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Examination of Principles of Palliative Care to Bolster the Focus on Quality of Life in Head and Neck Cancer Survivorship

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ABSTRACT

Introduction: Potential reductions in perceived quality of life (QoL) are associated with the diagnosis of head and neck cancer (HNCa) and the consequences of its treatment. HNCa survivorship care is intended to address the challenges experienced in biopsychosocial domains of functioning that influence perceived QoL. However, owing to the conventionally medicalized provision of HNCa survivorship care, comprehensive consideration of QoL may be excluded and ultimately restricted to the provision of palliative care. If principles of palliative care are included throughout HNCa survivorship care they may serve to bolster the focus on QoL. The purpose of this study centred on the identification and description of laryngectomees' and physicians' perceptions of the inclusion of principles of palliative care that may support QoL in HNCa survivorship care.

Methods: A web-based questionnaire was developed to collect data pertaining to laryngectomees' and physicians' perceptions of principles of palliative care in the context of HNCa survivorship care both under ideal circumstances and in actual practice. Descriptive and inferential statistics were used to summarize and analyze the laryngectomees' and physicians' responses. Correlational analyses also were completed to identify relationships among participants' perceptions.

Results: Data indicated that the laryngectomees and physicians believed that the principles of palliative care *should* be regularly included in HNCa survivorship care. However, the laryngectomees' and physicians' responses suggested that the inclusion of these principles in HNCa survivorship care in actual practice is more limited and quite variable in nature. As such, significant differences were identified between the participants' perceptions within the context of ideal circumstances and actual practice.

Conclusions: The findings of the present study provide insights into laryngectomees' and physicians' perspectives of the principles of palliative care in the context of HNCa survivorship care. A commonality among these foundational principles is their role in enhancing QoL. Thus, the findings of the present study provide information that may promote the inclusion of aspects of care that bolster the focus on QoL in HNCa survivorship care.

Keywords: Quality of life, head and neck cancer, total laryngectomy, survivorship, palliative care

SUMMARY FOR LAY AUDIENCE

Individuals who are diagnosed with head and neck cancer (HNCa) are likely to experience substantial reductions in their quality of life (QoL) even after the completion of their cancer treatment. However, the care provided to these individuals tends to be aimed at treating the disease itself and is commonly limited in its capacity to fully address QoL issues. Care that is targeted to fully address QoL issues is commonly provided only in the end-of-life context when the medical subspeciality of palliative care often becomes involved. To increase the focus on the QoL of individuals who have completed treatment for HNCa, the principles of palliative care may be included in the care that is delivered outside of the end-of-life context. This study sought to gather information on the perceptions of individuals who have completed treatment for HNCa, specifically those who have undergone total laryngectomy (i.e., removal of the voice box), and the physicians who provide care for HNCa survivors. These individuals were asked about their opinions regarding whether certain principles of palliative care that support QoL should be present in the posttreatment care received by HNCa survivors under *ideal circumstances*, and whether these principles are *actually* present in HNCa survivors' posttreatment care.

The information gathered indicated that HNCa survivors and physicians believed that the principles of palliative care *should* be regularly included in HNCa survivors' posttreatment care. However, the HNCa survivors and physicians also believed that in actual practice the inclusion of these principles in HNCa survivors' posttreatment care is more limited and variable. A commonality among these principles of palliative care is their role in supporting and enhancing QoL. Therefore, this information may inform how the focus on HNCa survivors' QoL could be increased in the care they receive after treatment completion.

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CHAPTER 1

Introduction and Review of Literature

Overview

> *For the meaning of life differs from man to man, from day to day and from hour to hour. What matters therefore, is not the meaning of life in general but rather the specific meaning of a person's life at a given moment.* (Frankl, 1962, p. 110)

Quality of life (QoL) presents as a construct that serves to link together one's life experiences (Doyle, 1994). By providing a cohesive connection between an individual's experiences, including those within health and illness, the construct of QoL captures the perceived meaningfulness of one's life. By extension, one's personal valuation of QoL may be further conceptualized as the perception that "life is worth living and that living has meaning" (Doyle, 1994; Doyle & MacDonald, 2019, p. 445). As part of this perception, physical, psychological, and social functioning are traditionally considered to be central, as well as health-related factors, sexuality, and spirituality (Gritz et al., 1999; Klein et al., 2014; Lawton, 2001). When considered collectively, this array of factors that contribute to one's perception of QoL portends that perceived QoL is highly dynamic and individualized (Doyle & MacDonald, 2019). Thus, QoL is likely to vary considerably over the course of one's life and from person to person (Mount & Cohen, 1995; Revicki et al., 2000). However, although one's subjective perception of QoL is expected to be variable in nature, the conceptual schema of the construct of QoL whether perceived positively or negatively by the individual, is a constant throughout the life course.

Since the conceptual schema of QoL serves to link together one's experiences within health and illness, the confrontation of any disease class or entity exerts a profound impact on

QoL. A poignant example of such a disease is head and neck cancer (HNCa) since the consequences of the disease and its treatment manifest in profound disturbances to the array of factors that contribute to one's perceived QoL (MacDonald et al., 2021). As such, the perceived meaningfulness of an individual's life is likely to be significantly impacted by the experience of HNCa (Doyle & MacDonald, 2019; Lee et al., 2017). More specifically, potential reductions in one's perceived QoL are often concomitant with the diagnosis of HNCa and the myriad short- and long-term consequences of its treatment (i.e., disturbances to the ability to breathe, eat, and engage in verbal communication) (Gritz et al., 1999; Hassan & Weymuller, 1993; Murphy et al., 2007; Terrell, 1999). While the confrontation of HNCa may precipitate one's QoL to be negatively perceived, QoL as a construct remains as a consistent schema that continues to link together the individual's life experiences, including those associated with the disease. Thus, although the focus tends to be on disease management, if QoL-related outcomes are to be optimized and individuals treated for HNCa are to return to as meaningful a life as possible, the focus on QoL within the clinical field of head and neck oncology must be bolstered.

