck and tends to be associated with radiation exposure (American Cancer Society, 2018g). There often are no symptoms other than the presence of a nodule, making detection difficult (American Cancer Society, 2018g). PTC can spread to the head, neck, and lymph nodes but rarely spreads to other areas (American Cancer Society, 2018g).

FTC tends to occur in older individuals, more often in women, and is a more aggressive form than PTC (American Cancer Society, 2018g). It can also spread to the vascular system (American Cancer Society, 2018g). Spread of cancerous cells to distant areas of the body is uncommon but happens more often with FTC than PTC (American Cancer Society, 2018g). PTC and FTC both develop at the thyroid hormone production centers. MTC, discussed next, develops at a different cell location that does not control the same functions as the thyroid hormones do (American Cancer Society, 2018g).

MTC is the third type of thyroid cancer. This cancer is found in C cells located within the thyroid (American Cancer Society, 2018g). MTC has a poorer prognosis than the other two types, is rarer, and does not respond to radioactive iodine treatment (American Cancer Society, 2018g). MTC is said to occur more frequently in females than males and can have a familial cause or be sporadic (American Cancer Society, 2018g). Testing is done to determine the cause. Removing the thyroid is part of the treatment for this type (American Cancer Society, 2018g).

ATC is the fourth type of thyroid cancer and is the most aggressive of the four. The typical survival rate is about 1 year from time of diagnosis (American Cancer Society, 2018g). It is also the least common thyroid cancer type and, in contrast to MTC, occurs more often in men than women (MedlinePlus, 2018). A link may exist between ATC and radiation exposure, just as with PTC (MedlinePlus, 2018). Metastasis to the neck has typically occurred by the time ATC is diagnosed (MedlinePlus, 2018). Treatment options include full or partial thyroidectomy, tracheotomy, radiation, chemotherapy, and clinical trials (MedlinePlus, 2018).

Anaplastic Thyroid Cancer

ATC is a rare and aggressive form of thyroid cancer. These tumors can double in size in just 1 week (Molinaro et al., 2017). Although ATC accounts for a small percentage of thyroid cancer diagnoses, it causes most thyroid cancer deaths (American Cancer Society, 2018g). ATC is an undifferentiated type of thyroid cancer, meaning the cells do not look like normally functioning thyroid cells and are more malignant than differentiated cells (American Thyroid Association, 2018c). ATC can develop from previously diagnosed PTC or FTC (American Cancer Society, 2018g).

Patients diagnosed with ATC tend to be 60 years of age or older, and the average survival rate is only 6 months (American Thyroid Association, 2018c). One in 5 patients diagnosed with ATC will survive for 12 to 14 months after diagnosis, but there are long-term survivors as well (American Thyroid Association, 2018c). In 2015, a study by Glaser noted a median survival rate of 3-5 months for patients of ATC, which demonstrates improvement in survival over the years.

While it is true that differentiated thyroid cancer rates continue to rise, ATC is markedly decreasing, possibly because of improved testing, early diagnosis, and increasing ultrasonography use (Molinaro et al., 2017). In the study by Glaser et al. (2015), it was noted however, that although ATC is said to account for on 1%-2% of all types of thyroid cancer diagnoses, it accounts for half of the deaths resulting from thyroid cancer. Because this disease is so rare and aggressive, true incidence rates are not known, but its rates are said to be higher in Europe than the United States (Molinaro et al., 2017). Also due to the rarity of an ATC diagnosis, candidates for long-term research are few, and there are no specific therapies for curing it or prolonging survival (Molinaro et al., 2017).

Diagnosis and treatment. All ATC incidents are considered Stage IV due to this disease's aggressive and lethal nature; however, there are three categories in this stage: IVA, IVB, and IVC (Molinaro et al., 2017). There are no metastases or lymph node involvement in Stage IVA. In Stage IVB, the cancer cells have spread beyond the thyroid, and Stage IVC is when the disease has reached distant metastases. This stage is the most serious (Molinaro et al., 2017). A multimodal treatment approach is employed for individuals diagnosed with Stage IVA or IVB. Only palliative care is recommended for Stage IVC (Molinaro et al., 2017).

ATC diagnosis and treatment can be complicated. Patients with this diagnosis can present very differently as the pathology can vary between individuals (American Thyroid Association, 2018c). Tumors can be of different sizes and presentations and can contain spindled, epithelioid, and pleomorphic giant cells (Molinaro et al., 2017). The variations between patients and between cell types can make diagnosis and staging difficult.

How the undifferentiated cells look and behave makes treatment more difficult as well. In other thyroid cancer types, treatments work because the cells function like normal thyroid cells. With ATC, normal cell functions such as iodine uptake and thyroglobulin synthesis are absent (Molinaro et al., 2017). As a result, several treatment approaches are used to reduce tumor size and prolong survival (Molinaro et al., 2017).

The combination of surgery, external beam radiation, and chemotherapy maximizes patient outcomes (American Thyroid Association, 2018c).

If the tumor is amenable to resection surgery, prognosis can be better. Complete removal is sometimes not possible; therefore, debulking, or removing as much of the tumor as possible, is done (Molinaro et al., 2017). Debulking relieves airway pressure and allows for greater quality of life and longer survival (Molinaro et al., 2017). This is important as suffocation causes most ATC deaths (Molinaro et al., 2017). However, surgery is sometimes not possible due to tumor size or location. In these cases, various therapies are combined (American Thyroid Association, 2018b).

Chemotherapy, combined with other treatments, has been effective with ATC (American Thyroid Association, 2018c). Combinations of several chemotherapy drugs are common. Combinations of taxanes, anthracyclines, and platins are most effective (Molinaro et al., 2017). Doxorubicin has been most useful, although more successful when combined with one of the other drug types than when used alone (Molinaro et al., 2017). Treatment often involves radiation and chemotherapy, which seemingly delivers the best outcomes despite lethality of the disease (Molinaro et al., 2017). Until new treatments are discovered, combining these therapies is the best route to survival.

New treatments are continually sought and explored. Using tyrosine kinases is one such development (Molinaro et al., 2017). Tyrosine kinases are enzymes believed to play a role in cancer cell development and growth (Paul & Mukhopadhyay, 2004). It is thought that tyrosine kinase inhibitors can stop or slow cancer cell growth (Paul & Mukhopadhyay, 2004). A number of these inhibitors are being used to treat ATC:

everolimus, sunitinib, axitinib, levatinib, and sorafenib are just a few (Molinaro et al., 2017). New molecules used to attack ATC include combretastatin A4 phosphate and efatutazone (Molinaro et al., 2017). Possible future agents include cetuximab, bortezomib, and cerdiranib (Molinaro et al., 2017). Immunotherapy is also an emerging treatment for cancer in general and specifically for ATC (Molinaro et al., 2017). Many treatment approaches are being researched, and with how rapid the progression of ATC can be, it is imperative that new treatments be developed (Molinaro et al., 2017).

Just as with differentiated thyroid cancer or any cancer diagnosis, ATC diagnosis and treatment comes with many symptoms that can negatively impact quality of life. Common symptoms are hoarseness, cervical pain, difficulty swallowing, shortness of breath, and wheezing (Molinaro et al., 2017). ATC surgery results in some pain and healing time, which impact day-to-day functioning and impair patients' abilities to go about their usual activities for some time. Radiotherapy and chemotherapy can result in lethargy, appetite loss, and nausea. Palliative care such as pain medications, using a feeding tube, and tracheostomy can help manage these side effects and others (American Thyroid Association, 2018c). All treatment approaches take their toll on patients and their coping abilities regardless of disease stage.

Impact on quality of life. ATC and the resultant hyperthyroidism and hypothyroidism can affect patients' emotions in many ways (American Cancer Society, 2018g). Under the best circumstances, a cancer diagnosis can be traumatic and devastating. Hewitt and Holland (2004) estimated that one third to one half of individuals diagnosed with any type of cancer experience significant levels of distress. With thyroid cancer, surgery, scans, radiotherapy, routine blood work, and chemotherapies can all impact patients' emotions (American Thyroid Association, 2018a). Impaired thyroid function and frequent hormone imbalances further complicate patients' experiences.

Hypothyroidism is typical at various treatment stages and can result in irritability, depression, anxiety, mood swings, poor focus, and sleep problems (American Cancer Society, 2018h). These effects, combined with the physical symptoms, can significantly impact quality of life (Hewitt & Holland, 2004). Patients can feel isolated and alone. The fact that thyroid cancer can happen at younger ages then other cancers and that many people do not know much about this type of cancer can intensify the isolation and loneliness (Taylor, 2013). ATC patients may struggle to find information about their diagnoses and to connect with other patients they can learn from.

For some patients, diagnostic testing can be long and arduous, and tests like ultrasounds and biopsies may not provide conclusive results (American Thyroid Association, 2018c). Surgery and gland dissection are necessary for confirming diagnoses in these patients (American Thyroid Association, 2018c). Even after final diagnosis confirmation, relief cannot be experienced as treatment then begins.

ATC treatment can be very taxing. It may require one or many surgeries and a full or partial thyroidectomy, which involves opening up the neck and removing part or all of the thyroid gland (National Cancer Institute, 2018). Thyroidectomy can destroy vocal cords and result in hoarseness or permanent speech problems (American Thyroid Association, 2018b). Following surgery, questions arise about what to expect physically. A fear of stitches opening can make patients very cautious about head and neck movements (National Cancer Institute, 2018). Anxiety can increase at this stage as the next steps involve final diagnosis and the beginning of even more unfamiliar treatments (National Cancer Institute, 2018). Patients often fear what will come next and how difficult treatment might be at a time when they may already feel pushed to their limits (National Cancer Institute, 2018).

Life while undergoing radiotherapy, chemotherapy, or both can be a struggle. Patients can have problems with pain, focus, sleep, lethargy, hoarseness, difficulty swallowing or breathing, lack of appetite, and nausea (Molinaro et al., 2017). Treatment is aggressive because ATC is aggressive, and its impact on quality of life is fierce and unavoidable.

Sleep is an important human need and essential for healing. Sleep amount and quality can affect focus, energy, weight gain, pain, stress, anxiety, depression, and coping ability (Sharma et al., 2012). Sleep problems even without a cancer diagnosis are common, but a thyroid cancer diagnosis and treatment can exacerbate these problems. There seems to be a circular relationship between cancer diagnosis and sleep problems, at times making it difficult to which came first (Sharma et al., 2012). Sleep problems may have come first and can worsen with the illness’s effects. These problems can intensify all of cancer’s physical and emotional effects and further affect coping abilities. Sleep problems related to thyroid cancer and unstable hormone levels can continue even after treatment. Sharma et al. (2012) found that sleep problems can linger long after treatment ends and be long-term issues for survivors.

Factors Impacting Coping With Thyroid Cancer

Gender and Social Norms

Thyroid cancer can equally affect men and women, with the illness course being the same for men and women (American Thyroid Association, 2018b). Treatment options and course are also the same for both (American Thyroid Association, 2018b). Diagnosis rates tend to be higher in women while men tend to be at greater risk for recurrence (National Cancer Institute, 2018). Although gender does not impact the course of thyroid cancer, coping can be affected by accepted gender roles and social norms.

Societal norms for acceptable male behaviors can impact men's ability to cope with thyroid cancer. How men are socialized in the United States tends to negatively affect how they cope with physical and emotional difficulties (Hoyt, Stanton, & Irwin, 2013). Men are expected to cope independently, to present themselves as strong or unaffected, and to avoid appearing vulnerable (Hoyt et al., 2013). Gender expectations of men often result in their suppressing emotions, especially those thought to be unmanly or that make them appear insecure (Hoyt et al., 2013). Societal expectations for men can disconnect them from their emotions and keep them from getting the help they need (Hoyt et al., 2013). As Hoyt (2009) wrote, "Chronic illness, particularly illness that arouses feelings of helplessness and powerlessness, may be especially likely to evoke gender role conflict in men" (p. 982). This conflict can interfere with men processing their experiences effectively and their actively seeking treatment and support (Hoyt et al., 2013). As a result, men may feel ashamed about their feelings and struggle with coping.

Feeling weak or vulnerable and expressing feelings of fear or depression are typically more accepted among women, and women tend to share emotional experiences with friends and family more readily than men (Hoyt et al., 2013). Women’s abilities to safely express emotions and difficulties affords them more opportunities to seek information and help from others and to do so more easily. Women tend to lean on others more readily and look for connection and support when dealing with difficulties more than men (Hoyt et al., 2013).

Not only are men not expected to express vulnerability, they are also not expected to reach out for help. It is still considered less than masculine to reach out for help (Hoyt et al., 2013). Because men typically avoid connecting with others, they are less likely to seek help or psychological treatment and avoid attending support groups (Hoyt et al., 2013). These differences are a significant disadvantage for men when struggling with cancer and its many emotional and physical impacts.

Perceptions

Individual perceptions of situations and challenges impact emotional reactions and states and can affect coping abilities (Hoyt et al., 2013). Individuals who perceive cancer treatments as uncomfortable or their diagnosis as unfair may have more negative outlooks and can influence coping abilities in various ways. From a cognitive behavioral perspective, maintaining irrational cognitions about a situation can result in more intense or frequent negative emotions such as anger, depression, and anxiety (Sucala et al., 2013). Cognitions and emotions are closely related, and therefore there is also a relationship between emotional and physical experiences (Sucala et al., 2013). Binashi, Castelli, Varetto, Leombruni, and Torta (2013) stated that if patients are detached from their emotions, they may struggle to differentiate between physical and somatic symptoms as a result of emotional arousal. Individuals coping with cancer benefit from being in touch with their emotions, their bodies, and their physical and emotional needs. The more in tune they are with their bodies and their emotions, the better they are able to cope (Binashi et al., 2013).

Emotional Expression and Coping Style

People with negative or worrisome coping styles will carry these styles into threatening situations like a cancer diagnosis. This coping style can increase depression and anxiety and decrease a person's sense of control over the situation (Folkman, 2008). They may feel overwhelmed and trapped. They also may feel like they are victims. Positive and problem-solving coping styles allow patients seek the positives and actively participate in their treatment (Folkman, 2008). More positive outlooks result in better motivation and engagement in the process and positively impacts treatment and healing (Folkman, 2008).

Life meaning also can affect coping abilities (Anagnostopoulos, Slater, & Fitzsimmons, 2010). People who feel a sense of meaning and connectedness in their lives often have lower depression and anxiety levels. Having a sense of life's meaning can help people view a cancer diagnosis as also having some meaning, even if that meaning is not understood.

Feelings of depression and despair develop more easily when people lack a sense of meaning in their lives. When life events seem meaningless and random, cancer patients may feel they are victims to random luck or some unfairness in the world. On the other hand,

> A patient who feels that life has purpose and coherence may actively engage in cognitive restructuring, to find positive meaning in and see the side benefits of the adverse circumstances, construct a better match between expectations and what is realistically possible and redefine or reevaluate the stressful situation. (Anagnostopoulos et al., 2010, p. 145)

Formal and Informal Supports

Formal supports are necessary to keep patients informed about their disease and at ease with their treatment (Morley & Goldfarb, 2015). Formal supports can include physicians, nurses, social workers, psychiatrists, technicians, therapists, and support groups (Anagnostopoulos et al., 2010). Physicians are patients' first lines of contact, and how they interact with patients is crucial (Lanceley & Clark, 2013). Patients look to their providers as having answers and possible solutions. As Lanceley and Clark (2013) stated, "The onset of cancer is a psychic trauma evoking hidden fears and conflicts and causing anxiety; rational thinking becomes distorted, giving rise to apprehension about threats to bodily integrity, isolation and loss, and the possibility of death" (p. 183). Patients look to their providers to help them through their illnesses and the anxiety and traumatic emotions that accompany them. Their guidance will dictate the treatment process. Patients can feel more at ease if they trust their physicians (Morley & Goldfarb, 2015).

Nurses play an integral role in cancer patient care (Chan, Wong, Ching, & Winsom, 2016). They often spend more time with patients then physicians do, and patients tend feel more relaxed around nurses. Feeling more at ease can help patients feel more comfortable asking questions that they may have not thought of or were afraid to ask their physicians (Chan et al., 2016). Positive communication and familiarity with cancer and treatment plans are essential for nurses working with cancer patients (Chan et al., 2016). Nurses who are not well-trained could miss signs that patients need help or are trying to express their feelings indirectly.

Cancer diagnosis and treatment almost always cause psychological distress. Patients are trying to determine how they can retain meaning in their lives when every aspect is threatened (Anagnostopoulos et al., 2010). Psychological treatment can support healing and recovery but is not typically a focus in cancer treatment. Some people may prefer individual counseling in which attention is focused on their specific emotional needs and on integrating thoughts and feelings (Merckaert et al., 2010). Others may prefer group settings that offer a sense of belonging and camaraderie with peers going through similar experiences (Batenburg, 2014).

Psychosocial and psychological interventions for patients can have many benefits, including improved quality of life (Matthews, Glackin, Hughes, & Rogers, 2014). Patients benefit from being able to discuss their experiences in full. Openly discussing fears, worries, and uncertainties can help patients better process what is happening to them (Merckaert et al., 2010). For this reason, medical providers should consider incorporating psychological and social resource recommendations in their treatment plans (Merckaert et al., 2010). Patients with these types of support tend to feel a greater sense of control over their situations and feel better informed about treatment decisions (Merckaert et al., 2010). Family and friends can also feel a sense of relief and avoid overwhelming patients with excessive emotional support as they are not the only source of support (Deno et al., 2012).

Informal supports also play an important role in helping patients through difficult experiences. An informal support system can include a spouse or partner, family members, friends, coworkers, neighbors, and any others who lend emotional and relational support (Deno et al., 2012). Close family members and spouses can be included as integral parts of the treatment process and kept abreast of any pertinent information or changes that will help them supported their loved ones (Morley & Goldfarb, 2015). Offering group sessions or informational discussions to guide loved ones' efforts (Morley & Goldfarb, 2015). At a time when patients are compromised, those closest to them can be their best supports.

Spouses can be a patients' greatest ally in the diagnosis and treatment process as they typically know the patients better than anyone else does. Spouses play a unique role for patients as they are present day in and day out (Robbins, Lopez, Weihs, & Mehl, 2014). One might think this role would solely be related to emotional support. However, spouses often provide informational support as well (Robbins et al., 2014). Spouses may have more energy to research information and may more effectively absorb important information. Patients may be overwhelmed, unable to ask questions or write down information. Spouses or partners can be their voices and memories (Robbins et al., 2014).

Friends and other family members may not play the same role as significant others as they may process the emotions of the situation differently (Zebrack et al., 2014). Patients may sometimes feel as though their friends do not fully understand what they are going through and may not want to burden their friends with their experiences (Zebrack et al., 2014). However, when friends maintain open and honest lines of communication with patients, these relationships can be supportive and comforting (Morley & Goldfarb, 2015).

Online Support

The Internet is another important patient support. Online support can range from surfing search engines for cancer-related information to interacting with others via online support groups, chat rooms, and blogs (Yli-Uotila et al., 2013). Sites such as Facebook give users 24/7 access, easy ways to communicate with others, and a feeling of empowerment through their use (Woerner, 2015). People with transportation issues can search for information and connect with others from the comfort of their own homes (Yli-Uotila et al., 2013). The symptoms and impacts of a life-altering diagnosis can prevent regular face-to-face group participation (Harkin et al., 2016). The online environment makes access to social connection and information more convenient.

Providing a uniquely safe environment is another positive aspect of online groups. Patients can feel a sense of anonymity over the Internet and disclose only what they choose (Yli-Uotila et al., 2013). The online environment can also provide the opportunity to share an individual’s true self (Tosun, 2012). Topics that individuals might hesitate to address in face-to-face groups for fear of rejection or criticism might be more easily shared online (Tosun, 2012). Communicating in online support groups can help people who find social interactions difficult feel more open to self-disclosure (Ellison, Steinfield, & Lampe, 2007). Being able to openly share a personal situation with others experiencing a similar situation can be a connecting and empowering experience.

For ATC patients, the Internet facilitates connections with others that might not have been available before, often due to distance or because of how rare an ATC diagnosis can be (American Thyroid Association, 2018c). Connections can be made with other cancer patients across the United States and around the world (Woerner, 2015). Yli-Uotila et al. (2013) noted that online emotional support is sought as frequently as informational support, indicating the need for peer and emotional support. The increased ability to directly connect with peers addresses the social isolation common among cancer survivors (Harkin et al., 2016).

Not only can cancer patients feel connected to others and gain more information about their situations, online participation can be a platform for processing thoughts and feelings by writing them out, which can help to add organization and structure to traumatic experience and help patients reframe their experiences by gaining new insights from others (Shim et al., 2011). Writing out one’s experiences and discussing them with others can also reduce negative emotions related to the diagnosis and help to process thoughts and feelings (Shim et al., 2011). Of the many ways the Internet can be useful to patient and survivors, participating in online groups can improve their disease knowledge and management and improve their self-confidence, emotional support, and overall quality of life (Magnezi, Bergman, & Grosberg, 2014)

Although the Internet can provide easy access to many positive support resources, some cautions regarding its use should also be considered. Ensuring that the information found online is relevant and valid is important (Kim et al., 2013). Material posted on the Internet can be fake, and information sources must be considered (Kim et al., 2013).

Patient coping styles are another consideration. Cautious and highly anxious patients could see information about others' experiences as more anxiety provoking than calming (Cohen, 2011). A cancer diagnosis tends to result in a wealth of emotional reactions. Fear and distress are shared with some frequency in online environments (Harken et al., 2016). Reading about potentially negative experiences or worst-case scenarios can be difficult for some (Liu & Yu, 2013).

Coping styles of other Internet users whom one might connect with are another consideration. Differences in outlook or coping approaches should be considered when receiving input from others. Zhao et al. (2015) studied the use of online communities for cancer survivors and the beneficial roles participants play for each other. Portier et al. (2013) noted how obtaining and giving support can be beneficial experiences for cancer survivors. Despite these cautions, the Internet can be a positive source of support for patients and survivors.

Summary

Cancer is the focus of significant research. This is a disease can be deadly, inflict significant pain, and cause life changes. Many different types of cancer are studied, with a large focus on lung, prostate, and breast cancers. Some of the less deadly or rarer cancers, such as thyroid cancer, receive less research attention. More specifically, little if any research has been conducted on the experience of a new normal as an ATC patient or survivor and using online groups for support. In Chapter 2, I addressed these gaps in the knowledge and discussed what is known about adjusting to a new normal as an ATC patient or survivor and the types of support these patients and survivors find through participating in online support groups.

In Chapter 3, I discuss the research methods and design used in this study. I detail the study methodology, the reasons for the specific methodological choice, sample selection and recruitment, and data gathering and analysis procedures. I also discuss my role as the researcher and the ethical considerations and procedures that governed this study.

Chapter 3: Research Method

Introduction

This study was an exploration of the types of support that ATC patients and survivors receive through participating in Facebook's ACT support group. To determine these types of support, I gathered online interactions in the identified support group during a specific 3-month period. In this chapter, I present the methodology used for this study. I begin with a discussion of the research design and rationale. I also discuss my role as researcher, the study methodology and instrumentation, data collection and analysis, and issues of trustworthiness. I conclude with a section on ethical considerations and a chapter summary.

Research Design and Rationale

I chose a generic qualitative research approach as the methodology for this study. Qualitative research is used to understand a human experience and the meaning individuals give to that experience in their lives (Merriam & Tisdell, 2016). A generic qualitative research approach allowed me to learn about the participants' experiences and present information from their perspectives. Merriam and Tisdell (2016) described qualitative research as way of learning about experiences, meanings, and descriptions rather than statistics and numbers. This approach focuses on human interaction in a way that incorporates subjectivity and personal values as part of the human experience (Auerbach & Silverstein, 2003).

Gaining a deeper understanding of a particular event or experience is the purpose of qualitative inquiry. More importantly, when using this method, researchers seek to understand the meaning that participants assign to their own experiences and how they make sense of their worlds (Merriam & Tisdell, 2016). How people are in everyday life and the meaning behind the data gathered are the focus for qualitative researchers (S. J. Taylor, Bogden, & DeVault, 2016). Silverman (2016) referred to qualitative research as a way of understanding how the words connect to the world beyond the actual text, specifying that the meanings beyond the words are key.

Lune and Berg (2017) noted that qualitative research is the study of the meanings, concepts, characteristics, symbols, and descriptions of things. Qualitative research is inductive in nature, and the end product is a rich description of an event or experience (Lune & Berg, 2017; Merriam & Tisdell, 2016). Qualitative researchers use observations and intuitive understandings obtained in the field to help develop theories about study results (Merriam & Tisdell, 2016). In so doing, a description of an experience is developed from the details and themes that emerge from the participants' accounts of their own experiences. Working from the details toward more general themes, researchers come to an understanding and a description of the experience as a whole (Merriam & Tisdell, 2016).

Results from qualitative studies are typically presented with words or pictures rather than numbers and statistics (Merriam & Tisdell, 2016). The results are presented in descriptive writing that helps to express the lived experience studied, and quotes from documents or interviews may be used to support the findings (Merriam & Tisdell, 2016).

This type of research paints a picture or details a thorough understanding of people's experiences because the goal is a descriptive understanding of people's experiences (Merriam & Tisdell, 2016). This is in contrast to quantitative analysis, which requires obtaining numerical data from which conclusions can be drawn through statistical analysis (Groeneveld, Tummers, Bronkhorst, Ashikali, & Van Thiel, 2015). Analysis in a basic qualitative study involves identifying themes that emerge from the data (Merriam & Tisdell, 2016). Data obtained from each participant, which can come from observations, document review, or interviews, are documented, read, and reread to identify similarities between participants, and these similarities form the basis for the emergent themes, which then become the categories used to describe the findings (Merriam & Tisdell, 2016). The themes and categories are the results (Merriam & Tisdell, 2016). Qualitative researchers develop concepts and understandings from the patterns in the data rather than using data to calculate, prove, or disprove hypotheses (S. J. Taylor et al., 2016). This analysis is an ongoing process that continues until no further themes or findings arise (Merriam & Tisdell, 2016). Only when no more similarities or themes seem to present in the data and those that have been identified seem to repeat again and again can the researcher be confident that analysis is complete (Merriam & Tisdell, 2016). The final product is "the overall interpretation or the researcher's understanding of the phenomenon of interest" (Merriam & Tisdell, 2016, p. 25).

To summarize, the goals of qualitative research are to identify how people make sense of their situations, to identify the meaning they attach to their lives, and to interpret these meanings. The essence of a thing is sought in qualitative research (Lune & Berg, 2017). These methodological goals aligned with the goals of this study, which is why I chose a basic qualitative design to explore the identified research questions.

Role of the Researcher

Because I used archival data in this study, I did not take the role of observer, participant, or observer participant. Researchers are the primary instrument for data collection and analysis in qualitative research (Auerbach & Silverstein, 2003). This was my role as well in this study. Subjectivity is not only inevitable but also valuable in qualitative research (Karagiozis, 2018). In much of qualitative inquiry, researchers and participants both contribute to the purpose and the outcomes of the study (Pozzebon, 2018). When conducting research, the researcher's own values come into play because they impact analysis and interpretation as well as transform the outcomes (Pozzebon, 2018). Researchers and participants both impact the research at all points along the way.

Many branches of science have challenged seeing the researcher as a valid part of the study and consider the researcher's involvement in a study as a barrier to valid outcomes (Finefter-Rosenbluh, 2017). In qualitative research, even though there may be limitations to the researcher being the primary instrument, the benefits outweigh the limitations. The limitations are monitored and kept in mind throughout the study rather than assumed to have a detrimental impact on study results (Finefter-Rosenbluh, 2017). Qualitative researchers are encouraged to specifically address their presence in the study and their role as the researcher (Finefter-Rosenbluh, 2017). Researchers need to remain aware of cultural impacts and personal values and avoid projecting theirs onto the study participants (Karagiozis, 2018). Continual self-monitoring of biases, beliefs, and experiences is necessary for maintaining balance between researchers' personal goals and study goals (Finefter-Rosenbluh, 2017).

Finefter-Rosenbluh (2017) discussed the differences between being a researcher as a study outsider versus as a study insider. As outsiders, researchers may find it difficult to obtain participant trust or resist participation for fear that they will not be able to accurately represent the participants' experiences (Finefter-Rosenbluh, 2017). As insiders, it can be difficult to maintain a neutral point of view without personal experience interfering with data collection and analysis (Finefter-Rosenbluh, 2017). In both cases, the researcher needs to remain aware of their impact on the study process and engage in constant self-evaluation (Finefter-Rosenbluh, 2017).

Researchers need to be clear about how they may shape the study and how their experiences, values, and culture can affect their perspectives (Merriam & Tisdell, 2016). For the purpose of study validity and reliability, researchers need to have a thorough understanding of how personal perspectives and biases can affect interactions with participants, data analysis, and even the study outcomes (Karagiozis, 2018). In qualitative research, researchers are encouraged to write about their own experiences related to the study population (Karagiozis, 2018). Qualitative researchers should openly discuss how their experiences contribute to, impact, and possibly even distort presenting the experiences (Karagiozis, 2018).

My having had thyroid cancer was not necessarily a study limitation and could be considered a benefit in data collection. Auerbach and Silverstein (2003) stated that qualitative research does not discourage incorporating subjectivity but instead requires the researcher to acknowledge their own subjectivity and values as well as reflect on them in a systematic and disciplined way. I have firsthand knowledge of testing, diagnosis, and treatment procedures as a thyroid cancer patient and survivor. I also know that my life as a survivor requires continued adjustment and presents continual challenges. In qualitative research, subjectivity and personal values are seen as beneficial to the research process (Auerbach & Silverstein, 2003). As a survivor, I have a unique perspective to offer through this study.

My motivation for studying thyroid cancer patients and survivors resulted from my 2007 PTC diagnosis, hearing others' experiences with the disease through support groups in which I was a member (these were not used in this study), and through sessions with clients in my private practice who have had thyroid cancer. The combination of an emotional reaction to cancer occurring while the disease impairs the gland that manages such functions as emotions and coping mechanisms was and is of interest to me. Furthermore, focusing on ATC allowed me to learn more about an aspect of thyroid cancer that I did not have firsthand experience with. Another reason for my interest in exploring ATC and the support patients and survivors may need and seek online is due to the aggressive and lethal nature of the disease.

The focus of this study involved exploring the types of support individuals with ATC receive through online support group participation. It was necessary to avoid having my own experience with thyroid cancer cloud my judgment as the researcher. The focus on ATC patients and survivors was a way to avoid this influence because I was not diagnosed with ATC. Additionally, I consulted monthly with another licensed clinical social worker who has a significant history of private practice work but who was not involved with this study to process any of my personal biases that could have become issues during the research process. I kept a detailed and running journal of thoughts and feelings that arose during data collection and analysis process. Another resource that was available to me was a peer supervision group that met once a month. The group consisted of therapists with a variety of experience levels and backgrounds. I spoke with these professionals and used their feedback regarding my research as well.

Methodology

Participant Selection Logic

Conducting a qualitative study of archival data with a thematic content analysis can be a painstaking process. My goals in this study were to document participants' descriptions of their experiences, explore how they experience having ATC, identify how they define their experiences, and report the themes that reflect their perspectives. Documenting the needed information can be time consuming, and, therefore, a small sample size was determined to be optimal for this study. Using one specific online support group allowed for a small sample size; yet, I was able to generate large amounts of data from multiple cases in the one group.

I chose an online support group as the participant sample for several reasons: the significant role that the Internet and Facebook play in people's lives today, the ease of access to information, needing only an administrator's approval for access to the group, and the readily available nature of archival data that this format provides (see Cameron, 2011). The Internet plays a key role in many aspects of people's lives today, including how they manage their health. Yan and Tan (2014) stated that the Internet is changing the way people manage their health and health-related information. Bender, Jimenes-Marroquin, and Jadad (2011) noted the convenience of online groups and the increase in their use for coping with health conditions.

Lunnay, Borlagdan, McNaughton, and Ward (2015) referred to social media as a particularly useful tool for accessing detailed information and interacting with participants, which is necessary in qualitative research. Participants openly share their thoughts, feelings, and experiences with the group via their posts. Facebook was chosen specifically for this study due to its wide use by people of all ages and backgrounds. According to Liu and Yu (2013) and Tosun (2012), Facebook is one of the most visited online social networking sites and is used by people of all genders, races, and ages for connection and support. Support groups on Facebook present an opportunity to access information on support-seeking behaviors through members' posts. Their posts are considered archival data, which offer a unique way to access people's thoughts and feelings about their own experiences.

Facebook is a public online platform (Sugiura, Wiles, & Pope, 2016). Because of the nature of the website, not only are firsthand accounts of experiences accessible for study, there are new challenges and ethical considerations related to this research (Sugiura et al., 2016). Townsend and Wallace (n.d.) discussed the difference between public and private information on the Internet. They noted that users of a given platform have all agreed to the platform's terms and conditions, which also govern how information might be used for research purposes. Facebook is a public social media site where users agree to their information being public when they join. As stated on the website,

> “Facebook Pages and public groups are public spaces. Anyone who can see the Page or group can see your post or comment. Generally, when you post or comment on a Page or to a public group, a story can be published in News Feed as well as other places on or off Facebook” (Facebook Help Center, 2019, para. 5).

Users can manage their own privacy levels and therefore using data from this source requires only the assurance of the users’ identity and anonymity being protected (Townsend & Wallace, n.d.).

Gupta (2017) discussed using the Internet as a research source and described two types of research and analyses using the Internet: nonintrusive or engaged and passive or active. Nonintrusive research is strictly observational does not interrupt naturally occurring interactions in the community. Engaged research involves direct interaction with members (Gupta, 2017). Passive analysis is where there is only observation and participants do not know the researcher’s presence. Active analysis is when the participants are aware of a researcher being present. According to Gupta, the only consideration in using Facebook is whether or not the participants’ identities would be disclosed at any point. Facebook users can choose whether their profiles are public or private, making the research exempt from the need for informed consent.