In general, the field of oncology has a propensity to regard one's illness experience through a disease-focused lens that unwittingly can eclipse consideration of QoL. More specifically, oncological practice tends to be directed by a biomedical model of care in which the physical aspects of disease are emphasized and the psychosocial aspects are minimized (Bornbaum et al., 2013; Engel, 1977). Moreover, although indices of the quantitative period of survival often guide practice in oncology, this perspective provides a narrow and insufficient view of an individual's lived experience of illness (Doyle & MacDonald, 2019; Galvin & Todres, 2013). As such, consideration of an individual's perceived QoL is likely to be displaced by the predominant disease focus in oncology. However, if oncological care provision does not address factors fundamental to QoL, treatment and rehabilitation are unlikely to comprehensively address one's illness experience (Doyle, 2005; MacDonald et al., 2021).

It is important to acknowledge that the disease-focused approach to oncological care has brought about vital advances in disease management. It is, however, often only when treatment does not irradicate the disease that QoL is addressed as the main focus of care (Strand et al., 2013). In such instances the principles of palliative care are utilized to achieve the shift from disease-focused care to QoL-focused care (MacDonald et al., 2021). By extension, consideration of QoL is commonly reserved for individuals who receive end-of-life care. However, acknowledging the potential for significant detriments to QoL associated with definitive treatment for HNCa, it is negligent to not provide care that addresses the QoL of HNCa survivors. In other words, "it is paradoxical that individuals who are *dying* receive care that is more conducive to the preservation of quality of *life* than survivors who are still *living* without the potential of imminent death" (MacDonald et al., 2021, p. 2). It follows logically that HNCa survivors' QoL may be more comprehensively addressed if the principles of palliative care are applied outside of their traditional end-of-life context.

Ultimately, the principles of palliative care may serve to bolster the focus on QoL in the care provided to HNCa survivors for whom death is not an imminent outcome. In the sections to follow, a comprehensive introduction to considerations of QoL in HNCa will be presented. Subsequently, the disease focus that guides practice in the area of oncology will be discussed to illustrate the concomitant exclusion of the consideration of QoL. Next, the notion of cancer survivorship, which was originally proposed to augment the disease focus in oncological care will be examined. The medicalization of survivorship and its limited scope of QoL-focused care in the context of HNCa will then be presented. Finally, the foundational principles of palliative care will be delineated in consideration of their relevance to bolstering the focus on QoL in HNCa survivorship. The collective information addressed will serve to provide an enhanced structure to the understanding of care in the context of HNCa survivorship.

Considerations of Quality of Life

The construct of QoL can and does exist with or without the confrontation of a disease. In essence, although health-related factors and the experience of disease may be central among the variables that influence an individual’s perceived QoL (Murphy et al., 2007), QoL can be conceptualized as a distinct construct that may be understood with or without the intervening forces of disease. Accordingly, conceptualizations of QoL allow the focus to lie on the individual, and not on the presence or absence of disease. By extension, consideration of contributors to perceived QoL may facilitate an awareness of the notion that a disease is not a valid way to identify an individual. When consideration of QoL is the focus, one is reminded that there is always a *person* behind the disease, and it is that individual who has the unique ability to judge how they are doing (Myers, 2005). When the focus on QoL is bolstered it allows consideration of the *person* to be brought to the forefront of care provision and emphasizes that a person is not reducible to their diagnosis. Thus, the operationalization of QoL is warranted in the context of the present treatise.

QoL denotes individuals’ perceptions of their position in life as contextualized by their physical, psychological, and social functioning (Doyle & MacDonald, 2019; World Health Organization [WHO], 1997). An individual’s personal values, beliefs, past experiences, and level of independence further influence perceived QoL (Murphy et al., 2007; WHO, 1997). Among the many factors that influence one’s valuation of QoL, considerations of spirituality, sexuality, symptoms, pain, and health-related factors are also central (Gritz et al., 1999). As such, owing to the nature of the domains of its determinants, QoL is recognized not only to be dynamic in situations of both health and disease, but also to be highly subjective (Mount & Cohen, 1995; Revicki et al., 2000). Accordingly, QoL is individualized and the interaction between the domains of functioning that contribute to one's valuation of QoL is not uniform from person to person (Myers, 2005). Hence, the ability to describe QoL accurately must be done on an individual basis.

For example, two individuals may have comparable diagnoses of HNCa (i.e., similar tumour size, location, and stage) and receive similar treatment, however, their perceived QoL has the potential to vary substantially. Thus, although there is consensus in the literature that an individual's QoL is likely to be negatively perceived secondary to their experience with HNCa (Doyle & MacDonald, 2019; Gritz et al., 1999; Hassan & Weymuller, 1993; Maclean et al., 2009; Terrell, 1999), a linear relationship does not exist between the experience of HNCa and core domains of QoL owing to their subjective nature (Huber et al., 2010). In essence, Mount and Cohen (1995) posited that "the relative importance of each determinant of QoL varies tremendously from individual to individual" (p. 123). Thus, the relationship between the experience of disease and one's QoL cannot be characterized as linear since QoL is idiosyncratically influenced by the determinants that contribute to one's perception (Lawford & Eiser, 2001; Mount & Cohen, 1995). In other words, the relative weighting of the various domains that determine perceived QoL is unpredictable in nature (Myers, 2005; Perry et al., 2015).

QoL is also recognized to be a multidimensional construct (Curran et al., 2007; Ninu et al., 2015; Sayed et al., 2009; Singer et al., 2013). Nevertheless, the overall effect of HNCa on an individual's QoL is unlikely to be directly proportional to the sum of the deficits in the core functional domains that modify one's perceived QoL (i.e., physical, psychological, and social domains of functioning), especially since these domains are unlikely to be mutually exclusive (Doyle & MacDonald, 2019). For instance, if QoL is quantified through the administration of a QoL measurement instrument (e.g., The European Organisation for the Research and Treatment of Cancer Quality of Life Questionnaire [EORTC QLQ-C30] and/or The European Organisation for Research and Treatment of Cancer Head and Neck Cancer Module [EORTC QLQ-H&N35]), two individuals may "score" the same quantified value of QoL. However, the same quantified QoL score does not indicate that each individual experiences the same perceived QoL since each individuals' idiosyncratic valuation of the multiple dimensions that contribute to their QoL must be considered. Rather, the unpredictable relationship between the functional deficits a HNCa survivor may experience in biopsychosocial domains is more aptly characterized as interdependent and reciprocal in nature with a somewhat multiplicative effect on the survivor's QoL (Doyle & MacDonald, 2019; Perry et al., 2015).