Because the data in the present study were from Facebook and considered archival, permission to access these data was required from group administrators but not from individual members (Cameron, 2011). It was also not necessary to contact group members for interviews or to complete surveys as the data were already available on the group site. These factors made using online posts and archival data more practical for me as the researcher. Additionally, I ensured that the group members' identities remain anonymous throughout the collection and analysis process. No identifying information related to the group or the members was used and any names that may have been embedded within members' posts were changed to X's during the transfer of data for storage.

Instrumentation

Archival data in the form of posts retrieved from Facebook's ATC support group were collected for this study. As such, I was primary data collection instrument. Being the primary instrument included recording, categorizing, coding, and analyzing these data. No questionnaires or surveys were used, and no interviews were conducted.

Procedures for Recruitment, Participation, and Data Collection

Because archival data were used, the following description is of the steps I took to ensure that these data would be available. I conducted a thorough search of Facebook for public and private groups that target the needs of thyroid cancer patients and survivors. Once I identified potential groups for participation, I contacted the group administrators via Facebook Messenger. When I received a response, I briefly explained the study objectives and how participant confidentiality and identity would be protected. I also requested access to the group and group posts. Upon further interest by an administrator, all aspects of the study such as data collection methods, purpose and goals, data analysis methods, and means of protecting members' privacy and confidentiality were described in detail. If group administrators had any other questions, these were addressed as well.

Once an administrator agreed to my using posts to the group, I provided a letter of cooperation (see Appendix A) outlining the study details and how data would be used. The administrators were asked to sign and return this letter, showing proof of approval to access the group and the group posts. The Facebook group used in this study was chosen because the group administrator followed through with all communications and returned the letter of cooperation. Other groups did not pan out for several reasons. One group contacted did provide written permission for using posts to the group. However, I determined that this group's focus was too broad to be useful for this study. This administrator was thanked for her approval and notified that the group would no longer be considered for the study. One group's administrator gave verbal permission, but the group experienced an administration change. As a result of this change, I was advised that consent could no longer be given.

The signed letter of cooperation from the administrator of the ATC group used for this study will be kept on file electronically, as well as in paper form in my personal office. This document will be destroyed with the other study documents following study completion. The ATC group administrator was also advised that a copy of the study results and discussion would be available after the study was concluded.

As of October 30, 2018, Facebook's ATC support group had 396 members. As stated in the letter of cooperation, I was the primary researcher and the only one who read through posts on the group pages. Posts between August 1, 2018 and November 30, 2018 were gathered for data analysis. The specific date range was chosen to keep the data set a manageable size.

Data Analysis Plan

Thematic content analysis was used to analyze the data collected from the support group. I began data analysis by carefully reading and reviewing members’ posts, with the intent of identifying the types of support they received from posting to the group. I noted where similar ideas emerged. I then grouped the data by these emergent ideas, reread the data in these groups, looked for more specific themes in the data, and categorized the data accordingly.

I anticipated at the start of this study that the different types of support group members receive would be communicated and would emerge from the data. In keeping with categories identified by Cohen (2011), I began with three main categories for the types of support in the present study: social, emotional, and informational. Social support as a category may include statements of companionship and connecting with others in the group (Cohen, 2011). Emotional support could include self-disclosure, empowerment, understanding, and a place to release emotions related to their experiences as patients and survivors (Cohen, 2011). Informational support might be more about gaining medical information, advice, knowledge about available resources, and increased awareness about ATC (Cohen, 2011). Additional categories as well as different examples of these three categories emerged during my own data collection and analysis, as seen later in Chapter 4. Data were stored, managed, and analyzed with the use of the NVivo software.

Issues of Trustworthiness

Researching the human experience allows for contributing personal and professional experience to a study (Karagiozis, 2018). At the same time, researchers need to remain aware of ways to avoid altering the results and ensure trustworthiness. The goal is to obtain knowledge of the participants' experiences and report them in a way that benefits from the researcher's own knowledge but to not allow this knowledge to alter the results in any way.

Minimizing subjective bias is one of the main considerations when conducting qualitative research (Merriam & Tisdell, 2016). As the primary researcher, my job was to collect participants' posts, document them, identify similarities and themes in the statements, create categories based on the emergent themes, and report the collaboration of results, void of my own subjective bias. As previously stated, an ongoing journal, monthly peer supervision, and one-on-one consultation were also used to minimize subjective bias.

Ethical Procedures

In accordance with Walden University's policies, institutional review board (IRB) approval was sought and received prior to commencement of data collection. This Confirmation of Ethical Standards (CES) has an IRB record number of 02-07-19-0032022. The IRB was provided a full description of the study, data collection methods, and analysis methods as well as the plan to protect participants' information throughout the study. As previously stated, group administrators were contacted for approval to access group members' posts prior to the study. A letter of cooperation (see Appendix A) was signed by the administrator for the group that was used in this study. Contact information for Walden University's Research Quality Center and my committee chair were provided to the group administrator to verify this study's validity.

In compliance with Walden University's research, ethics, and compliance policies, participants' identities were protected throughout the study. As the primary and sole researcher, I was the only person related to the study who accessed the group, saw group members' names, and saw the group posts. No personally identifying information or names were used in this study. All digital materials were kept on my password-protected laptop and were subsequently transferred to an external hard drive at the end of this study. This hard drive will be kept in a locked cabinet. Paper documents were kept in a locked file cabinet in my office, which is also locked and secure. At the end of the required 5-year period for maintaining records, all paper documentation, including any confidential information, will be destroyed via document shredding, and digital files will be completely erased from the external hard drive. At study completion, the group administrator was notified of the ability to receive a copy of the results and conclusions. These documents are also void of the participants' personal and confidential information.

Summary

In this chapter, I discussed the design, methodology, the plans followed for data collection and analysis, as well as the potential issues of trustworthiness and the ethical procedures followed. The study was a generic qualitative research design, chosen because the focus of the study was to gain a deep understanding of an experience of ATC from the participants' perspectives. This type of design allows for an exploration of experiences and the meanings which people assign to their experiences. I discussed the thematic content analysis that was used as a process of identifying codes, categories and themes among the data. I also addressed how the use of the site Facebook and the archival data posted on the page impacted the use of the data and the approvals needed. In Chapter 4, I present the results from this investigation.

Chapter 4: Results

Introduction

I used a qualitative approach in this study to learn about the experiences of ATC patients and survivors through their participation in an online support group. As the researcher, my goal was to explore the experience of being diagnosed with ATC, to explore patient and survivor experiences with diagnosis and treatment, and to identify patient and survivor needs. I also wanted to explore the adjustment to a new normal and what the role of participation in the online support group on Facebook is in meeting those needs. I chose a qualitative approach because this method of research seeks to understand phenomena from the perspective of the participants, which was the main focus of the study (see Vaismoradi, Turunen, & Bondas, 2013).

According to Elo et al. (2014), qualitative content analysis refers to the process of describing phenomena from the content found among the data, and thematic analysis is a process of combing through the data collected and the content to identify the categories and the themes that emerge from the data. My study involved thematic content analysis, with the goal being to conduct an in-depth review of group members' posts and comments, finding similarities. The words and phrases that repeated with some frequency became the codes within the data. I then was able to recognize similarities among the codes and grouped these accordingly, creating the main categories of data. Within these categories, I was able to discern some of the subtle homogeneity among the codes in each category. From the categories and smaller subcategories, I began to pinpoint the emergent themes within the data. These themes were the overarching patterns or meanings underlying the identified categories.

In my study, the phenomena of having ATC, the needs of patients and survivors, and a description of the types of support found through group participation were the phenomena to be described. The following two research questions guided the study:

> Research Question 1: How do ATC patients and survivors express their needs in the identified online support group?
>
> Research Question 2: What types of support do ATC patients and survivors receive through participating in the Facebook ATC support group?

Group members' posts and related comments were the focus of data collection and analysis. The process involved the analysis of the data, coding frequently used words and phrases and grouping the codes into categories. From these codes and categories of information, I could interpret the themes that existed amongst the data. The categories were the types of support given and received by group members, and the themes were the underlying meanings. Together, these formed the study results.

In this chapter, I first discuss information about the demographics of the participants. Next, I discuss the means of data collection and recording, including any variations from what I presented in Chapter 3. The process of data analysis is then reviewed as well as points related to evidence of trustworthiness in the results. Finally, I present the results along with a summary of the chapter.

Research Setting

The setting for the research study was a support group on Facebook, which was formed to help those affected by ATC. The group was a closed group; those who wish to join are required to be approved by a group administrator before access to view or create posts or comments is granted. Group administrators approve or deny membership based upon the answers to these three questions: Are you or a loved one being treated for ATC? Where are you being treated? Where are you currently located? The purpose of these questions is to maintain the integrity of the group.

The group is a place where members can post thoughts and feelings, ask questions, share information, and receive information and support from one another. As stated on the group's about page on the site,

> This group is for those who either have ATC, families, and friends of those fighting it, or who have lost a loved one to Anaplastic Thyroid Cancer, a rare thyroid cancer that accounts for less than 1% of all Thyroid Cancers. Because there are so few cases of it, it is difficult to get current, accurate information as to treatment. Please join this group to share information and hope if you or a family

> member or friend are fighting this disease. You will see we have members that span the globe, all with the same hope of finding a cure for ATC.

Group members can gain different types of support from participation. Davis and Calitz (2014) referred to online support groups being a place where members can ask the difficult questions; access unique perspectives or treatment approaches; access experiential information; interact with others who also have a rare diagnosis; and have access to support without the limitations of location, accessibility, or schedule. It is a place for patients and their loved ones to gain and give support as they cope with this aggressive disease.

Through the data collection process, I found that membership consists of patients, survivors, spouses, children, parents, grandchildren, cousins, aunts, uncles, nieces, and nephews of those diagnosed with ATC. Some were in the group to gain information for their own knowledge and decision making, whereas others were there to find out information for their loved one and to assist in decision making, caretaking, and treatment planning. According to research by Harkin et al. (2017), 20%-30% of cancer patients and their spouses noted feeling increased depression or anxiety following diagnosis. Both the patients themselves and their loved ones are affected. Furthermore, the impact on loved ones can affect the level of support they can give (Harkin et al., 2017). It seems likely then that participation in such a group could be helpful for patients and loved ones alike. Based on the data presented, members were present in the group to receive and give support throughout the process of coping with ATC, whether directly or as a support person to their loved one.

Demographics

All members of the group included in for the study were of adult age, as confirmed by the group administrator. Additionally, all members had been impacted by the diagnosis of ATC somehow, either personally or through a loved one's diagnosis. The type of impact is part of the questioning that is required for group membership to be approved. Beyond this, it is essential to note that collecting information from an anonymous social media page limited the amount of demographic information available to me as the researcher.

After the data collection, group membership totaled 427 people. The posts used in my study within the identified date range (i.e., August 1, 2018, through November 31, 2018) consisted of 166 members' contributions. There was a total of 2,384 posts collected and analyzed for the study. The breakdown of race, cultural background, and socioeconomics for group members was unknown and not documented in any way within the group. Group members are men and women with 75% of the group being female and 19% male, which I determined through comparison of names and pictures of member profiles; the other 6% I was unable to identify conclusively one way or the other. Differences may exist in post content and type of support sought after by males versus females; however, this was not specifically explored or defined as a focus in this study.

At the start of the study, I had assumed that the group members would all be ATC patients or survivors; however, as stated earlier, the group is comprised of family members and loved ones of patients and survivors as well. Friends of patients and survivors are also welcome as members, although I did not identify, through the written content of posts, that anyone actively posting within the date range chosen for the study were merely friends of a patient or survivor. I determined that the members who posted within the identified date range were patients, survivors, spouses of, children of, or nieces and nephews of patients.

The family members who were participants in the group tended to be there to gain support for their loved one diagnosed with ATC. These individuals were speaking on behalf of their loved one and obtaining information about the diagnosis and treatment plans. Two samples of these types of family members' posts from the data collected are as follows:

> My mom finished her 10 x radiation sessions about three weeks ago. Starting chemo next week. She is complaining about a stretching/pulling sensation in throat. There is also a bit of swelling on right side of neck. Radiation did shrink tumor in neck by 1cm, and lung metastasis same. But that was scan three weeks ago. Is this feeling natural to have? Is it tissue shrinking, recovering, or growing?

And "My dad sometimes chokes on his own Sputum & has trouble passing it is there anything you guys recommend he do." Everyone in the group had been impacted by the diagnosis of ATC in some way and was looking for some support in coping. Another member posted this:

> I am here because my dad was just diagnosed with ATC. We are doing everything we can to get all the information and resources available to help us on this journey. He is going to be starting radiation and chemo, and my first question to anyone who may be able to help is, how can he prepare nutritionally for this and

during treatment? Do you have any resources you can point me to that can help him stay strong during the treatments?

Group members spanned the globe in terms of where they lived. Some members identified where they were from or where they were seeking treatment within their posts. Locations that I was able to identify through posts were Canada, the Philippines, Australia, the United Kingdom, Oklahoma, Maryland, Los Angeles, Arizona, Texas, Seattle, Virginia, Memphis, New York, and Tennessee. Examples of these posts are as follows:

- "We are currently at UCLA but looking into MD Anderson and their satellite center in San Diego which is closer to us. Anyone been treated at UCLA?"
- "Here in Queensland Australia."
- "Sending prayers from Toronto Canada."
- "Love and prayers from Oklahoma."

The group is open to people all over the globe, and through my data collection, I did see that group members were from many places, including different states and even different countries.

Data Collection

The data collected consisted of group posts and comments occurring within the group setting between the dates of August 1, 2018 and November 31, 2018. The process of collection and recording of posts took me about 4-5 weeks, with sessions occurring every few days for several hours each time. My goal was to record group members' posts and comments exactly as they were written in the group; therefore, I copied and pasted posts and comments in files under the memos tab in the NVivo database, maintaining the exact wording of participants.

First, I copied and pasted group members' posts in date order in the memos section in the NVivo software tool. I then copied and pasted associated replies and comments under the initial person's post. Once I transferred one thread of posts and comments, I would add the post that occurred next chronologically and include the related replies and comments under that post, and so on. The process of transferring posts continued until I had all posts and comments from August 1, 2018, through November 31, 2018 documented in NVivo. The use of NVivo helped with keeping track of the data as well as storing and maintaining it. In any instances where people used names to identify each other, I deleted the names and replaced them with X's to ensure that the participants' identities were protected and individual members were not identifiable.

The recording of the data took considerable time in part because posts on Facebook do not necessarily occur in strict chronological order. There would be sections where posts seemed to flow in order and then there would be a post with related comments that would not fit in date order. For example, there may have been posts dated September 8th, then September 6th, then September 9th, and then August 17th. As I copied and pasted the posts into NVivo, I made sure the transfer of the information occurred in chronological order. I decided that this process would maintain better organization of the information, although this resulted in some back and forth in the process and was more time-consuming.

In terms of maintaining organization among the data recorded, I first pasted the main post in NVivo under a heading of the date when it published on Facebook. I then inserted related comments by other members below the initial post. These additional comments were indented and bulleted to signify that it was a new statement and a comment by another member, rather than a continuation of the initial post. Subsequent comments by different members were separated by double spacing and bullets to organize statements further and differentiate between members.

One aspect of the data I had not expected or discussed in the proposal phase of the study was the use of emojis. During data collection, I copied and pasted these into NVivo along-side the written statements, just as they were used within the text by the authors. There were several times when group members only used emojis. I documented this as written text as well, separated between members by indenting, bullets, and double spacing.

The number of group members who actively posted between the identified dates totaled 166 members. It is unrealistic to assume that all group members would have posted within the date range chosen. There are times when members might be more active than others, based upon their needs and what might be going on in their lives. The posts that were collected and documented however are believed to be a good representative sampling of what generally occurs within the group.

Several studies note the fact that not all group members actively post in online groups. Research by McKenna, Myers, and Newman (2017) and by Bender, Jimenez-Marroquin, and Jadad (2011) note behavior referred to as lurking in online groups, where members only read material posted in the group and do not actively participate in posting themselves. These members' participation is not visible and therefore is not open to analysis. I could assume that these members are receiving informational support through their membership and their ability to read the information posted by other members. I might even consider that they are gaining a sense of comradery in seeing similarities in the posts and their experience. Despite those assumptions, however, there is no way to actually document or analyze what they may be receiving from group membership.

Data Analysis

The process of data analysis with qualitative data can be a time-consuming and tedious one, just as with data collection (Saldana, 2016). Data needs to be read, reviewed, reread, and sorted through for a researcher to identify similarities within the data (Saldana, 2016). My goal as the researcher was to do just this. Following data collection and documentation, I started at the very first post, reading through posts and related comments, analyzing what members might be expressing. At first, I was looking to see if posts appeared to fit into the expected categories of emotional support, social support, and informational support. These three groups were ones identified in previous research studies by Cohen (2011); Yli-uotila et al. (2013); Yan and Tan (2014); and Vlahovic et al. (2014). I came to identify the existence of these three categories, as well as some additional ones.

Social Support

I could identify many posts containing expressions of social support. Some of these took the form of supportive statements such as "be positive," "good luck," "hang in there," and "chin up." There were statements expressing consideration for others, such as: "keep us updated." and "hope all is good." Some comments voiced inquiries of concern such as "just asking," "how are things?", and "any update?". Then there were motivational statements such as "never give up," "you've got this," "you are strong," and "you're a warrior." Messages expressing a wish to maintain some type of socialization were seen as well, such as, "let's car pool" and "let's plan a get-together". And then there was the expression of social gestures, such as "thank you," "such kind words," "wonderful," "inspiring", and "take care".

I identified these words and phrases as codes. From reading and rereading these codes, I began to identify similarities among them, words and phrases being repeated over and over by different members. Through those repeated words and phrases, I identified different groupings of social support, which formed subcategories of supportive statements, socialization, inquisition or concern, motivation, and consideration for others. From there, I identified and confirmed the main category of social support among the data. Table 1 outlines the breakdown of these codes and categories.

Table 1
Types of Support

Category	Code/subcategory	Explanation	Example
Social	Inquiry or concern	Asking about another member's status or experience	"Just asking where your husband was treated."
	Supportive presence	Expressing a positive and supportive presence	"No, but we are here."
	Consideration	Expression of caring	"My heart goes out to you and your family."
	Companionship	Statement made just for maintaining social interaction	"Sign us up lady, we can carpool."
	Connectedness	Demonstrating closeness with a member or members	"that sounds just like me"
	Appreciation	Expression of acknowledgment	"Thank you. I was carried all the way by so many."

Category	Code/subcategory	Explanation	Example
	Motivation	Prompt for other members to remain hopeful or positive	“One day at a time, right? Keep on doing whatever you need to.”
	Encouragement	Statement of praise or a way to boost another member	“That is a lot to take on, you, are a really strong woman.”
	Reassurance	Statement to provide comfort and calming	“You are strong; That is what your brother would want.”
Emotional	Self-disclosure	A member stating an emotion	“So very frustrating”
	Emotional understanding	A member expressing an emotion towards another member	“I am so sorry for your loss”
	Release of emotion	A statement of emotional reaction	“Now I am concerned”
	Emotional description	A member describing an emotion they felt	“the surgery appointment was like a punch in the gut”
	Emotional gesture for empowerment	A member giving a gesture of emotion to another member	“hugs”
Informational	Diagnosis course	Posts containing information about a member’s path to diagnosis	“I was diagnosed when I began having trouble breathing. I was very shocked; I had surgery very quickly because my tumor was pressing in my esophagus. It was wrapped around my vocal cords and compromised my trachea. Thankfully I was at a hospital where a doctor who had experience with Anaplastic was located. I became his patient (Dr Kenneth Ain at the University of Kentucky).”
	Disease and treatment experience	Posts containing information about a member’s experience of the disease and treatment effects	“My Dad was diagnosed with ATC December 2017. He underwent surgery, chemo and radiation at MGH. In May they told us it had metastasized to his lungs, several tumors, and gave him a few months. He decided to go home and trial immunotherapy with no expectations but mere glimpse of hope that maybe it might buy us some more time together as a family. Today he had his 5th round of Opdivo (480mg IV infusion every 4weeks) and a PET scan. The preliminary report showed all but one tumor in his lungs are GONE.”
	Causal factors	Posts regarding member’s thoughts on causal factors or links	“If it isn’t too traumatic to think about it has anyone else have a similar unexplained swelling/inflammation event that you don’t mind sharing? Do you remember any unexplained hospitalization or complaint? Part of me feels like METS seem attracted to areas very prone to usually uneventful inflammation.”
	Recommendations/Advice	Posts with recommendations and advice for other members	“Get to a hospital that specializes in these advanced cancers. Several on here are treated at Kettering. Go there. ASAP.”
	Increased awareness of ATC	Posts with reference to available articles or research information	(link to article posted) https://meyercancer.weill.cornell.edu/news/2017-04-02/cell-therapy-provides-shot-cure-fatal-thyroid-cancer?fbclid=IwAR1ALM9WwSJk4jWOpfSION3PU4jxGcCzBIdcP66kxkXtctEyP57B2JLnKYA Cell therapy provides shot at a cure for fatal thyroid cancer - April 2, 2017
	Survival rates	Posts with the length of survival noted, for those still alive and for those people have lost	“XX (with picture) 1966-2018. My Twin”; and “Do not lose hope. I am a survivor since 2009.”
Empathetic	Comradery	Sharing a common emotion or emotional experience	“My brother was diagnosed in May and just passed away in September. Thanksgiving will be hard for all of us. He was only 59.”
	Connectedness	Some expression or gesture of understanding another member	“I was diagnosed in April 2011 and was told the same thing! Do not give up hope!!!!! I had 33 radiation treatments with chemo! Any questions please ask!!!”
	Expression of empathy	Some expression of empathizing with another member	“This was our exact situation with my mother. We spent months in GI working on GERD. She had every GI test.... we never thought nor did any of the doctors we went to suspected Bad Thyroid cancer...”
	Existential presence	A member simply referring to an existential being or power	“Praise God”
	Giving understanding to an experience	A statement referring to a spiritual meaning behind an experience	“Only God knows when our time is to go”
	Existential focus	A statement by a member of general existential focus	“Let’s all set the intention that all is well”
	Existential request	A member asking for the spiritual support of others	Please pray that I continue to hold my own”
Support through use of emojis	Emotional sentiment	An emoji which expresses some emotion	□
	Support	An emoji that refers to support given to another	□

(table continues)

	Gesture of understanding	An emoji which expresses a feeling of understanding	□
	Gesture with spiritual meaning	An emoji which expresses some spiritual message	□□
	Encouragement	An emoji expressing encouragement	□
Administrative	Adherence	A statement giving reminder about group protocol	"Please make sure friends and family members answer the three questions we ask to allow others to join. Thank you!"
	Notice	A statement giving notice about some event	".... if you want your loved one remembered in our 2018 Memorial Slide show at the Intl ThyCa; Thyroid Cancer Survivors' Association Conference in Chicago in two weeks, please send me a picture and full name."
	Rule explanation	A statement outlining a rule	"If you invite a friend or relative to join this group please ask them to respond to the 3 questions they receive, or they may be declined. Posts in this group are private and only seen by other group members. The admins try our best to screen against potential spammers or fake requests. ……Thank you for helping us keep this a useful, quality group and resource."
	Welcoming others	A statement making new members feel noticed and welcome	"Welcome to the group all new members...I'm sorry you have been given this diagnosis but so glad that you are here."

Emotional Support

Another group of words and phrases I found within a group member's posts, which I came to see as being related to emotional support. First, I started to notice words and phrases which seemed to be emotional in nature. I was able to identify different types of emotional statements and began to identify codes among these, such as these examples:

- "My biggest regret is not taking him as soon as he was diagnosed. I don't think I'll ever forgive myself"
- "I want my sweetheart to be happy once I'm gone. I want her to find peace after all of the worries. I want her to find love! I can only say what I feel. X, my wife, is here with me and we are both teary. At your own pace, do what most sweethearts would want of their loved ones"
- "Sorry to have to tell you, she is no longer with us. I have been too broken hearted to post"

These statements all seemed to note a level of self-disclosure, aside from just being emotional in nature. Here I began to see a group of posts expressing self-disclosure.

Another group of statements or codes seemed to be that of emotional understanding. Examples of these are as follows: “I hate that you know what I am talking about but also glad I am not the only one”; “sorry to hear what you are going through. Lots of love and compassion in this group”; and “So sorry X. I know exactly how he feels. I am feeling much better now though. thinking of you and your brother and family”. There appeared to be a thread of understanding here, rather than just an emotional statement, which became a second subcategory.

Next, I identified some emotional statements such as these: “I just feel so clueless as to how to help her and my dad”; “I am so scared that he does not have that much time”; “we were really shocked”; “Sorry, it is just so good to find this group, I just feel so helpless”; and “I'm so broken that we lost this battle. We tried so very hard. Please do not give up”; “Our dad was so strong, and we were so intent on understanding the diagnosis, defying the prognosis. He did not even get 90 days from diagnosis... it is just unfair and cruel”; and “Life is forever changed...cancer ruins everything”. These words seem to be a release of emotion for the authors. I did not come across any questions or descriptions in connection with the words; there was just a release of emotion which the author was feeling, whether that was hopeless, shocked, or ruined. These were emotional statements, but more specifically, comments that were a raw release of emotion.

Another group of codes seemed to fit in the emotional support category, but more specifically, seemed to give a description of emotion. Some example of these is: “My mind is in lockdown mode, just waiting for death to knock on my door within the year, if not sooner"; "I cry because my husband's cancer was removed entirely well except for one lymph node and yet cancer stole him away. I wish all ATC patients could be lucky. It's so terrifying"; "He told me the other day he did not think he would make it and feels as if he is dying a slow, painful death. I know he must feel awful and the pain is tremendous"; and "I am so sorry for everyone's loss...I shake my head in disbelief every day at the aggressiveness of this cancer". These statements were emotional, but a more descriptive way of sharing how they are feeling.

Lastly, within the category of emotional support, there was a group of posts or statements that seemed to be gestures of empowering others. Examples of this are noted here: "Please cherish every minute of every day you have together"; "I have to believe it can be achieved and I fight every day for it"; "Yes, it is scary, but I am here to say you can do it"; and "On a personal, emotional level -- try to take each day as it comes and focus on living in the moment. Not easy, I know". The statements here are emotional in nature but also seem to be encouraging hope and a sense of empowerment among other members. They have a message to convey.

My process of analysis here was reading the posts and comments and identifying words and phrases that were emotional. Some of the statements simply expressed an emotion, some had an additional characteristic to them, and some had a specific type of emotional purpose to them. These differences I saw became the subcategories among the codes. These subcategories all had the common focus of giving or receiving emotional support, and so the main category here was emotional support.

Informational Support

Sharing information was a focus of many posts within the group site. At the end of the analysis process, I found examples of informational support most frequently. Posts may have been about how a member was diagnosed, survival rates, medical facilities, available treatment options, or specific providers that members had experienced. All of these posts were in the form of detailed information which one member was passing on to the group as a whole or to a specific member. These posts may have been in response to another member asking questions, or just as a result of the author having the information and believing it was important to share with the group.

As I read through these posts, I started to identify some codes. Groups of these codes repeating then formed categories. One such category was that of diagnosis course. Some codes or phrases included in this category are: “My friend didn’t notice a thing. She went in for a routine end of year physical and ... wow”; “My mother had a chronic cough that they thought was either asthma or reflux… she also had chronic goiter w/o nodules. (Hashimoto’s which is mainly autoimmune/inflammation) About one year later she developed ATC”; “how old r u? What were the circumstances behind your ATC diagnosis?”; and

> “Hi, I felt a lump in my throat one day, and everyone thought it was nothing until my Dr. sent me for a cat scan... from there she sent me to the Mayo Clinic in Jacksonville, Fl. They did surgery right away but only could take sections around the thyroid because he said there was too much cancer wrapped around it! So, from there I went through 7 weeks of radiation and Chemo (Taxol and

> Carboplatin) then feeding tube. That was seven years ago??? They said I probably got it from Radiation that I had 20 years before from another cancer that I had Hodgkin's lymphoma".

These statements were specifically related to details about how members were first diagnosed and therefore seemed to form a subgroup of informational support.

The next trend of codes I started to see was that about the disease experience and treatment experience. The phrases I was seeing were like these examples:

- "I'm at stage 4C. I've had my thyroid removed in Jan 2017 and had RAI in March 2017. Then ATC popped up out of nowhere and was diagnosed Oct 2018. It has spread through my lung and to my liver, and I have a tumor and thrombus in my heart. I found out I had this after the large thrombus in my heart sent a blood clot down my right arm. Had emergency surgery to repair that when it was discovered something else was wrong. Turned out to be ATC"
- "I'm only on oral chemo 2 of them, never had radiation"; "Yes seems like every 7 to 8 months the tumors grow in my windpipe, and I'm having trouble breathing I have a track for 2 yrs. now"
- "He's doing ok at the moment thanks, he had six weeks of radiotherapy to treat the anaplastic element in the summer and then two weeks ago he had Radioactive Iodine Therapy to treat the papillary and to ablate the remaining part of the thyroid. Appt to see the oncologist this Weds to discuss scan results".

These statements centered around details about how they experienced the disease and how members experienced treatments. Again, members may have been asking questions about other members' experiences or the authors may have just posted their experience thinking it would be helpful to others. The similarity here though, was that the focus of the posts was to share experiential knowledge of symptoms and treatments.

The next trend I saw in the posts was related to causal factors. Some of the posts which repeated centered around members' thoughts or beliefs about what factors may have contributed to the diagnosis of ATC. Some examples of these posts are as follows:

- "Many of the published papers talked about inflammation and this cancer. In the bios, I kept seeing people mention things that point to that as an early sign being missed. Sometimes it is just a persisting infection, and then this ATC was diagnosed as part of the process. I had an event like this myself—hospitalized with my throat literally swelling shut from infection, suspected sepsis, and they thought strep but could literally never culture it for five full days in the hospital. Anyways, got home, better for a bit and then within the next year a follicular bit we had our eyes on grew. Didn't pull it got distracted with life and a year later ATC mixed into a growth."
- "I had constant colds and flus that seemed to have all my glands and nodes awake. As a result, it pushed my lump out from my collarbone, and that is how I found mine in a physical examination as all tests failed baring an

MRI. In essence colds and flus saved my life. So yes, I guess in a way inflammation did play a part."

- "I read all the papers also. I noticed exactly the same thing. My mom had tons of internal inflammation- she suffered from IBS and had to eat extremely mild and clean. She passed away in February and I will say she had many tumors in her small intestines and that is extremely rare. She suffered from inflammation in that area her whole life. If you look that up- you will find how rare it is for Even ATC to go to the small intestines. I share your same observations."
- "Many years ago, like in the 80s, we grew up near crop fields where planes would drive thru to drop pesticides, we could smell it walking out of our home. I was a kid at the time, but I remember. Also, not sure if my dad's prior prostate radiation therapy contributed or being over medicated on Cephlex, an antibiotic used to treat his knee replacement infection which he took for about two years straight."

These statements by members all refer to thoughts they have had on what may have been a cause of the ATC diagnosis. The posts are informational but focus on potential causal factors.

Another group of codes within the informational support seemed to fall into a category of recommendations and advice. The phrases and statements here took the form of advice to other members about ways of coping with treatment effects, questions about what others have done, and recommendations related to treatment plans, providers or facilities. Some examples of these types of posts are as follows: “Did you get a tracheoesophageal puncture? Which chemo drug(s) did you have? X, have you considered a clinical trial with immunotherapy or proton therapy (https://www.proton-therapy.org/science/)?”; “Has anyone used CBD oil for side effects from chemo like lack of appetite? If so what brand?”; “It is so hard to speak what someone else should do, but for me, surgery, radiation followed by chemo worked”; “I recommend both of these doctors also”; “Yes, MD Anderson is the place to be!! Dr. Maria Cabinillas is the endocrine oncologist and Dr. Zefereo is the head and neck surgeon. Both have done amazing things for my dad. Dr. Cabinillas is a pioneer in ATC treatment”; and “Yes, the Guaifenesin really helped my dad”. The above posts, again, may have been in the form of a question to the group, a response to a member’s questions, or just sharing information to help another member. They are informational with a focus on suggestions and advice.

Increased awareness of ATC was another type of post I began to see repeatedly on the group site. Examples of these posts are:

- https://www.rxleaf.com/post/11432/big-pharma-cancer-patent Pharma Will Now Hold Patent for CBD/THC Cancer Treatment I watched a GMA piece about this drug today - a nine-year-old boy with thyroid cancer responding to it. NTRK gene fusion. FDA Approves Larotrectinib for NTRK+ Cancers Jason M. Broderick @jasoncology Published: Monday, Nov 26, 2018
- “https://meyercancer.weill.cornell.edu/news/2017-04-02/cell-therapy-provides-shot-cure-fatal-thyroid-

> cancer?fbclid=IwAR1ALM9WwSJk4jWOpfSION3PU4jxGcCzBIdcP66kxkXtctEyP57B2JLnKYA Cell therapy provides shot at a cure for fatal thyroid cancer - April 2, 2017”

Here members posted links to articles and information about research progress and potential breakthroughs in ATC. The goal of these posts seemed to be a desire to increase members’ awareness about ATC and medical advances. Again, informational but with a specific focus, here sharing medical knowledge and advancements.