Quality of Life following Treatment for Head and Neck Cancer

HNCa refers to malignant neoplasms that mainly originate from the epithelial lining of the paranasal sinuses, nasal cavity, oral cavity, salivary glands, pharynx, and larynx (Howren et al., 2012; Murphy et al., 2007). Squamous cell carcinomas of the mucosal surfaces of the upper aerodigestive tract account for approximately 95% of all HNCa diagnoses (Campisi & Giovannelli, 2009; Sahovaler et al., 2019). Individuals who are diagnosed with and treated for HNCa are faced with an overwhelming collection of biopsychosocial treatment sequelae that go beyond the impact of the disease proper to substantially impact perceived QoL (Bjordal &

Kaasa, 1995; Murphy et al., 2007; Wolff, 2007). This is particularly true when malignant tumours arise in the larynx (Damrose & Doyle, 2019).

The larynx is located at the junction between the respiratory and digestive tracts, such that it is essential in breathing for respiration and speech, as well as for airway protection during swallowing (Sahovaler et al., 2019; Starmer, 2019). The larynx is comprised of multiple structures situated in three subsites including the supraglottis (epiglottis, false vocal folds, ventricles, aryepiglottic folds, and arytenoids), glottis (true vocal cords, including the anterior and posterior commissures), and the subglottis (Sahovaler et al., 2019). Laryngeal carcinoma may develop above, below, or directly on the vocal cords (i.e., supraglottic, subglottic, or glottic, respectively) (Bailey et al., 2007; Marur & Forastiere, 2008; Silver & Ferlito, 1996; Vokes, 2012). While tumor site has important implications on treatment modality selection, consideration of additional disease-related factors (i.e., tumour staging, lymph node involvement) and personal factors (i.e., age, cognitive status, goals of care) further influences viable treatment options (Marur & Forastiere, 2008; McQuade et al., 2016; Shah & Lydiatt, 1995; Vokes, 2012; Walden & Aygun, 2013).

Both surgical and non-surgical treatment modalities may be utilized in contemporary management of laryngeal carcinoma (Deschler, 2005; Forastiere et al., 2003; Forastiere et al., 2013; Sahovaler et al., 2019; Wolf et al., 1991). Surgical options for laryngeal carcinoma include partial or total laryngectomy, as well as minimally invasive procedures such as transoral laser microsurgery or transoral robotic surgery (Jackel et al., 2007; Sahovaler et al., 2019). Typically, tumours that originate in the supraglottic region are managed through partial (conservative) laryngectomy procedures completed by either an open or transoral approach. Small tumours that arise from the glottis may be treated with transoral laser microsurgery, while larger tumors of the glottic or subglottic larynx require total laryngectomy (Starmer, 2019). While subtotal laryngectomy preserves the natural pathways of respiration and deglutition, total laryngectomy results in the disconnection of the lower airway from the upper respiratory tract. That is, secondary to the removal of the larynx, the mouth and nose are no longer in communication with the trachea. A new airway is created when the trachea is brought forward and its superior cartilaginous ring is secured to the anterior surface of the base of the neck (Damrose & Doyle, 2019; Deschler, 2005; Eadie, 2003; Sharpe et al., 2018). As such, owing to the functional significance of the anatomical structures impacted by total laryngectomy, its influence on QoL can be profound. This will be discussed at length in upcoming sections of the present treatise.

In an attempt to preserve the structure and function of the larynx, laryngeal cancer may be treated non-surgically with radiation therapy with or without chemotherapy. In radiation therapy x-ray technology is utilized, while in chemotherapy anti-cancer drugs are employed to control, destroy, and shrink cancer cells (Hillman et al., 1998; Marur & Forastiere, 2008; Wolf et al., 1991). Radiation therapy and/or chemotherapy may be used separately or in conjunction with surgery to treat laryngeal cancer, but in either case, the side effects of these methods of disease management are notable, with a significant impact on QoL (Kearney & Cavanagh, 2019). More specifically, despite offering organ preservation, radiation and chemotherapy may cause a broad range of physical (e.g., pain, xerostomia, dysphagia, mucositis, fibrosis, nausea), psychological (e.g., distress, depression, anxiety, negative body image), and social (e.g., disrupted social interaction and participation, the experience of stigma) consequences that are likely to have a profound effect on QoL (Bornbaum et al., 2012; Cohen et al., 2015; Howren et al., 2012; Kearney & Cavanagh, 2019; Reeve et al., 2016; Ringash et al., 2018; Vartanian et al., 2017). Nevertheless, when organ preservation is not possible, considerable biopsychosocial challenges also arise secondary to total laryngectomy. Alterations to breathing, swallowing, and verbal communication experienced by a laryngectomee[1] provide insightful examples of the aforementioned reciprocal and interdependent relationships that exist between deficits in the physical, psychological, and social domains of functioning that influence QoL.

Alteration to Breathing Following Total Laryngectomy. In total laryngectomy, the surgical separation of the upper (nasal passages and pharynx) and lower (trachea, primary bronchi, and lungs) airways necessitates the establishment of a permanent tracheostoma at the level of the sternal notch which directs air into and out of the lungs to facilitate breathing (Hilgers & Ackerstaff, 2005; Lewis, 2019). This represents major disruption to the anatomy and physiology of one's pulmonary health and pulmonary environment (Lewis, 2019). More specifically, since the airway is reliant on the tracheostoma postlaryngectomy instead of the mouth and nose, the upper airway is rendered void of the functions previously associated with normal respiration, thereby producing considerable changes in breathing (Hilgers & Ackerstaff, 2005; Lewis, 2019).

Most notably, when air no longer passes through the upper respiratory tract, its functions and contributions to respiration including humidification, warming, and filtration are precluded (Harris & Jonson, 1974; Hilgers & Ackerstaff, 2005; Lewis, 2019; Todisco et al., 1984; Togawa et al., 1980; Torjussen, 1968; Usui, 1979). As a result of the inhalation of unconditioned air via the tracheostoma, mucus production is increased in response to decreased heat and moisture exchange and filtration of airborne particles (Lewis, 2019). In turn, laryngectomees commonly experience increased and excessive sputum/phlegm production and concomitant coughing,

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[1] Although it is not "person-first language", which inherently acknowledges that the individual who has the disease is not reducible to their diagnosis, the term "laryngectomee" is positively regarded and preferred by those who have undergone total laryngectomy (Doyle, 2018).

shortness of breath, forced expectoration, and crusting at or within the stoma (Hilgers et al., 1990; Hilgers & Ackerstaff, 2005; Lewis, 2019; Pruyn et al., 1986). Additionally, since air does not pass through the nasal cavity and nasopharynx following total laryngectomy, odorant molecules are prevented from reaching and stimulating the olfactory epithelium (Santos et al., 2016). This loss of olfaction contributes to additional negative sequelae including the impairment of taste, decreased appetite, poor nutritional status, reduced enjoyment of meals, and weight loss (Lewis, 2019; Risberg-Berlin et al., 2006; Santos et al., 2016; van Dam et al., 1999).