The last group of informational support posts I identified as I read the data was surrounding survival rates. Members’ posts such as, “Maybe your mom is the longest survival. I asked Dr. Brierley the longest survival of his ATC patients and he said a year”; “I was diagnosed Feb. 2016, had radiation and chemo, Doxorubicin, still here. So, it's worth trying. I live in Boise and was treated here”; “My husband lived 15 1/2 months”; “My brother was diagnosed this May and passed away Sept. 8 at the age of 59. It is an awful, very aggressive disease”; “My Mom is in remission 5+ years now”; “I am a seven-year survivor of ATC”; “I am 16 years out and radiation saved my life”; and “Do not lose hope. I am a survivor since 2009 (9-year survivor)”. These posts point to both low and high survival rates. Members seemed to post these as a way to express both hope and sorrow and to urge other members not to take a diagnosis of ATC or their time with loved ones for granted. The information they shared focused on the aggressive nature of ATC and the fact that there are favorable survival rates.

Spiritual Support

There were many posts by members that repeatedly referred to having faith in life after death and in the act of prayer. These statements repeatedly showed up so much, that I began to feel that there may be another category present which I had not considered previously. One type of message by members was an expression of there being a purpose to life, a purpose beyond the ATC diagnosis and treatments. Some examples of these are as follows:

- "We are with her in spirit."
- "We were not given a spirit of fear. Stay strong and of good faith. No matter what these scans show the trust that God will always be with you for he is good. We don't always get our answers the way we want it or at the time we want it, but he is always with us. Prayers for you today."
- "You will meet your loved ones again."

Other posts were references to an existential presence, posts such as these: "Thank God for miracles;" "God Bless your dad;" "God is my rock;" and "Jesus comfort XX and bring her soul peace during these last days." Another type of post I saw frequently occurring amongst the data were posts with a general existential focus. Some examples of these posts are as follows: "Let's all set the intention that all is well;" "sending positive thoughts;" "Such a blessing;" "Sending healing thoughts;" and "Keeping your family in my thoughts tonight." These statements do not imply a particular belief in God or a specific religion, but more in a general spirituality.

Some of the members' posts had to do with sharing their own faith-filled experience. Two such posts are the following:

- "I had the best prayer warriors, family & friends support, amazing doctors & most of all, my faith in God. I could actually feel a 'physical' feeling from all of the prayers from everyone and felt calm going in for my surgery."
- "I to pray for her transition to be smooth and without fear. Someone, I know once told of a friend who had been of a strong Christian faith. When he passed away his children were by his side to say goodbye. Suddenly after being pronounced dead he came back to life and reached out to his children saying, 'It's real it's real, tell everyone it's real!' And then he died. He was an of old age and had lived an eventful life which is much easier to take than when time is taken all too soon, but the comfort is knowing what he saw just before taking his final breath must have been pretty awesome. I'd like to think of it that way when the time comes. Something so beautiful that X could never have even imagined."

These members are sharing experiences that they have had which have strengthened their faith in a higher power. There is a spiritual tone to the posts with the intent of increasing faith or hope for other group members.

Some of these posts took the form of offering some understanding of a difficult situation. These posts were as follows: "I am hanging on tight to my Faith. It's what had got me this far;" "it is all in Gods time;" "May he Rest in Peace;" and "I'm so blessed &

thankful for every day I have. I feel like I really got a second chance." These phrases are expressions of belief that there is a deeper meaning to the loss and the challenge of ATC. And lastly, some of the posts were a request or gesture of a spiritual nature. "Praying for you;" "Prayers for your Mom;" "Thank you everyone for the prayers;" "now she needs lots of prayers;" and "If you read this - and even if you don't believe --- please close your eyes and ask God for a miracle" are some examples of these posts. These statements by members are a type of social gesture but with a spiritual meaning. They are asking for and giving caring and support but in a spiritual way.

Following my review of the posts, identification of codes and then a grouping of the codes into subcategories, I identified the subcategories of having faith, the existence of a higher power, general existential belief, faith-filled experience, giving meaning, and spiritual gesture. All of these subcategories have the thread of a focus on spirituality, leading me to determine that the main category of spiritual support exists. Spirituality was a new and unexpected category to come out of the data.

Empathetic support

There were then posts that seemed to develop into yet another category of statements by group members. I noticed that there were statements, sharing a members' experience with symptoms, side effects, treatment, or their loved one's experiences but that also seemed to express something more than just the informational details. Note here in these posts, the set of codes I identified as an expression of commonality:

- "My FIL is in the same boat with the paralyzed vocal cords. Hoping for some relief. We have done all the tests but waiting for follow up."

- “Two weeks after the last radiation treatment I started to notice an improvement in my mouth. I had had 30 radiation treatments, but no chemo. It has been six years since radiation and many foods still do not taste the way I remember. I never eat anything if I don't have a liquid to help me swallow.”
- “This was our exact situation with my mother. We spent months in GI working on GERD. She had every GI test.... we never thought nor did any of the doctors we went to suspected Bad Thyroid cancer.”

These statements share details about experiences but in a way that communicates a commonality with other members. This commonality developed into a subcategory.

Comradery became another category I noted while reading through posts. Some members’ statements seemed to express a sense of ‘we are in this together’. Examples of posts like this are as follows:

- “We are in the same situation. Our dad started trouble with his throat and then breathing after his 23rd radiation treatment. He's been in ICU and intubated for six days now. Our bright spot is he tested positive for BRAF. The issue now is how to get it in him b/c it's a pill and he's intubated.”
- “I sure hope your mom has the BRAF mutation as they are getting promising results with that targeted therapy. Unfortunately, my dad doesn't have it.”
- “We all understand your fears and concerns.”

There seems to be a sense of kinship expressed within these posts. I identified comradery as a second subcategory here.

Other posts I read pointed to a connectedness among group members. “My husband died at 53 from this;” “My brother passed away in September at the age of 59. Diagnosed in May and died four months later. It’s a cruel disease;” “My husband was on this combination as well. He also was not BRAF positive. Sadly, those meds only held his cancer stable for four weeks then it started growing rapidly. Your husband has an awesome response;” and

> This sounds like me! Most likely they will continue to keep a very close watch. Hopefully, the chemo and radiation took care of anything that was left post surgery. I did finally have some nodes removed that were very stubborn, but my diagnosis was in 2009. Best wishes to you for continued good reports.

These statements communicate that the process of ATC is a difficult one, which ‘we’ all understand. They express, ‘I am connecting with you on this experience’. And so, I noted a subcategory of connectedness among these posts.

Lastly, many posts gave a general expression of empathy towards other members. There are some examples: “We also lost a loved one to this horrible disease”; “I remember the fatigue during my treatments was so overwhelming”; and “I am in the same situation as you, except about 3-4 weeks out. Anaplastic is a beast and is very fast”. The purpose of these statements appears to be sharing some similar experience to other members, but also expressing a deep emotional understanding, beyond the details. I found there was another notable subcategory, expression of empathy.

Support Using Emojis

In the process of collecting and documenting posts and comments from the group page, I noticed there was a frequent use of emojis. These use of this modern form of communication would sometimes accompany the written words and sometimes they stood alone. The use of emojis was not a form of communication I anticipated when first developing the study and writing up my proposal. The more I saw these, the more I realized that they had to be included and perhaps even in a category of their own.

Although some of the emojis seemed easy to identify their meaning and may have had the potential to be categorized along with the written posts, there were also many that did not seem to have precise definitions or fit with the previously identified categories. I decided that from the codes, different categories of emojis appeared. I recognized some of the emojis as an emotional sentiment. Examples of these include a happy face, a sad face, a broken heart, or a shocked-looking face. Some of them expressed a gesture of support. These took the form of fingers crossed, a four-leafed clover, different colored hearts, or a bouquet of flowers. Some emojis seemed to have a spiritual meaning, often being prayer hands, sometimes one set and sometimes multiples in a row. These smaller subcategories all seemed to communicate a similar intent of support through the use of emojis, and so this became my sixth category among the data.

Administrative Support

Lastly, there were several posts among the data that had to do with administrative needs for the group. These posts were as follows:

- “Please make sure friends and family members answer the three questions we ask to allow others to join. Thank you.”
- “Hello all, Though this is a hard post to make ....I just want to make sure all see it, who wants to; if you want your loved one remembered in our 2018 Memorial Slide show at the Intl ThyCa; Thyroid Cancer Survivors’ Association Conference in Chicago in two weeks, please send me a picture and full name.”
- “I’m one of the admins, so when someone requests to join the group, there are three questions that pop up for them to answer. Have they or a family member been diagnosed, if so, are they receiving treatment and where? If you are already in the group, no need to worry.”
- “Welcome to the group all new members...I’m sorry you have been given this diagnosis but so glad that you are here.”

These posts seemed a vital part of the data but did not fit precisely into the previous categories of support. These posts were about adherence to group expectations, rule explanation, giving notice about goings-on within the group, and a way to formally welcome new members. I considered these to be subgroups and the main category identified was administrative support. Empathetic support was the seventh and final category I found within the data set.The purpose of qualitative analysis is to come to an understanding of a phenomenon from the viewpoint of the participants (Vaismoradi et al., 2013). I wanted to maintain the integrity of the words that members were posting and therefore, I recorded members’ statements precisely as written within the group page. I made sure to keep posts well organized and free from any personally identifying material. I took my time to read through the posts and reread them. Reading through the narrative material and breaking the text up into meaningful parts allowed me to start to find similarities in the writings. I noted similarities amongst the material and began to group codes according to these similarities. These similarities then formed the subcategories and categories.

The first groupings I identified aligned with the anticipated categories of emotional, social and informational support. Words such as happy, sad, glad, sorry, thankful, treatment, trials, and radiation are just some of those which stood out. Feeling words often signaled that the post was related to emotional support. Expressions of social interactions or social cues were signs that the post fits into the social support group. And statements that detailed treatment plans asked questions about treatment options, or gave information about providers led me to believe that the post might fit into the informational support group. These words were codes for me to pay attention to and assess whether the post fit into a given category.

Other categories emerged from the data along the way. There were codes from the words and phrases that did not fit into the initial three categories. Many members posted messages including words or phrases such as, “prayers, thoughts and prayers, and sending blessings,” which became my codes. Among the codes, I identified similarities. It became clear that many group members shared a feeling of support and hope through spirituality. Members often referred to as feeling continued hope or faith to cope with the diagnosis. The category of spiritual support emerged. I identified a fifth code related to the use of emojis as a form of communication. Many group members made use of emojis in their posts. The use of emojis seemed to have a unique message and appeared to demonstrate a new category of support.

Lastly, there were messages posted within the group discussion that was purely related to administrative matters. These posts tended to be written by the group administrators and referred to how individuals might join the group, questions or criteria for membership, notifying members about events to pay attention to, and parameters related to the purpose of the group. I was not surprised to find that the administrative posts were the least frequent. However, I determined that they had an important enough message to be included as another type of support.

The process of data analysis in this study was one of reading through members' posts and comments to identify meanings and messages. I took my time and pinpointed similarities among the data. I identified codes that I used for grouping and labeling categories. And then through a more in-depth interpretation of the categories, the patterns and themes emerged from the data, which led to the study results.

Evidence of Trustworthiness

Credibility

Credibility in a research study refers to whether or not the information reported matches with what participants said and whether results are accurate (Elo et al., 2014). The plans for maintaining credibility in this study have not changed since the proposal phase of the study. One way in which I maintained credibility throughout the study was through the use of participants' actual wording of statements. The posts from the group members were simply copied and pasted into the computer software during the data collection process. No text was changed or edited in any way, outside of taking out peoples' names to avoid identifying anyone in the study.

In this current chapter, there have been times when I have used direct quotes from group members to support my interpretation of the data. The use of direct quotes helps to keep a focus on what group members have said and maintains the credibility of the discussion. Later in the presentation of the results, I will also be including actual excerpts from group members' posts. Using individuals' specific wording for as long in the process as possible has been necessary to keeping with the meaning behind the posts and comments published within the identified group. Using members' own wording also helps to maintain credibility.

Through a process of peer-debriefing, a researcher can work to ensure that the participants' ideas, thoughts, and feelings are communicated in the data and the results, rather than mine as the researcher (Houghton, Casey, Shaw, & Murphy, 2013). Steps were taken to ensure that my agenda did not take over, such as de-briefing my committee chair and discussing the process of data collection and analysis with colleagues along the way. Discussing the study with others can help keep an objective view of the data, hear my thought processes out loud, and hear feedback from others related to how I am proceeding with the study.

Personal self-awareness is also essential throughout the research process (Elo et al., 2014). Evaluation of my own bias and possible agendas can be kept in check through the peer de-briefing process just mentioned. Another tool for monitoring self-awareness is keeping a reflective journal along the way. Through my collection of data, development of codes, identification of themes, and emerging categories, I kept notes in a journal related to the thoughts and feelings I was having along the way. Keeping a journal helped to keep me on track in terms of the focus of the study, aware of what I might be feeling related to the material and decipher what was related to study results or to my thoughts and feelings. They would be useful in the reporting process and in demonstrating what my train of thought was in terms of coding and analysis. The journal would also serve to minimize any personal bias that could interfere with or cloud results and conclusions. These notes were discussed along the way with a colleague and with my committee chair, as to maintain credibility in the study.

Collecting data until I achieved saturation is another way of ensuring credibility (Houghton et al., 2013). In my collection if the data, I continued to copy posts and comments within the 3-month date range identified. Within this date range, many posts and comments had been repeated by several members. This repetition signaled the point of saturation. Coming to a place where thoughts, messages, and meanings shared by group members were beginning to repeat, demonstrates that enough data were collected to find credible results.

The choice of using purposive sampling in this study helped to maintain the credibility of the data as well. Purposive sampling is when the researcher chooses a sample based on their having the most knowledge about the study topic (Elo et al.,2014). The ATC group selected for the study consisted of patients, survivors and loved ones of those diagnosed with ATC. These members are unquestionably considered to be experts in dealing with the disease.

Transferability

Transferability refers to whether or not results of a study could be duplicated with another group or in another setting (Elo et al., 2014). I believe that the reproduction of the study is possible with another group having a similar focus. Being that group membership was diverse, open without restriction as long as ATC has impacted you or a loved one, and with membership coming from a variety of locations around the world, it would seem that having another group with the same parameters for membership would result in similar interactions. No other factors seemed to be impacting how people shared, what people shared or why.

I believe conducting a similar study with a group focused on giving support to those with ATC or loved ones with ATC, but in an in-person setting, would yield comparable results. I do not think that the types of concerns, questions, and advice shared within the group were strictly related to the online setting. The online environment can impact some aspects of how people share, but I believe that the content of what is shared and the reason for people participating in such a group remains the same. Therefore, the results of what types of support group members received could be anticipated to stay the same in another study.

Dependability

Dependability refers to whether or not the data would be the same if collected at another point in time or under different conditions (Elo et al., 2014). The study data and results could be seen as similar if collected at another date in time, within reason. It seems that if data were collected a year ago or 2 years from now, there would not be many variations in the posts and the information shared between members. Looking at some date much further in the past would change results however, as Facebook, online support groups, and how these are used have changed over the years. Facebook has only been open to everyone since 2006 and it was that year when the ability to form groups on Facebook began as well (Loomer, 2012). With the development and changes in the technology, looking back father than that would not be possible. Taking a look at the use of online support groups between 2006 and maybe 2011 or so might produce different results, as the usage of Facebook has increased over the years; it was in 2011 that the use of Facebook had reached 8 hundred million users (Loomer, 2012).

Equally, I think that looking at some point in time into the future would impact results because the use of Facebook or online groups could change. Additionally, the status of the diagnosis and treatment for ATC could also change. If at some point much later in the future, treatments change and ATC is no longer considered to be terminal, people are more knowledgeable about ATC, or if ATC is curable, it is quite possible that the results of this study would be different from what I found today.

Confirmability

The confirmability of a study refers to the way in which the researcher interprets the data. A study has confirmability if there is someone other than the researcher who can look at the data and the results and come up with a similar determination about the results and the meaning behind the data (Elo et al., 2014). The report of data analysis, the process of coding and categorizing, and the results were discussed with my committee chair and with other colleagues who were not involved in the study. During the review of the material with these individuals, I found that they agreed with the process of coding and the themes and results found, confirming the study's conformability.

Study Results

Here I will present the results from my study. There were 2,429 statements collected and analyzed from the group members' posts within the date range of August 1, 2018, and November 31, 2018. The identified research questions were these:

1) How do ATC patients and survivors express support in the identified online support group?
2) what types of support do ATC patients and survivors receive through participation in the Facebook ATC support group?

Through my collection of group members' posts and comments on posts, I was able to identify answers to these two research questions. In the following paragraphs, I will discuss my observations and findings, supported by direct quotes from the collected data.

How Members Expressed Support

There were several ways that group members expressed support within the targeted Facebook group. Members shared information, emotions, and interacted in social ways. Some of the group members shared personal details, introducing themselves to the group, such as this member: "I'm 32, and my Dad is 56. From a small town In Maine. He needed to go to Boston for all of his care and treatments. He was diagnosed around Christmas last year." Some member's posts shared their demographics, as is seen here: "I appreciate the useful input and positive energy. My Dad is in southern VA.” Sharing these details seemed to be a way of members sharing about themselves and allowing others to get to know them.

Other posts talked about experiences with diagnosis and treatments. This member shares about their diagnosis experience:

> Almost five years ago after a sore throat for a couple of weeks & small lump for a few months, I was diagnosed with Thyroid cancer after an ultrasound was positive, no questions. But it was only ‘the good kind of cancer’! The next day I went in for my simple surgery to remove my ‘good kind of cancer’ and they found Anaplastic Thyroid Carcinoma (ATC). That's the BAD rare one! Always terminal and was told to go to a cancer clinic or find a cancer research study somewhere, because they removed all but 2% or so, my entire Thyroid, and would probably only have a few weeks to a few months to live.

The following post by another member is sharing about their progress in treatment:

> I got out of the hospital yesterday! I finally am starting to feel somewhat better □. My chemo has been on hold almost three weeks. And I have no plans yet!? I'm all done with MD Anderson. I'm going to do this in KC now. Thank you, everyone, for the prayers and kind words!

And this member shares the disappointment of treatment not being successful: “I am so sorry to tell you all that treatment has not worked for me. I tried my hardest. Please continue the fight for me. I am in Hospice care. My family is here taking good care of me." Members all have had different experiences and seem to utilize the group page to express them and share with others.

Some posts are from others, sharing about what their loved one has been experiencing. This member shares about her husband:

> I am sorry to hear about your Dad. My husband also has ATC and is participating in a year-long clinical trial. No surgery, no chemo, no radiation. The cancer had metastasized into his central lymph system by the time it was diagnosed. Tomorrow, he is halfway through the bi-weekly treatments and has another CT scan. Prayers for strength for your family as all of you go through this.

In this post, someone is sharing their parent's experience:

> Hello everyone, I am here because my dad was just diagnosed with ATC. We are doing everything we can to get all the information and resources available to help us on this journey. He is going to be starting radiation, and chemo and my first question to anyone who may be able to help is, how can he prepare nutritionally for this and during treatment? Do you have any resources you can point me to that can help him stay strong during the treatments?

These posts not only add to the sharing of patient experiences and ATC information but also act as a source of support for loved ones.

There are posts on the group page focused on emotions, both negative and positive. Some examples of negative emotions are here: "I am devastated to report that my best friend and mentor passed away on Saturday evening" and "Really getting annoyed now." Positive expression of emotion was seen in posts as well, found here:

"Glad that's over! I felt better within a week or two;" "I heal very well, fortunately, and within two weeks I was healed and feeling great;" and "My neck scan came back clear!! The swelling is edema as a result of damaged lymph nodes. Doctor very pleased with results, and onward with Keytruda!! I feel so blessed today." Group members are sharing their emotions along the way. Both the authors of the posts and the readers can benefit.

I documented posts which shared information about treatments or knowledge that members had gained along the way. Some posts gave advice and guidance to other members. Examples of such posts are as follows:

- "I would not get a second opinion on pathology. I'd get a second opinion on care immediately. There is positively no time to waste at all. Make sure the cancer center you are at is top notch and has dealt with this, numerous times. My husband had radiation 33 days in a row and chemo once a week after radiation. Total chemo was for ten weeks total if I remember correctly."
- "you should find out if he is positive for the BRAF mutation because there are some targeted treatments for BRAF positive patients."
- "I recommend that you read other posts on this site. They are very educational."
- "Demand immunotherapy as well. IMO that's what the cure will be. It's the future of cancer treatment. The chemo has been so very hard on my FIL. They stopped it early. The immunotherapy is shrinking cancer, but it takes a few months to kick in, and the cancer is so aggressive most can't

go without radiation and some chemo. Get a notebook and start keeping great notes. It's a must because this will all get very confusing very fast."

- "It's important to know this for some of the trials… (article posted at cancernetwork.com) RCC Agent Lenvatinib of Benefit in Anaplastic Thyroid Cancer, John Schieszer, May 10, 2018."

The members who posted these messages were sharing information gained along the way for the benefit of other patients in the group who may not have heard the information previously.

Group members expressed statements of hope and times of struggle. Here are some examples of hope-filled posts:

- "I just got back from M. D. Anderson. The scan results are heartening! The combination of Chemo drugs: Tafinlar 50 MGMekinist 2 MG and immunotherapy drug: Pembrolizumab is having great results on me. The tumors have been reduced in size. Some significantly, up to 50%! I am happy to have more time with my family and friends."
- "Hello X! Don't lose hope, here in this group are living miracles, ATC can be defeated. Also, here you can find the best advice from people who had/have this disease or from family members of people who had this disease. Don't forget you are a fighter and a champion since the beginning of this battle, just don't lose hope."

These messages were shared to let others know that there are positive stories among ATC patients and that they can be hopeful.

In this next post, the member is sharing about their struggle to maintain hope along the way,

> I am new and was diagnosed in July. I recently finished 6 weeks of chemo and radiation with the news the there is no sign of disease in my neck. Sadly, the chest CT revealed a 2cm nodule in the right lung that was not present on initial scans. I'm looking for support and guidance. This is a very lonely road because even the doctors struggle with this disease. I want to be here for my seven-year-old daughter and am struggling to live instead of being consumed by this disease.

Here, the member expresses a deep level of fear and loneliness. He or she is also asking for support from the other members.

Many posts referred to the number of years they have had as survivors, as proof of reason to hope for the best. Here are some examples of these: “Do not lose hope. I am a survivor since 2009 (nine years);” “My dad is a survivor of not quite seven years;” and “I am going on 16 years so tell her to keep fighting.” These posts defy the statistics that are out there about ATC, which state that patients usually have only a few months, to at most 2 years in terms of survival rates (American Thyroid Association, 2018c). Other members can find hope and positivity in these higher numbers.

Types of Support

By the end of my analysis of the data, there were seven categories identified in terms of the support expressed and received within the group. These categories are as follows: informational support, emotional support, social support, empathetic support, spiritual support, administrative support, and support through emojis. As discussed in the first chapters of this study, I expected to find evidence of emotional support, informational support and social support in the group. Through the data collection process, I noticed that there were three more categories, spiritual, administrative, and emojis. Last I identified the category empathetic support, which emerged further along in the process of analysis. In addition to the demonstration of these categories, themes emerged from the data, which I will discuss as well. The themes are the underlying meanings in the data, the messages that come through in the members' words.

Informational Support

The informational support category was the largest of the seven, with 945 references attributed to this group. I was surprised that this wound up being the biggest group, as I hypothesized that the emotional and social support categories would be the most prominent. The fact that this was the most common type of support offered and received, after careful analysis of the data made sense, however. I can see that with ATC being such a rare and aggressive disease, information is vitally important. From a review of the members' posts, I can see how valuable the platform of the online group can be for sharing and having access to the most up to date information on treatment options. Related to its rarity, not all providers or facilities across the world are well-versed about the disease of ATC and its treatment. The online group is a perfect format for patients, survivors, and loved ones to share what they know and have experienced about the best treatments, the best hospitals, and the best providers. Group members who are new to ATC can quickly have access to streamlined information about how to give themselves or their loved ones the best chance for success and survival. Information, and in particular, timely and accurate information is crucial to patients' survival.

Secondly, there appears to be a great deal of information on the Internet, but not all of this information is accurate. Some of the information available from providers or the Internet can be conflicting or confusing. Having a group with experienced and knowledgeable patients, survivors, and loved ones allows for a level of comfort and security in the information one is receiving. Participation in the group for this purpose can reduce confusion and anxiety for patients and loved ones.

Repeated review of members' posts led me to the identification of words and phrases which focused on sharing information with other members over and over again. I noticed too that within the category, many posts presented with a similar focus. There were smaller groupings of similarities, which I identified as subcategories. I also found that together, these subcategories confirmed the presence of the main category of informational support. Beyond the category of these codes, I also found a theme that emerged from the data. All of the information shared by members seemed to have the purpose of helping others get the best information they could. Being able to obtain the best and most up-to-date information, allows patients to access the best treatment they can. Another way of saying that, is that members are helping other members to have the best chance for survival. From this idea, I recognized that the overarching theme within the category of informational support was encouraging survival.

Social Support

The second most frequent group of posts I found, I categorized as social interactions. ATC group members were able to find a place of comradery and understanding. Members could socialize, give confidence, encourage each other, and talk about their experiences with people who genuinely understand. Again, as stated in the beginning chapters, thyroid cancer and especially ATC, are diagnoses that are a mystery to most people. Patients and loved ones can struggle to find other people with whom to talk to about the experience. Members of this group can feel a sense of acceptance and belong with people who have experienced ATC.

Within the category of social support, I identified subcategories; members' posts grouped by the type of social support they seemed to express. Beyond those subcategories, I could interpret an overarching theme within the data. From reading the posts and comments, the words and phrases, the categories and subcategories, I saw a theme of connection emerging. Group members were expressing a need to connect. All the social gestures and statements seemed to have the same underlying theme of connecting. And so, the theme or underlying meaning beyond the category of social support was a connection.

Emotional Support

The category of emotional support is the third group of posts identified. In these posts, members shared feelings of fear, worry, sadness, gladness, shock, thankfulness, gratefulness, and loss. Members consoled one another when someone's battle with the disease resulted in death. Group members connected through feelings and emotions that they may not have felt comfortable sharing outside the group, for fear of being judged or misunderstood. Additionally, feelings associated with cancer, terminal illness, and death can be uncomfortable topics of discussion for those not experiencing it. The group offers a place where these challenging feelings can be expressed freely and responded to with genuine acceptance.

From the exploration of the codes, subcategories, and the main category, I was able to interpret the data and identify an emergent theme. The theme present among emotional support was that of caring for each other. All the posts and comments under this category seemed to express a caring for one another and a need to care for each other, that was the underlying reason for sharing these emotions. Members may have been expressing happiness, fear, sorrow, or excitement for a cathartic release of emotion. However, I could see that beyond just an expression of the feelings themselves, was a message that they cared about one another. Members cared enough about one another to be vulnerable and to share their feelings as a potential benefit to someone else.

Spiritual Support

The spiritual support category was one which I had not expected from the onset of the study. After collecting and documenting the data within the date range set, it was noticeable that many posts surrounded the topic of spirituality. This expression of spirituality took the form of a belief in God, a belief in prayer, sharing prayers for each other, sending blessings or positive thoughts, and keeping faith in something more significant. I discussed the repetitive nature of these statements and their difference from other posts with my committee chair. The discussion confirmed that another code was needed to accommodate these posts.

Through the nature of the posts, it was clear that group members shared a sense of hope in divine power and the potential for the existence of something beyond this physical world. Those coping with a terminal illness see spirituality as helpful and motivating. Gifford et al. (2018), noted that not only can spirituality give those with cancer a sense of meaning and strength, but the connection through spirituality can also allow for growth and promote healing. There are strength and hope that life here on earth is not all there is at a time when people are facing death.

I was also able to identify a theme related to the category of spiritual support. I pinpointed several subcategories first, which grouped spiritual messages according to shared similarities. The similarities in the messages being posted began to give me some insight to the underlying message within the entire category. The theme I identified was about members expressing the belief that there is some guiding force or purpose beyond all of this. The statement, all of this, referring to our conscious day-to-day existence and the members' experiences with ATC and treatments. Throughout the posts, it seems that the group members share a belief in there being more than just what we see or experience here in our physical world. The theme is an expression of faith and hope; that message is, there is more.

Administrative Support

Next is the category of the administrative group of posts. This grouping demonstrated the was the lowest frequency of posts, but still an essential part of the group. Group administrators posted messages about parameters for group membership or related to events happening or plans within the group. Members could feel that their administrators played an active role in maintaining the integrity of the group and that they were passionate about the group purpose. Group cohesion can often be maintained or enhanced through such definite oversight.

Beyond the category, I was also able to identify a theme that emerged from the data. The posts in this category were administrative in nature and may not seem to have more of a purpose than that. I was able to extrapolate; however, that the reason for having guidelines and oversight relates to respect and caring. There is a respect for the group and the group members. It is crucial that the group space is kept a safe place for members to talk and share topics that may be difficult to express. The message is that, as a group we care enough to have a process. That is the theme underlying this category of support; we care and respect each other enough to have a process, monitor the process, and communicate happenings to all members.

Support Through Emojis

The use of emojis was another way to express support in the group. This is a new and emerging form of communication used in social media today; people send emojis on their phones, in text messages, and through various social media formats. The use of emojis for communication was no different in this group. Some examples of the emojis that were used by members are shown here: □ ❤□♥□ □ □ □. Some emojis seem to be easily defined, where others seemed capable of having different interpretations. It will be interesting to see how this form of communication evolves.

Initially, I was unsure if I would include emojis under the already identified categories (emotional, social, and spiritual) or if they would be a category of their own. Some emojis are clearly defined while some are not so clear. Because of this lack of clearly defined meanings, I decided it best to keep the emojis in their own category. Emojis can be used all on their own, without the use of any words and I thought this another point to assign them their own category. Emojis communicate support to group members just do the written words.

As I combed through the data and explored the category of emojis, I thought more about what was being expressed here through the use of emojis. There seemed to be a theme of wanting to express thoughts and feelings, but more creatively than just with written words. The use of emojis allows people to communicate thoughtfully and creatively. Emojis are a digital way of sending a card or flowers over the Internet. These symbols communicate a message that, I care. The message may be the same, but it says something more than words can. The theme I have identified here being, I care even more than words can express.

Empathetic Support

The last category to emerge was that of empathetic support. This grouping initially came from a dilemma I identified where some posts seemed to fit into both the informational support and social support categories. There were posts by members that were informational in terms of the details they were sharing. However, the purpose of sharing the circumstances was not strictly for informational purposes. I was able to identify another meaning for members sharing the information.

I determined that the posts were indicative of social support; members were sharing this information to connect socially. I noticed the reference in the literature regarding qualitative research and coding, that if there is a point when a researcher is unsure of the category or code for a data set, the reason could be that there is another potential code emerging (Houghton et al., 2013). I discussed the finding with my committee chair, and we decided that exploring this more deeply would be helpful to see if there could be another code or category emerging. I conducted a further review of the data, engaged in some brainstorming in my reflective journal, and came to find that the common thread in these posts was that members were sharing the information with the purpose of expressing empathy for others and receiving compassion from other members. The information allowed members to connect on a deeper level, where they could empathize with one another, therefore being a separate category from the rest.

After reading posts and identifying these codes, I was able to draw connections between the codes which led to the groupings of commonality, comradery, connectedness, and expressions of empathy. These were my identified subcategories. Then, from these groupings and the common thread amongst them, I began to establish yet another new category. I labeled this category empathetic support. This category seemed to include all the posts and comments which expressed support in a way that also communicated empathy with the other members. Beyond this, through an exploration of the subcategories and the main category, I identified a theme among the data here as well. The overarching theme here seemed to be that they were expressing a deep, gut-level, understanding with one another. They were connecting and supporting one another, but in a way that was deeper than just a social connection or cognitive understanding. The theme was that of a deep understanding.

Other Results

I conducted some queries in the NVivo system, such as text searches and word frequencies. Several words repeated throughout the members' posts. In the informational code, there were 245 references to the word radiation, 226 to cancers, and 201 to chemo. Other frequent words in this code included treatment, weeks, ATC, surgery, trial, and tumor. The code for social support resulted in 145 references to the word thank and other words with significant frequency were news, hope, great, wonderful, and good. Expressions of emotional support often included some version of the word sorry, showing up 168 times in the posts collected. The other words frequently used included loss, hope, happy, love, glad, feel, and hugs. Within the category of spiritual support, the most frequent words cited were variations of the word prayer, with the number of references totaling 237. Additional words that showed up with great frequency under this code included blessings, family, and references to God.

The following figures (Figure 1-5) are the word clouds resulting from the data queries conducted:

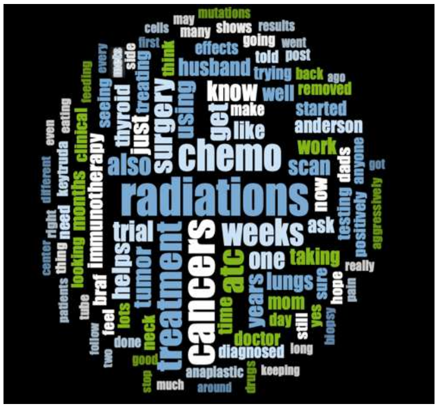

Figure 1. Word cloud – Informational support.