In consideration of these objective, physical impairments of the pulmonary health and functioning of laryngectomees, it follows that the pulmonary changes that result from total laryngectomy are likely to have a substantial impact on the psychological and social domains of functioning. More specifically, these challenges related to respiratory function within the physical domain have been found to be associated with a broad range of challenges within the psychological domain such as fatigue, sleeping problems, depression, anxiety, self-esteem, and problems with sexual functioning (Ackerstaff et al., 1994; Batioglu-Karaaltin et al., 2017; Hilgers et al., 1990; Hilgers & Ackerstaff, 2005). Additionally, these challenges both within the physical and psychological domains have the potential to negatively influence a laryngectomee’s desire for social interaction and feelings of social anxiety (Ackerstaff et al., 1994; Hilgers et al., 1990; Lewis, 2019). Therefore, the influence of pulmonary changes and the concomitant interdependent deficits within these multiple areas of functioning on a laryngectomee’s perceived QoL cannot be understated (Ackerstaff et al., 1994; Hilgers et al., 1990; Lewis, 2019).

Fortunately, laryngectomees’ perceived QoL has been shown to be positively impacted by improved pulmonary functioning and respiration afforded by the implementation and use of a heat and moister exchanger (HME) (Ackerstaff et al., 1993; Ackerstaff et al., 1998; Ackerstaff et al., 2003; Bien et al., 2009; Hilgers et al., 1991; Hilgers & Ackerstaff, 2005; Lewis, 2019). HMEs function to augment the heat and moisture exchange, filtration, and resistance capacities of the postlaryngectomy airway and, thus, serve as a primary tool for facilitating improvement of the pulmonary functions that most significantly impact QoL (Lewis, 2019; Zuur et al., 2007). Although use of an HME provides significant pulmonary functioning gains and concomitant improvement of perceived QoL, alteration to a total laryngectomees' swallowing function further influences the domains of functioning involved in one's valuation of QoL.

Alteration to Swallowing Following Total Laryngectomy. In addition to the marked alterations to breathing secondary to total laryngectomy (Bohnenkamp, 2019), the structural changes secondary to total laryngectomy can also result in dysphagia (i.e., reduced swallowing efficiency) (Lazarus, 2005; McConnel, 1988; Starmer, 2019). Pre-treatment, many individuals experience aspiration which increases their risk of aspiration pneumonia. This risk is mitigated through laryngectomy; however, swallowing efficiency becomes significantly more impaired (Starmer, 2019). Postlaryngectomy swallowing problems experienced in the physical domain of functioning can include somewhat diminished tongue function which may impact efficient manipulation of foods and/or liquids (Lazarus, 2005). An additional problem within the physical domain may also pertain to the higher pharyngeal swallowing pressures that are required to propel a bolus through the pharynx, thereby making it more challenging to swallow certain types of food (Lazarus, 2005; McConnel, 1988). The consistently high intrabolus pressures observed postlaryngectomy compounded by stricture (i.e., narrowing of the pharynx and/or upper esophageal lumen) substantially restrict bolus flow through the pharynx and passage into and through the esophagus (Davis et al., 1982; Lazarus, 2005; Starmer, 2019; Zhang et al., 2016). Bolus flow through the upper pharynx also may be impeded by the development of scar tissue that forms an immobile pseudoepiglottis secondary to vertical closure (Davis et al., 1982; Lazarus, 2005; Starmer, 2019).

When a laryngectomee experiences deficits to their swallowing function the effects are often also extended to the psychological and social domains of functioning. For instance, depression, anxiety, and stress are more commonly reported in laryngectomees who experience dysphagia compared to those who do not experience swallowing difficulty (Maclean et al., 2009; Nguyen et al., 2004). The experience of dysphagia has also been reported to heighten a laryngectomee's social withdrawal and/or isolation (Doyle, 1994; Threats, 2007). More specifically, the experience of dysphagia commonly exerts a wide-ranging influence on laryngectomees' ability to participate in culturally accepted eating behaviours at social gatherings and can deter laryngectomees from engaging in shared mealtimes in social settings (Patterson et al., 2015; Threats, 2007). More specifically, secondary to the experience of dysphagia, laryngectomees may struggle to conform to social customs surrounding eating and drinking that influence acceptable methods of consumption, food choices, and accepted timing of meals (DeRenzo, 1997). As such, dysphagia can prompt laryngectomees to attribute a strictly nutritional and survival-based meaning to food that may clash with socially defined perceptions of food which have minimal connection to nutritional factors but are instead in place to define and solidify social relations (DeRenzo, 1997). Accordingly, the perceived indignity and/or stigma of restricted food choices and noticeable compensatory strategies to improve bolus flow may be amplified in social settings and promote social withdrawal (Patterson et al., 2015; Starmer, 2019). Taken together, the physical, psychological, and social challenges concomitant with the experience of dysphagia secondary to total laryngectomy exert a significant impact on the laryngectomee's perceived QoL (Doyle, 1994; Eisbruch et al., 2011; Gillespie et al., 2005; Starmer, 2019).

Alteration to Verbal Communication Following Total Laryngectomy. In quiet respiration prior to laryngectomy, inspired air travels through the nasal (and/or oral) cavities and abducted vocal folds at the level of the larynx, filling the lungs. Quiet expiration is a passive event, in which relaxation of the thorax/abdomen and lungs propels air through an abducted larynx and the oral and nasal cavities (Bohnenkamp, 2019). For normal voice/speech production, this expiratory air passes through adducted vocal folds, creating a sound source that is further shaped and manipulated as air travels through the vocal tract (Bickford et al., 2013; Eadie, 2003; Sharpe et al., 2018). Thus, the extensive surgical alterations to the upper aerodigestive tract also render the laryngectomee incapable of natural laryngeal voice production. More specifically, following total laryngectomy, not only is one's larynx removed, but one's ability to inspire or expire via the oral and nasal cavities is also eliminated, thereby fundamentally changing the way voice and speech can be produced. The elimination of a HNCa survivor's means of natural verbal communication following total laryngectomy is undoubtedly a significant loss with a broad impact on QoL (Eadie et al., 2013; Eadie et al., 2014; MacDonald et al., 2021). However, to restore communication, several methods of "alaryngeal" communication exist, including esophageal speech (ES), tracheoesophageal (TE) speech, and electrolaryngeal (EL) speech.