Figure 2. Word cloud - Social support

Figure 3. Word cloud – Emotional support

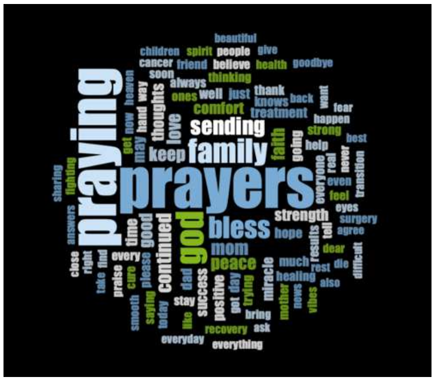

Figure 4. Word cloud – Spiritual support

Figure 5. Word cloud - Empathetic support

I also took a look at the frequency of words overall, not just within the specific codes. In this query I found that the most frequent words used were radiation, cancer, chemo, just ATC, sorry, surgery, treatment, prayers, and thank. This can be seen in Figure 6:

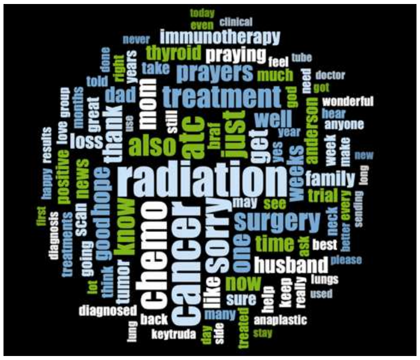

Figure 6. Word cloud – All words

I conducted specific word searches for the words: patient, survivor, and ATC, as these are the focus of my study. ATC showed up in posts 186 times, patient 37 times and survivor 21 times. I found it interesting that, at out of these three, survivor was the least frequent. I contemplated if this could be a reflection of the low number of survivors there tends to be with ATC.

Summary

In this chapter, I presented the results which came out of the data collected. I used a significant number of posts written in the group setting for analysis. After review of the data collected, I determined that I had achieved saturation of the data. I was able to assess saturation by the number of statements that were repetitive throughout the posts within the date range of August 1, 2018, through November 31, 2018. And again, saturation of the data is evidence of there being a large enough sample size and that the study results are considered credible.

Seven different categories of support resulted from a careful and repetitive review of the data and codes. During the proposal phase of the study, three types of support had been hypothesized to emerge from the data, which were informational support, social support, and emotional support. I saw that three more categories emerged following the data collection process, being administrative support, spiritual support, and support through emojis. Then finally, through further analysis, the category of empathetic support emerged. The final results then were the presence of seven categories of support expressed and received by patients and survivors, either from their participation in the group or through the involvement of loved ones on their behalf. I established the presence of themes following the identification of the categories of support. These themes were the patterns I found in the messages being expressed by members within the group. In Chapter 5, there will be further discussion of interpretations of the results, recommendations for future research, and the potential impact of the research study on social change.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

ATC is a rare disease and is an aggressive form of and the least common type of thyroid cancer (MedlinePlus, 2018). Due to its rarity, many people do not have first-hand knowledge about the disease. There are even providers who lack information about the disease and treatment because it can be so rare: "My local hospital is great, and it's doctors are talented, but their experience with my type of cancer was extremely limited" (Nickless, 2019, para. 6). More specifically, they lack information about the direct experiences of the patients and survivors of ATC. Because of this, the goal of this study was to explore the experience of ATC from the perspective of patients and survivors.

As noted in earlier chapters, the number of people diagnosed each year with thyroid cancer has been increasing. Goswami et al. (2018) noted thyroid cancer tripling in incidence since the 1980s. Treatments also continue to advance, and as a result, more and more patients are living as survivors (American Thyroid Association, 2018a). This increase in the rates of survival has led to people having to adjust to living a new normal; a normal after experiencing all the treatments, procedures, and dealing with their effects. One survivor expresses this here, "My life is different now, but it's still good" (Nickless, 2019, para. 16).

There continues to be a lack of knowledge about thyroid cancer, especially ATC, and few current studies address survivorship (Goswami et al., 2018). With this in mind, I hoped to explore an ATC Facebook group's experience of the new normal, the needs of patients and survivors in the group, and the types of support that the members gain from participation. The focus of the study was to obtain group posts between the date range of August 1, 2018 and November 31, 2018, and through thematic content analysis, determine the types of support expressed by group members. The findings included seven categories of support revealed: informational support, social support, emotional support, spiritual support, empathetic support, administrative support, and support through emojis. These results demonstrated that there is a great need for online support groups and that patients, survivors, and their loved ones can access several types of support through this format.

Interpretations of the Study

To begin, I will discuss some of my findings that confirmed the existing knowledge in the literature. Cameron (2011) conducted a study focused on online support group use related to intimate partner violence and found that these groups provided informational, emotional , and social support. The findings from my study confirmed the presence of these three categories of support for the ATC group members. In terms of social support, some group members posted, “I completely agree…… positive attitude does help” and,

> Thank you for the response, and for continuing to support the group although your husband lost his battle. I truly appreciate the group and have been trying to read through more of the discussion. It would be quite a task to build the database anyway.

Some posts that were references of informational support by the group members were , “We gave my dad CBD oil. I am not sure if it helped, but I like to think it helped with pain and appetite during radiation and chemo” and “Yes, I remember city of Hope being a positive source. You can ask your oncologist team to follow up with MDA or Mayo Clinic.” And lastly, some examples of posts referring to emotional support were , “This is really frustrating, I agree” and “Sorry for the loss of your beloved father.” The statements in these posts confirmed the original three types of support I expected to find through my research.

Cohen (2011) also explored the types of support received through online support group participation. This author noted the categories of support as emotional, informational, and social support as well. More specifically, the author pointed to members looking for information on treatment alternatives, gaining health-related information, getting experiential knowledge, tackling isolation through peer support, being able to express frustrations, seeking hope, feeling empowered, and getting help with coping. All of these reasons for group participation were found within my study as well. Here is one example of a member expressing feelings of hope, “we are incredibly thankful and remaining hopeful for now.” Another group member referred to some feelings of frustration and regret, “I wish I had stayed off the web too, but I kept researching for miracle cures. I should have spent those hours cuddling with my husband instead of wasting time.” And here is an example of a member posting about relying on the group for support and empowerment, “this group is so helpful and always here. Great advice from all... live each and moment, stay strong and positive and just love and support Your Mom and family."

The data collection process in my study also confirmed the presence of a new normal for patients and survivors. The following are several statements by patients, survivors, and loved ones referencing the physical, social, and emotional changes that result in a new normal for these individuals:

> It's been a bit of a challenge to deal with socially. I'm fine with the way things have healed up and look, that doesn't bother me. I'm proud of my scars... It's very hard to not have your REAL voice, or now sound like a robot, especially being a woman. It's the hardest when going to loud places like restaurants, bars, or events. People have a hard time hearing me, so as a laryngectomy, you tend to just not talk or stay to yourself. Concerts are tough, not being able to sing. I sure miss singing. I feel like most people I come in contact with are even nicer or more helpful now, but you get a few here and there that are just mean or rude. The first year was a lot to adjust to……. After about 1 1/2 years after surgery, I started to grieve the loss of my voice. I'm doing great now and have accepted the new me.

As well as "My bladder control was affected when doing chemo. Like chemo, radiation, and cancer weren't bad enough. It was so degrading. The last chemo was eight months ago, and still, have mild issues, but it has slowly gotten better"; "It has been six years since radiation, and many foods still do not taste the way I remember. I never eat anything if I don't have a liquid to help me swallow;"

> Have any of you had issues with neuropathy during chemo treatment? If so, what did you do? Yes, and I still do. I finally started taking Gabapentin at night to give enough relief to sleep. Now I take it when I get up and at dinner. If a long day with a lot of neck-straining I take a midday dose. 600mg per dose. Helps with all nerve problems.

And “My late husband had many nerve issues and permanent nerve damage from Carboplatin…from my understanding it can strip the coating on nerves.”

The experience of a new normal, just as the patients and survivors in the study group have described, has also been referenced in numerous places in the literature. Katz (2011), stated that “many people assume that once treatment is over, they will instantly go back to feeling normal again……. six months after completing treatment, she still feels exhausted and is frustrated by her lack of energy” (p. 5). Katz pointed to how the diagnosis and treatments have forever changed cancer patients and survivors. Firmin et al. (2014), S. D. James (2012), Katz, and Mendez (2015) all touched on the debilitating effects of thyroid cancer and its treatments as well as the impact this has on long-term quality of life. Firmin et al. and Shannonhouse et al. (2014) paid scholarly attention to the fear of recurrence that often remains and impacts the lives of survivors. Mapes (2015) discussed the physical and cognitive changes that occur and impact functioning. How patients are affected both positively and negatively by cancer and treatments are reflected in work by Baker et al. (2016), S. D. James, Katz, Steger (2012), and Tamminga et al. (2016). These authors discussed the lingering impact on employability, identity, and self-image, all of which were confirmed in my results as well.

Posts collected from the group site confirmed the need for support and the presence of significant quality of life issues for patients and survivors. Quality of life issues and a substantial need for support had been documented many times in the literature as well, such as with studies by Applewhite et al. (2016), Morley and Goldfarb (2015), B. C. James (2016), Rogers et al. (2017), Duan et al. (2015), Gamper et al. (2015), and Buchmann et al. (2015). Morley and Goldfarb found that patients expressed a great need for information, emotional support, and psychological support and that many of these needs remain unmet. Buchmann et al. (2015), Applewhite et al., Goswani et al. (2018), and Lyons (2017) focused on how differentiated thyroid cancer patients demonstrate high levels of distress comparable to cancers with worse survival rates. I assumed that this is also the case with ATC, which has lower survival rates in comparison to differentiated thyroid cancer. Rogers et al., Gamper et al., and Gallop et al. (2015) all referenced the long-term impacts on quality of life long beyond the period of active treatment as survivors.

The following posts from my data collection process are examples of these unmet needs for patients and survivors: “So very frustrated. I received this report today regarding my daughter's molecular testing. I have no idea what the next steps are;” And,

> 4th dose of Keytruda tomorrow! I phoned the hospital as my neck has become very swollen this past week. They have brought my neck scan forward to tomorrow. Feeling a bit nervous. My neck surgery was in February 2018. My scan

> six weeks ago showed all good. This swelling started after the scan. I hate to think there is a connection.

As well as,

> The hardest part is having faith when things aren't going as planned or hoped. It's such a big opportunity in learning to surrender to what is, isn't it? I keep trying to bring myself back to the present moment whenever I start thinking about the what if's and the future, as it completely overwhelms me and steals my peace.

And,

> My mom was diagnosed with ATC July 2018. It has metastasized to the lungs. She is currently undergoing 20 treatments of radiation and will be exploring immunotherapy in a few weeks. Her tumor is just under 7cm. We have yet to learn whether the radiation is helping. It's an overwhelming time as we navigate this road. A steep learning-curve. Hoping to learn more and connect with others experiencing the same journey.

These patients, survivors, and loved ones are expressing questions, concerns, emotions, and support. From participation in the group, they are receiving information, guidance, advice, and comradery they feel they are not getting from interactions with providers. In their research, Duan (2015) and Lyons (2017) noted a lack of sufficient support by families and providers as well as feeling invalidated in their experience.

Lack of consistent or up-to-date knowledge is another reason for patients and survivors feeling a tremendous unmet need. Participation in a group such as this ATC support group can give members access to information from around the world and on the latest trends in treatment, which was confirmed by my findings. As stated by Carter (2017) on the MD Anderson Cancer Center site, “because anaplastic thyroid cancer is extremely rare, there’s limited reliable information on this disease” (para. 2). Glaser et al. (2015) and Smallridge and Bible (2019) also referred to the rarity of ATC, the aggressive nature of the disease, and the low survival rates as barriers to connecting with similar individuals for support or being in a geographic location where they would have access to providers well-versed in aspects of the disease. Garlapow (2016) discussed how patients can often feel isolated and ill-equipped to cope with their diagnosis and how online support can offer individuals connections to information and support.

Group participants’ statements here demonstrate the wealth of knowledge that shared in the group setting:

> The biggest thing I would recommend to anyone is finding Doctors who have treated a lot of these cases or that are open to working alongside a research hospital that has. this is not a cancer to be treated by someone who has seen one or two cases or even one or two a year.

And,

> While we were exploring MDA, we were also still working with the doctors at UCLA. UCLA has one of the top 5 cancer centers in the country, but not a lot of experience with ATC. My Dad's UCLA docs initial recommendations were VERY different from MDA, and they also had fewer options. We told our docs at UCLA we were going to fly to MDA for a second opinion and they were VERY

> cool about it. They all told us after we made the decision, I would do the same thing.

These posts signify the lack of knowledge that can exist with providers, limited opportunities for in-person support with peers, and the significant benefit online support groups provide, such as the one I chose for the study. In the articles written by Ellison et al. (2007), Grande et al. (2006), and Harkin et al. (2017), the authors all point to the benefit of support groups and the specific benefit of online support groups for coping life-threatening illness.

The findings from my study also extended the knowledge base available in the literature. My findings resulted in the development of some new categories of support: spiritual, empathetic, administrative, and support through emoji use. There were also many points where survivors posted long-term survival rates, which certainly differs from the timelines often reported in the research and even noted by providers.

Here, I discuss one new type of support I found, spirituality. Spirituality is different from religious belief and refers to people's search for meaning and purpose in life (Rego & Nune, 2016). Patients with a life-threatening illness can often begin to question their lives, their purpose, and their spirituality. A time of disruption in life or when there is a conflict between an individual's personal beliefs and experienced life events, such as with a cancer diagnosis, is considered a time of spiritual distress (Rego & Nune, 2016). Finding ways in which individuals can attend to their spiritual needs when facing an illness like ATC, can help to improve coping, assist in adjustment to the new normal, and help to improve overall quality of life. Spiritual and existential issues in patients with life-threatening illness are an essential part of coping, and there is a close relationship between spiritual, social, and psychological well-being (Rego & Nune, 2016). Here are some posts from group members in my study, demonstrating the vital role of spirituality in their cancer experience and in coping: “Prayers from the Philippines;” “Let’s all set the intention that all is well;” and “now she needs lots of prayers. If you read this - and even if you don't believe --- please close your eyes and ask God for a miracle.” These statements express feelings of hope, faith, support, encouragement, and empowerment. Patients, survivors, and loved ones are sharing in a connected way, a sense of purpose, a sense of meaning and even a sense of control over a situation that can often feel very meaningless and hopeless. In the studies by Gifford et al. (2018), Schultz (2017), Gomez-Castillo (2015), Trevino and Naik (2015), and Ripamonti (2018), the authors all discuss that with a cancer diagnosis often comes an increase in the spiritual need for people. These authors point to the hope, meaning, a sense of purpose, and feelings of connectedness that spirituality provides for cancer patients, especially those with a terminal diagnosis. Improved quality of life, decreased suffering, lower levels of isolation, less despair, improved satisfaction with care, and enhanced healing are all noted as benefits of spirituality for patients and survivors (Gifford et al., 2018; Gomez-Castillo, 2015; Ripamonti, 2018; Schultz, 2017; and Trevino & Naik, 2015).

Two more ways I noted how my findings have extended the knowledge is in group members’ posts about the length of survival and posts highlighting the need for empathetic support. The literature points to very brief timelines with survivors, whereas the posts from group members included a report of survival times were considerably longer. An article by Glaser et al. (2016) reported a median survival time of 3.5 months. Min and Jin (2017) noted that most ATC patients would die before 6 months. And a study by Smallridge and Bible (2019) noted a range of survival to be between 6 months and 2 years. In a study by Shim et al. (2011), the author stated that patients would seek information online when they are unable to get answers they are seeking from providers and that often the healthcare system falls short in terms of meeting patient needs.

These posts noted here point to longer survival times by many group members and offer greater hope than what may be reported by providers: “I was still only given a 7% chance to make it a year…… it’s been a year and ½ since my surgery…. I have had two PET scans, CT scans and MRI's since surgery and have been declared CANCER FREE;” “It has been six years since my radiation treatment;” “new to this group and wanted to let you know that miracles do happen! I am a survivor of seven years;” and “diagnosed with ATC in September 2016…… I was told then rather harshly to go home get my affairs in order and make peace with whomever .... there was nothing that could be done for me, and I had 6-8 months to live! (posted August 2018).” After reading the literature, I am aware that ATC can be very aggressive and that many do die from this disease rapidly, however, from the posts in the group, I also see that there are many accounts of long-term survivorship. Group participation can be inspirational and hopeful for members who may only be hearing grim reports of survival.

Empathetic support is a need I did not find in the literature. Again through my review of the literature base, I have seen references to social support, informational support, emotional support, and even spiritual needs (Cameron, 2011; Cohen, 2011; Deno et al., 2012; Gomez-Castillo, 2015; Kim et al., 2013; Morley & Goldfarb, 2015; Schultz, 2017; and Zebrack et al., 2014). In the group posts, however, I found that there were several places where members shared experiences related to diagnosis and treatment with a purpose of connecting and empathizing with other members, rather than just sharing the details for informational purposes. These posts initially seemed to be informational, however, after a more in-depth analysis, I felt it was clear that the authors of the posts were trying to accomplish something else. These members were sharing with the intent of empathizing with others or were sharing the information to seek empathy from others. Examples of these posts follow here: “My FIL is in the same boat with paralyzed vocal cords. Hoping for some relief. We have done all the tests but waiting for follow up;” And,

> I had almost exactly the same, although my ATC reared its head ten years after my thyroid was removed along with all the cancer. I had 6 years of RAI treatment to ensure it would not reoccur. I have been thru the 5 days a week radiation for 6 weeks, and chemo once a week for 7 weeks. I lost my vocal cord and carotid artery. Surgeon took one from my inner thigh and replace it. My hypoglossal nerve was damaged during surgery, so swallowing is difficult for me. I am three months into Keytruda treatment now and doing well. My next MRI is in 7 weeks’ time to monitor progress. So far, I am blessed. Just stay strong and be positive! I am 65.

And,

> I am a 61-yr. young □ Australian female ... diagnosed with ATC in September 2016. I was told then rather harshly to go home get my affairs in order and make peace with whomever ... there was nothing that could be done for me, and I had 6-8 months to live!!!! Yeeks!!! Needless to say, that we couldn’t accept that and thus our road to looking after ourselves began.

These posts state specific information or details about treatment, but the purpose of sharing that information is not so that other members might explore those same treatment options or know what to ask their doctors, but so that the members could empathize with one another on their experiences. I believe that to be a significant difference in meaning.

In a study by Liu and Yu (2013), there is a reference to users of Facebook seeking companionship, which may be closer to my interpretation of empathetic support. Also, Portier et al. (2013) discussed the benefits of giving advice and support, rather than just obtaining this support in online cancer communities. The author notes this level of sharing as an outlet for the emotional distress that often accompanies a cancer diagnosis. These two studies seem to touch on what I saw with members’ posts when I refer to empathetic support. And several studies in the literature relate to the devastating emotional impact that cancer, especially rare cancers, can have for patients. They also point to the ways engaging in online support communities can improve psychological well-being, allow for a more authentic sharing of self, provide connectedness and companionship with like-impacted peers, and address the shock and insecurities that lead patients to be unable to have all their needs met by family or providers (Liu & Yu, 2013;

Portier et al., 2013; Shim et al., 2011; Tosun, 2012; Yan & Tan, 2014; & Zebrack et al., 2014).

Findings from the data demonstrate how patients and survivors have experienced distress from an ATC diagnosis and undergoing related treatments, how they have evaluated the stress, and how they have coped with the distress caused by ATC. As discussed by Lazarus (1999), some life events are more likely to cause psychological distress than others, especially those that are life-threatening. A diagnosis of ATC has the real potential to be lethal, and as the literature points to, most patients do not survive more than six months (Min & Jin, 2017). The studies by Roerink et al. (2013), Seok et al. (2013), Zebrack et al. (2014), and Rogers et al. (2016) all referred to cancer as significantly distressing. The prospect of having a disease that could cause a variety of impairments and pain, as well as threaten your survival, can undoubtedly be seen as causing significant distress for people.

Within the theory of stress and coping, there is a discussion of primary and secondary appraisal of stress. Primary appraisal refers to the time when an individual is assessing the potential impact of an event on their lives, whereas secondary appraisal refers to the assessment of their coping abilities to deal with the stressful event (Lazarus & Folkman, 1984). A patient diagnosed with ATC will likely research the diagnosis, research treatment options, and seek information from others to assess just how stressful they define the diagnosis to be.

Smallridge and Bible (2019) referred to ATC as a significant change in health status for patients that creates a shift in needs and life perspective. How a patient experiences this shift will impact their appraisal of their stress level and their coping ability. Their perception of illness, sense of control, and existential beliefs are all part of determining coping ability. Patients will likely continue to assess and reassess the situation and their coping ability using resources at their disposal to make decisions and determine coping strategies. The informational support, emotional support, social support, spiritual support, empathetic support, administrative support, and support through emojis offered through the online ATC support group are all resources for this purpose. ATC patients will ask themselves questions about their coping ability, such asn wondering how they might cope with the diagnosis and how they can cope with treatments. Membership in the online support group fulfills the needs for these resources for coping.

Limitations of the Study

Several limitations exist in this study. First, there was only one group chosen for the sample. The ATC group used in the study was a specific online group that exists on Facebook. There are likely multiple support groups for ATC that exist, some face-to-face groups, some online, some on Facebook, and some available through other online platforms. However, in this study, only this one particular Facebook group was utilized. Additionally, within this one group, only posts within a specified date range were collected and analyzed. These parameters limit study generalizability and study results. If the study included other ATC groups, in-person groups, and posts collected at different points in time.

Second, the study has limitations based on my own experience with thyroid cancer. Due to my experience as a thyroid cancer survivor, results are not entirely void of any subjective impact. The significant difference in diagnosis type minimized any adverse effect of this subjectivity and stage to that of the group members, the steps taken to keep a reflective journal throughout the study process, and the discussions had with a colleague and mentor (committee chair) along the way. There can still be some impact on results, and therefore this is noted as a possible limitation.

Finally, posts from group members, particularly of survivors, describe events that have occurred in the past and are in narrative form. The passing of time can potentially skew the recollection of memories. People often remember events differently than the actual events as they occurred at the time (Dahlstrom, 2014). Also, being a narration of someone's subjective experience tends to be a persuasive type of writing (Dahlstrom, 2014). Therefore, posts from patients and the long-term survivors may be a varied version of actual events, another limitation.

Recommendations

Here, I suggest several recommendations for future research following the results of this study. Taking a look at in-person support groups, referred to in the literature as offline groups, in comparison to online groups for ATC is one such recommendation. The goal would be to explore whether or not the needs are the same between those patients who seek offline group participation versus those who seek online support group membership.

In an article by Fullwood et al. (2018) it was suggested that participation in an online support group versus offline group might be better suited to those experiencing conditions that are rare or misunderstood, as ATC is. Conducting a study to explore this specifically with ATC patients and survivors would be helpful. Being able to compare the types of support gained from online ATC support groups and offline groups would produce significant information to add to the literature. Further research could explore the differences among patient and survivors' needs or the types of support offered. Other studies might have researchers an opportunity to gain information on whether differences exist related to physical ability and impacts of treatment side effects. These are essential questions to be answered.

Conducting a study that includes a comparison of several online groups for ATC is another suggestion for future research. The current study only took a look at one specific group and its members. There are likely several online ATC support groups in existence. Questions to be explored while studying these groups could give insight to whether or not all online ATC groups the same. How membership is different or the same from the group I chose for my study might be an area of research. Whether members discuss the same needs or receive the same types of support could be a focus of another study. And looking at differences between online groups which exist in forums other than Facebook could be a good area to explore. A wealth of information could be added to the knowledge base.

Exploring the benefit that passive group members, or lurkers, receive from group membership would also prove beneficial. Several studies exist regarding the phenomena of lurking on Internet support groups. The study by Fullwood et al. (2018) noted that those who choose to lurk in online support groups are likely getting less benefit than those who actively participate. The authors reference the following as possible reasons for lurking behavior in online health support groups: witnessing negative interactions in the posts between other members, having had negative experiences of their own in online settings, and having had their interests met just by attending the group without the need to contribute. Finding out whether these reasons remain the same when explored in a group related to ATC could add to the knowledge in the field. There is much to be learned about this behavior in online groups.

A separate study by Han, Hou, Kim, and Gustafson (2014) discussed the level of prior Internet use and comfort level with computers as factors contributing to whether or not group members actively contribute or lurk in online support groups. This study showed that participants' level of depression had an impact on the level of active participation, as well. It would be beneficial to explore these topics in terms of ATC patients and survivors, exploring whether these same factors impact participation.

Studying those ATC patients who choose not to participate in support groups at all, online or offline, would give insight into how these individuals are coping and meeting their needs. Perhaps this would shed light on the different needs or levels of need that ATC patients experience. I was able to identify a study from 2006 by Grande, Myers, and Sutton which discussed the differences between cancer patients who seek support group participation and those who do not. I did not find any that were more recent or that touched on the development of online groups with patients who choose not to participate in support groups, despite the format. This contribution may be another positive addition to the literature.

As discussed in the literature review in Chapter 2, the formal supports that patients have during diagnosis and treatment include the doctors, nurses, technicians, radiologists, therapists, psychologists, and social workers. These people all play a role in supporting the patient and their loved ones. These formal supports are a necessary part of treatment, healing, and well-being (Morley & Goldfarb, 2015).

Informal supports are equally crucial for the quality of life for patients during treatment and healing. In a study by Merckaert et al. (2010), results showed that paying attention to the psychological and social needs of patients was crucial to healing and improved quality of life. Informal supports can be a patient’s family, friends, spouse, fellow church members, or other community members.

Online resources are another type of informal support that can be useful for patients. Several studies such as those by Ellison, Steinfield, and Lampe (2007); Magnezi, Begmann, and Grosberg (2014); Woerner (2015); and Harken et al. (2016), include points by the researchers discussing the many benefits of having access to online support groups following a cancer diagnosis. Patients and survivors benefit from sharing their experiences, asking questions, sharing information, and connecting with others who have had similar experiences. These online groups can be safe communities for patients and survivors to help each other through the healing process. They are an invaluable tool. Any research building upon the knowledge we have about these support tools can help to relieve the burden that cancer can have. The benefits impact providers, patients, survivors, their loved ones and society.

Implications

In this section, I will discuss the implications for social change as a result of my findings from this study. Thyroid cancer causes a burden for the patients who are diagnosed, but also places a burden on medical providers, family members, and on our society, as it has an impact on resources. The types of impact include emotional, psychological, financial, and social. In one article it was noted by the author that, "the national burden of thyroid cancer in the United States, both in terms of the number of affected individuals and the absolute economic cost, is projected to continue to rise in the future" (Goswami et al., 2018, p. 1). Therefore, research, such as in this study, which add to the knowledge in the literature, can help to inform providers, treatments, and patient care. The benefits of what we learn from research lessen the burden of care on our system as a whole.

Improvements made to the resources available to patients and survivors can help to relieve some of the burden experienced by individuals and families affected by thyroid cancer, and in particular ATC. Experiencing distress is common when people hear they have cancer (American Cancer Society, 2018a). Improved access to support and resources can decrease levels of distress. When providers have thorough knowledge about patients' needs and how to meet them, there is an opportunity to develop new resources and for existing resources to be made more readily available to patients.

According to my results, the content of the posts published by group members shows that there remains a significant need for patients in the areas of emotional support, social support, informational support, and empathetic support. Administrative support and the use of emojis for communicating support also address needs. A study by Yli-Uotila et al. (2013), discussed how a need for informational and emotional support is connected to the behavior of cancer patients to search the Internet for resources that might meet these needs. Ensuring that all ATC providers discuss potential needs with patients and offer information about related resources can be worthwhile. Providers might consider individual therapy as an option, in-person support groups, and online support groups. Additionally, the study by Yli-Uotila et al, noted that having nurses connect with patients over the Internet to follow up after hospital visits minimized burden, especially when patients travel great distances for services or treatment. The psychosocial needs being a greater focus for medical providers with their patients is beneficial and can help to improve the efficacy of treatments.

Medical groups might consider having a social worker or therapist work at their location to meet with patients and families after diagnosis and throughout treatment. Two authors here state that, “in palliative care, psychologists are essential in providing support and counsel for end-of-life patients, their family, and other healthcare providers” (Rego & Nunes, 2016, p. 6). With a life-threatening diagnosis of ATC, the inclusion of a psychologist, therapist or social worker would be a positive approach towards patient care. They are having someone to meet with them shortly after receiving a diagnosis, whether same day or shortly after that, could reduce the amount of confusion and fear that is often experienced by patients. Discussing potential reactions to diagnosis and related emotions in a reassuring way might be beneficial. Patients could be introduced to resources right away, minimizing some of the distress that often follows diagnosis (American Cancer Society, 2018a).

Providers' offices might think about having a list of resources available to patients. The list could include information about local in-person support groups that exist, online support groups that are available, chat rooms and blogs. Having a nurse or social worker available to discuss the list with them, rather than just handing it out or having it sit on a desk, would help ensure that patients actually read the list, understand how to access the resources, and allows patients to ask any questions they might have about the resources listed. Patients might feel supported more globally if their providers demonstrated an increased concern for their emotional, psychological, and social well-being in connection with medical treatment plans. When patients think that there is a genuine focus on these needs, in addition to the medical needs, the easing of anxieties increases and in turn, a reduction in distress can occur, which can improve chances of healing. Wu et al. (2018) discussed how a focus on the quality of life and mental health needs supersede a singular focus on survival alone.

Another idea for addressing patients' needs is providing a small computer station for patients within a provider's office. This station would allow those who may not have Internet access at home or even a computer, access to these online resources. Nurses or social workers might be available to assist patients with logging on and locating the available resources, whether they be in the form of articles, sites, or blogs or in the form of online groups which they can become a participant. Assisting patients in the process of accessing these resources could increase the possibility of them using them. Additionally, patients might feel that their facility provided as much support as possible, above and beyond just the medical treatment.

Use of the Internet for support with health issues is valuable in many ways. This resource is cost-effective, can reach an enormous number of people, is available all day and all night, and people can participate anonymously (Yan & Tan, 2014). The use of online supports through social media has also been referred to by Garlapow (2016) as integral to the cancer care community. Online support groups are a place for people to feel safe and secure to post about their experiences and to ask others about their experiences. Participation offers a particular type of experiential knowledge that members may not receive otherwise, especially when dealing with such a rare diagnosis. Harkin et al. (2016) found that being diagnosed with a rare form of cancer can create an even more negative experience than a person diagnosed with one of the prominent four cancers (breast, prostate, lung, and bowel). This information points to a great need for support for those with diagnosed ATC.

Davis and Calitz (2014) conducted a study where they found participation in online support groups can be especially beneficial when coping with a life-threatening illness, as it allows for a sense of community and understanding, provides practical information, can create social regulation, give emotional validation, allow for improved mood and outlook, and increase resilience in terms of coping. Additionally, these authors refer to participation as a way to combat loneliness, known to impact stress hormone levels and immune function negatively. Therefore, online support group participation can benefit members socially, emotionally, and physically. Portier et al. (2013) stated even lurking behaviors are a type of participation in online support communities which can be helpful with coping, and so active participation is not required to experience the benefits of membership.

An ATC diagnosis and the related treatments can create physical problems that impact a patient’s ability to attend face-to-face support groups. Additionally, geographic location and the rarity of the diagnosis can negatively impact availability and access to face-to-face support. Participation in an online support group can address these issues and connect patients with social, emotional, and informational support they may not have otherwise (Davis & Calitz, 2014).

Bringing the use of the Internet to patients to increase the numbers of patients who might access these valuable resources could undoubtedly be a positive impact on treatment response and the level of burden on caregivers, providers, and society. The study by Grande et al. (2006) noted that cancer patients benefit from participation in online support groups, but despite the known benefit, there are still several people who do not access these groups. Perhaps with the encouragement and assistance of their medical providers, informing patients about the possible needs they could face, and discussing how these resources could help, more patients might connect with these resources. The impacts of being able to connect patients with these resources would likely include improvement in patients’ treatment response, quality of life, a lessened burden on loved ones and medical teams, as well as an impact societally.

The findings in this current study, regarding the many benefits of online support groups in meeting the needs of ATC patients and survivors impacts social change. Patients with ATC have enormous impacts on their physical well-being and quality of life (Molinaro et al. (2017). Gaining knowledge about this valuable resource can improve support and resources for patients while coping with the disease and related treatments. Supporting these individuals can help reduce stress, fear and anxiety. Folkman (2007) noted that positive emotions could be a benefit in terms of physiological and psychosocial coping ability. When patients' distress decreases, there is a reduced need by patients and the burden on loved ones and providers is reduced. A reduced need for treatment, medications, or other services minimizes the burden on our society as well, in terms of insurance, medical costs, personnel costs, and in terms of available resources overall. Research on how to support patients improves outcomes and therefore can have a significant positive societal impact.

Conclusion

In the current study, I examined the experience of anaplastic thyroid cancer patients and families. I explored the needs of the patients, survivors, and the involvement of their loved ones in healing. I learned about the informational needs that patients have, as this rare disease can leave patients feeling uninformed by providers. I read about their experience of a new normal following diagnosis, during treatments, and after, as the side effects change their lives in a variety of ways. I saw in their posts, the fears, the questions, the guidance, and the connectedness they expressed with one another. And through their posts, I could interpret the needs that met through group participation, as well as the deep appreciation they felt for the support they received.

ATC patients and survivors have many needs as they cope and adjust to their new normal. Participation in the online support group studied allowed members to access caring, advice, common-experience, warm regard, lived-understanding, spiritual connection, empathy, real-time information on treatments, and most of all, hope. All of these are needs patients have in adjusting to their new normal that they do not get, and possibly cannot get, solely from their medical teams and even mental health professionals. The variety in the types of support they can receive might only be accessible through participation in groups such as the one in this study. Members provide for each other a particular kind of connection and understanding not available from any other source. These groups play a unique role in meeting the needs of the ATC patient and survivor population. And participation in these groups should be encouraged and made as accessible as possible; they positively impact participants, their loved ones, and society as a whole.

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