In ES, the speaker injects air into the esophagus, which serves as an air reservoir. Release of this "esophageal air" can set residual pharyngeal and esophageal tissue into vibration, generating sound that can be shaped by articulators of the vocal tract (Cox et al., 2015; Diedrich, 1968; Doyle, 1994; Doyle & Finchem, 2019; Eadie, 2003; Sharpe et al., 2018). Laryngectomees who utilize the surgical-prosthetic method of TE speech undergo a surgical procedure in which a prothesis is inserted into a surgical fistula that is created between the trachea and esophagus (Blom et al., 1986; Eadie, 2003; Singer & Blom, 1980). Following a TE puncture, voice is produced when the laryngectomee inhales through and then occludes the tracheostoma. This pulmonary-driven air is then redirected through the TE prosthesis into the esophagus causing the muscles of the upper esophagus and lower pharynx (i.e., the pharyngoesophageal segment) to vibrate, thereby creating a sound source that is articulated in the oral cavity (Blom et al., 1986; Cox et al., 2015; Doyle, 1994). While the aerodynamic driving sources for both ES and TE speech utilize the same alternative voice source, the manner that the system is driven differs between these two methods (Doyle et al., 1988).

EL speech requires the laryngectomee to use an external electronic sound source (the artificial electrolarynx) that may be positioned against the neck (transcervical) or directed into the oral cavity (intraoral). The transcervical EL device transfers the external sound source through the neck tissues and these vibrations travel into the vocal tract and up to the oral cavity where sound can be articulated into speech (Cox et al., 2015; Doyle, 1994). The intraoral EL device uses a sound source which can be introduced directly into the oral cavity (Doyle, 1994). Although ES, TE, or EL speech methods may serve to restore a means of postlaryngectomy communication, ongoing consequences in psychological and social domains of functioning are not insignificant to QoL outcomes. It is important to note, however, that a hierarchy of superiority does not exist among the modes of alaryngeal speech and acquisition of a certain mode of alaryngeal speech over the others is unlikely to have implications on subsequent adjustment or QoL (Blood et al., 1992; Moukarbel et al., 2011).

Although the *mode* of alaryngeal speech acquired is inconsequential to QoL, the physical deficits that precipitate use of any mode of alaryngeal speech are likely to exert a negative influence on a laryngectomee’s psychological and social functioning, thereby influencing the laryngectomee’s valuation of QoL. More specifically, depression, distress, and reduced self-esteem may be prompted in relation to the sound of the laryngectomee’s new alaryngeal speech, which is perceptually distinct and distinguishable from the sound of normal verbal communication (Cox et al., 2015; Eadie, 2003; MacDonald et al., 2021; Sharpe et al., 2018). In turn, these psychological deficits may impact successful verbal communication, as well as the laryngectomee’s social participation and social roles (vocational and avocational), and result in social withdrawal or isolation (Eadie, 2003; MacDonald et al., 2021; Sharpe et al., 2018). In essence, the interactions between the physical, psychological, and social domains of functioning are substantial and multi-directional in nature (MacDonald et al., 2021). As such, the interdependent and reciprocal nature of the biopsychosocial deficits and the concomitant impact on QoL that occurs secondary to alterations to verbal communication becomes increasingly apparent (Doyle, 2005; Eadie, 2003).

Additionally, since verbal communication is most commonly the primary means one uses to directly raise and address their concerns, worries, and/or fears, a central vehicle for optimizing QoL has become limited (Doyle, 2005; Ma & Yiu, 2001). Thus, since the laryngectomee’s ability to verbally communicate is compromised, the ability of the clinician to make logical steps in recognizing and understanding the interdependent and reciprocal relationships between domains of functioning becomes of critical importance (Doyle & MacDonald, 2019). Clinicians must be aware that any given deficit experienced by a laryngectomee may extend to other domains of functioning, where the collective cascade of functional challenges exerts a potentially profound influence on QoL (Doyle & MacDonald, 2019). In essence, if the focus on QoL is bolstered in HNCa survivorship, it may serve to highlight the functional challenges since the conceptualization of QoL delineates domains of functioning in which laryngectomees may be struggling. Owing to the interdependent nature of the domains of functioning, the conceptual framework of QoL may serve to reinforce that if a clinician observes a deficit in one domain, it is likely that a reciprocal impact is being experienced in other domains of functioning that may not be observed or reported. If the clinician is aware of these reciprocal and interdependent relationships as triggered by increased consideration of the construct of QoL, the determinants of QoL may be more comprehensively addressed.

It is also important for clinicians to acknowledge that although QoL may become negatively perceived secondary to the experience of laryngeal cancer and the consequences of its treatment, the connecting force of the theoretical schema of QoL remains a constant in a HNCa survivor’s life. In essence, regardless of whether QoL is positively or negatively perceived, the conceptual schema of QoL evokes the notion that the obligation to measure, assess, and ultimately address HNCa survivors’ QoL remains constant. Thus, consideration of QoL in HNCa survivorship must not be eclipsed by a disease-focused approach that conforms to the biomedical model of illness and care provision. Unfortunately, the more traditional, albeit limited biomedical model guides the provision of care in the area of oncology and confines the consideration of QoL to other domains of care (Doyle & MacDonald, 2019; MacDonald et al., 2021). Accordingly, medical advancements concomitant with the disease focus in oncology have facilitated improved disease management, but this often comes at the expense of HNCa survivors’ QoL (Hadad, 2009).

The Disease Focus in Oncology

The prevailing disease focus that guides practice in oncology may obfuscate the importance of comprehensively addressing the multidimensional aspects of one’s illness experience and QoL (Davis et al., 2015). By extension, the *individual* who has the disease may be overlooked in favour of consideration of the pathophysiology and biology of disease as the primary entities of illness. It is acknowledged that certain aspects of the individual are likely to be considered through a disease-focused approach to oncological care, however, these tend to be the biological aspects (i.e., sex, age, race). Conversely, the psychosocial aspects of the individual may not be attended to in a rigorous or planned manner. Moreover, the disease focus in oncology may promote an emphasis on the analysis and interpretation of the disease process at the level of cells, tissues, organs, and systems (Galvin & Todres, 2013; Little et al., 1998). Thus, the disease focus in oncology is driven largely by consideration of objective data (Lee et al., 2017; Ueda & Okawa, 2003). It follows logically that the person diagnosed with and treated for the disease becomes easily identifiable simply as an organism, with concomitant loss of the recognition of the individual's subjective and multidimensional experience of illness and perceived QoL.

The disease focus that is characteristic in oncology may permit a reductionist approach to care that could promote a narrow focus on the biomedical causality of a HNCa survivors' illness experience (Davis et al., 2015; Galvin & Todres, 2013; Hitch et al., 2018; Knox, 2020). Founded on the scientific method, a reductionist approach to oncological care can discredit the broader context of a HNCa survivor's illness experience (Galvin & Todres, 2013; Hitch et al., 2018; Knox, 2020). A widely recognized outcome of the reductionist tendencies of disease-focused care pertains to its potentially dehumanizing effects (Galvin & Todres, 2013; Todres et al., 2009). Examples of the dehumanizing effects of medical reductionism include the experience of objectification and homogenization of the individual's unique illness experience (Todres et al., 2009). Objectification refers to biomedicine's tendency to transform individuals into objects "by focusing excessively on how they fit into a diagnostic system, part of a statistical picture or any other strategy by which they are labelled and dealt with" (Todres et al., 2009, p. 70). Similarly, the experience of homogenization denotes biomedicine's potential disregard for the uniqueness of the individual and concomitant preoccupation with categorizing individuals into tidy, distinct groups of others who are deemed alike (Todres et al., 2009). In both the experience of objectification and homogenization, individuals may be at risk of being counted simply as numbers or statistics. As such, the dehumanizing impact of disease-focused care may be further exemplified through the potential discrepancy between what is likely to be statistically significant and what is likely to be significant within the context of one's lived experience of illness (Todres et al., 2009).

In essence, in a disease-focused, reductionist approach to care, a relational perception of the HNCa survivor within the context of psychological and social domains may be displaced to accommodate heightened consideration of the physical domain of functioning (Bornbaum et al., 2013; Galvin & Todres, 2013). Oncological care that emphasizes the physical domain of functioning inherently represents a historically constrained and potentially insufficient conceptualization of disease management (Cassell, 2004). It is acknowledged that physical deficits create profound challenges in and of themselves, and thus, are critical to address. However, since physical deficits are likely to create challenges in other domains (i.e., psychological and social), *exclusive* focus on the physical domain is sometimes misdirected and insufficient.

The exclusive focus on the physical domain, in place of an individual's biopsychosocial experience of illness has been, in part, facilitated by notable technological advancements in managing disease (Davis et al., 2015; Knox, 2020). Since these technological advancements have improved quantitative metrics of survival, a side product of this success has been a fixation with overcoming disease at all costs (Cassell, 2004). Oncology's propensity to rely on technology for conquering disease provides another example of its dehumanizing effects. In essence, humanitarian knowledge may be displaced onto technology with the outcome of a dehumanized approach to oncological care (Kubler-Ross, 1969). More specifically, the dehumanizing effects may be felt secondary to oncology's reliance on technology owing to the discontinuity between the impersonal and objective nature of technology and the unique and subjective nature of a patient's experience of illness (Cassell, 2004; Seely & Mount, 1999). This results in a situation in which "what can be done in terms of healthcare technology is a good deal clearer than what *should* be done" (Barger-Lux & Heaney, 1986, p. 1314). Accordingly, disease-focused, life-prolonging oncological care is at risk of being more closely coupled with technological constraints than its impact on the individual who has the disease and their QoL (Barger-Lux & Heaney, 1986).

Metaphorically, this fixation on technology to overcome disease at all costs reflects the reality that the field of oncology has "invented sophisticated techniques to save people from drowning, but once they have been pulled from the water, [disease-focused care] leaves them on the dock to cough and sputter on their own in the belief that [physicians] have done all [they] can" (Mullan, 1985, p. 273). In essence, together, the scientific method, reductionist approaches, and technological advancements have made oncological care increasingly effective at addressing the physical elements that are fundamental to achieving a biomedically defined cure (Thomas, 1983). However, this disease-focused approach may exclude the individual, their subjective illness experience, and consideration of QoL, both during and after treatment (Todres et al., 2009).

The Survivorship Movement: A Noble Yet Insufficient Solution

The cancer survivorship movement arose, in large part, as a response to the lack of recognition and consideration of QoL issues and long-term symptom management in the area of oncology (Jacobs & Shulman, 2017). As such, the notion of survivorship was originally intended to oppose the narrow disease focus that has prevailed in the provision of oncological care (Berry et al., 2019). When regarded through its originally intended biopsychosocial lens, survivorship is conceptualized as the act and process of living through and beyond the diagnosis and treatment of cancer (Brearley et al., 2011; Feuerstein, 2007; Miller & Shuman, 2016; Mullan, 1985). Accordingly, from this biopsychosocial perspective, survivorship begins at the time of initial diagnosis and is not tied to the achievement of complete clinical remission of a malignancy as dictated by quantitative time-based calculations of treatment success. By extension, survivorship acknowledges the potential experience of long-term or late effects of disease management. Thus, this broad definition of survivorship promotes acknowledgment that, even from the time of diagnosis, care provision should aim to maximize cure *and* minimize the impact of the biopsychosocial treatment sequelae on QoL (Brearley et al., 2011; Ganz, 2011; Miller & Shuman, 2016). By extension, the notion of survivorship inherently advocates for increased consideration and recognition of QoL issues.

Interestingly, recognition of these biopsychosocial treatment sequelae and more specifically the toxic effects of chemotherapeutic agents on individuals' "performance status", represents the origin of the modern-day study of QoL (Karnofsky, 1961; Karnofsky et al., 1948; Karnofsky & Burchenal, 1949; Karnofsky et al., 1951). The work of Karnofsky and colleagues was ground-breaking in identifying that cancer *treatment* has the potential to negatively impact survivors' functional "performance status" and QoL. In essence, in the pursuit to cure disease, one's "performance status" may be profoundly impacted as a direct consequence of the treatment itself, over and above the impact of the disease proper. Unfortunately, this notion has been variably retained in the survivorship literature and, thus, the variety of survivorship definitions that exist must be acknowledged. For instance, some definitions reflect the infiltration of the biomedical disease-focused perspective since they define survivorship as a static state of being cancer free, as living in remission for a minimum of five years, or as a categorical measure of treatment efficacy (Cheung & Delfabbro, 2016; Miller & Shuman, 2016).

Unfortunately, the noble origins of the notion of survivorship, in which biopsychosocial considerations and items related to QoL were central, have also been variably retained in the actual provision of survivorship care (Baker et al., 2020). In essence, a discrepancy exists between the theoretical stipulations that lay out noble suggestions of what is meant to be included in survivorship care and the actual provision of care that is enacted during survivorship (Baker, 2020; Ganz, 2011). Accordingly, matching the provision of survivorship care to the ideals that originally motivated the conception of the survivorship movement has proven to be challenging (Baker et al., 2020).

For example, the notion of survivorship was originally intended to depict the biological *and* psychosocial deficits concomitant with the diagnosis and treatment of cancer (Mullan, 1985; Surbone, 2016). However, the originally intended conceptualization of survivorship is too commonly infiltrated by the influence of the prevailing biomedical model in the actual provision of survivorship care (MacDonald et al., 2021). For instance, despite finding its origins in advocating for increased consideration and recognition of QoL issues, survivorship care is currently guided by recommendations established by the Institute of Medicine (IOM). In the IOM's recommendations the *only* mention of QoL is found in a broad statement that recommends that cancer survivorship programmes should prepare providers to address healthcare and QoL issues faced by cancer survivors (Ganz, 2011; Hewitt et al., 2006). No specific, pragmatic, or easily actionable recommendations pertaining to QoL in survivorship are included in the IOM's guiding document. Furthermore, consideration of QoL in HNCa survivorship is also limited in American Society of Clinical Oncology (ASCO), National Comprehensive Cancer Network (NCCN), and Cancer Care Ontario (CCO) survivorship care guidelines (ASCO, 2021; CCO, n.d.; NCCN, 2021).

The same clinical practice guidelines noted above also suggest that multidisciplinary care that "involves the collaborative efforts of a wide variety of healthcare practitioners in the personalized treatment of cancer patients" (Cohen et al., 2015; Messing et al., 2019; NCCN, 2017; Shao et al., 2019, p. 385) is the accepted approach to oncological care, including survivorship care (Loonen et al., 2018; Morgan, 2009). More specifically, in theory, multidisciplinary care refers to a broad range of professionals from diverse disciplines working separately to independently contribute to the provision of comprehensive care that addressed patients' health and needs as holistically as possible (Mitchell et al., 2008). This multidisciplinary team approach is particularly relevant to manage the clinical and service delivery challenges that result from the complex nature of HNCa and its consequences (i.e., altered or lost function in physical, psychological, and social domains) (Messing et al., 2019). In the context of HNCa, a patient's multidisciplinary team may consist of the otolaryngologist – head and neck surgeon, medical oncologist, radiation oncologist, dietitian, speech-language pathologist, physical therapist, audiologist, psychologist, oncology social worker, occupational therapist, and/or dentist/maxillofacial prosthodontist (Messing et al., 2019; NCCN, 2017; Nilsen et al., 2020). Given the potentially oscillating and iterative trajectory of HNCa survivorship, this multidisciplinary team may change over time to reflect the dynamic nature of the changing clinical and psychosocial needs of the HNCa survivor (Mitchell et al., 2008).

Multidisciplinary teams are becoming more commonplace at the time of diagnosis and treatment planning (Loonen et al., 2018). Nevertheless, regardless of its praiseworthy theoretical underpinnings, multidisciplinary care also varies substantially in definition and practice, particularly in the provision of posttreatment survivorship care. That is, despite the inherent value of a multidisciplinary team approach that is presented in theoretically based literature, multidisciplinary team approaches tend to not be widely utilized in the reality of survivorship care provision (Messing et al., 2019). More specifically, the invaluable input and care provided by allied health professionals are often the first to be excluded and/or discontinued from the multidisciplinary team, in favour of the inclusion and/or continued involvement of those healthcare providers whose focus lies primarily on the prolongation of one's *quantity* of life (Messing et al., 2019; NCCN, 2017). Thus, consideration of the innumerable factors that contribute to a laryngectomee's QoL is also often the first to be excluded from the provision of survivorship care.

Ultimately, as an outgrowth of its varied definitions, the provision of survivorship care has become an extension of the biomedical model of care and in many respects, has become medicalized. Since it is the biomedical model that has permitted a disease focus in the area of oncology, a similar effect has been concomitant with the medicalization of survivorship care. The provision of this medicalized survivorship care could, by default, improve a HNCa survivor's QoL. However, it is more likely that factors beyond the physical domain of functioning will remain unaddressed and, thus, attempts at improving HNCa survivors' QoL are unlikely to be comprehensive and may neglect facets of the survivors' multidimensional illness experience.

To return to the previous example of alteration to a total laryngectomee's breathing and pulmonary functioning, the literature suggests that postlaryngectomy pulmonary rehabilitation in survivorship plays a significant role in the improvement of perceived QoL (Ackerstaff et al., 1993; Ackerstaff et al., 1998; Hilgers et al., 1991). As previously discussed, HMEs are a commonly used treatment option that are routinely implemented in the current standard of survivorship care of total laryngectomees to promote positive effects on pulmonary changes, as well as QoL, by replacing lost functions of the upper respiratory tract (Ackerstaff et al., 1993; Bien et al., 2009; Hilgers et al., 1991). Interestingly, this is an instance in which the cascade of QoL concerns related to pulmonary challenges are likely to be routinely addressed by the survivorship care that is currently enacted. More specifically, although HMEs are a treatment option that have been shown to positively effect laryngectomees' perceived QoL, HMEs achieve this by facilitating improvements of pulmonary functions that are based predominantly in the physical domain (i.e., reduced sputum production, forced expectoration, and frequency of coughing) (Ackerstaff et al., 1993; Bien et al., 2009). As such, the laryngectomee may by default experience reduced fatigue and sleeping difficulties, increased desire for social interaction, and ultimately, improved QoL following implementation of the HME, but this is likely a result of the decreased sputum production and associated coughing (Lewis, 2019).

Given the highly interdependent and reciprocal nature of the cascade of functional challenges within physical, psychological, and social domains of functioning, it follows that the implementation of HMEs as part of routine HNCa survivorship care may indirectly exert a positive influence on the downstream challenges experienced by laryngectomees in the psychosocial domains. Therefore, it seems QoL is addressed in the current standard of survivorship care when it can be facilitated by a physical/technologically based treatment option. However, the same cannot be said when a laryngectomee experiences reduced QoL secondary to challenges for which objective, physical treatment options do not exist (e.g., when the meaning of one's life, self-esteem, and/or hopes for the future are called into question secondary to their illness experience) (Ueda & Okawa, 2003). This exemplifies the medicalized nature of survivorship care and the discrepancy between the theoretical intent of survivorship care and the survivorship care that is typically enacted.

Additionally, in regard to the previous example of alteration to swallowing function, if a laryngectomee presents with dysphagia secondary to the formation of a pseudoepiglottis after vertical closure of the neopharynx in total laryngectomy, the current standard of survivorship care undoubtedly involves referral back to the surgeon for laser resection of the scar band to facilitate increased ease of swallowing (Starmer, 2019). If a speech-language pathologist is involved in the laryngectomee's survivorship care, consideration is likely to include therapeutic intervention, compensatory strategies, and dietary modifications to mitigate the physical effects of dysphagia and related stricture (Starmer, 2019). Thus, the current standard of survivorship care as it is typically enacted is likely to address the impact of dysphagia in the physical domain. However, it is unlikely to attend to the effects of dysphagia that extend to the psychological (e.g., depression, anxiety, and stress) or social (e.g., social withdrawal, desire to engage in shared mealtimes in social settings) domains.

To refer back to the example of alteration to verbal communication, following total laryngectomy the establishment of a new method of alaryngeal speech is likely to be included in standard survivorship care (MacDonald et al., 2021). Although the acquisition of a new mode of communication is rooted in the physical domain of functioning, as previously discussed it is also experienced extensively in psychological and social domains of functioning. The significance of the successful establishment of any method of postlaryngectomy verbal communication (e.g., ES, TE, EL voice and speech) cannot be understated. However, the influence of altered verbal communication in the psychological and social domains of functioning (i.e., depression and/or distress in relation to the perceptually distinct sound quality of alaryngeal speech and social withdrawal or isolation) may be beyond the usual provision of care that is typically enacted despite being within the breadth of the theoretical framework of survivorship care proposed by several organizations (i.e., National Coalition for Cancer Survivorship [NCCS], IOM, NCCN, ASCO, American Cancer Society) (Jacobs & Shulman, 2017; MacDonald et al., 2021; Nekhlyudov et al., 2017).

Furthermore, as alluded to in these examples and in the aforementioned ground-breaking work of Karnofsky and colleagues, even after treatment completion for laryngeal cancer (i.e., total laryngectomy and/or radiation therapy with or without chemotherapy) treatment sequelae have ongoing significant negative consequences on survivors’ physical, psychological, and social functioning and, thus, QoL. It follows that the period of posttreatment survivorship represents a particularly relevant moment along the clinical pathway for the assessment and consideration of QoL issues (Miller & Shuman, 2016). Moreover, paired with Karnofsky’s contributions to the QoL literature, the survivorship literature further justifies the need for increased focus on QoL specifically in the posttreatment phase of survivorship. For instance, the survivorship literature suggests that the phase of survivorship that begins following the completion of intensive therapy is characteristic of a time in which the individual may hold unrealistic expectations for rapid recovery, paired with the loss of the safety net of active treatment and the accompanying support of frequent appointments with clinicians (Miller & Shuman, 2016; Mullan, 1985; Stanton et al., 2015). Accordingly, studies have found that survivors commonly experience an escalation of psychosocial distress after treatment has been completed (Bjordal & Kaasa, 1995; Lim et al., 2014; Stanton et al., 2015). Therefore, taken together, the survivorship and QoL literature suggest that there is a particularly poignant need to bolster the focus on QoL following treatment completion.

In other words, owing to the disease focus that is inherent in the area of oncology, consideration of disease management is paramount during active treatment. However, if the provision of care is not also guided by considerations of QoL, when definitive treatment eliminates the disease, the inherent disease focus too often promotes the notion that there is nothing left to address. In essence, when disease management achieves a cure, and the malignancy is no longer acutely life-threatening, current models of care are often inadequate in attending to what remains; that is, the individual and the conceptual schema of QoL that links together their life experiences. Paradoxically, it is often only when treatment is considered to be unsuccessful, and achieving curative intent is deemed futile, that consideration of QoL has historically taken precedence over that of the disease proper. In such instances, the shift from disease-focused care to QoL-focused care is facilitated by the commencement of care that is guided by the principles of palliative care (MacDonald et al., 2021). As such, this traditionally connotes that consideration of QoL is reserved for individuals for whom treatment with curative intent is deemed futile and, thus, receive end-of-life care. However, if the foundational principles underlying palliative care are included in HNCa survivorship care the disease focus that is typical in the provision of survivorship care may be expanded to also include heightened consideration of survivors’ QoL.

Examination of Palliative Care

Ultimately, the principles of palliative care may serve to bolster the focus on QoL in HNCa survivorship. The palliative care principles extend the mandate of care beyond the disease-focused biomedical model to include the broader scope that is required to better address QoL issues secondary to one's illness experience (Hanks, 2008). Put simply, at the core of the principles of palliative care is the aim to enhance and support individuals' QoL (Hanks, 2008; Hui et al., 2013; WHO, 2019). Accordingly, conceptualizations of palliative care revolve around the understanding that *quantity* of life is not analogous to one's perceived QoL (Doyle & MacDonald, 2019; MacDonald et al., 2021). Hence, palliative care is defined as care "that improves the quality of life of patients … with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual" (WHO, 2019, WHO Definition of Palliative Care, para. 1).

The origin of this more contemporary definition of palliative care is rooted in Dame Cicely Saunders's pioneering work in terminal care research and the hospice movement during the 1960s (Bruera & Hui, 2012; Hui et al., 2013). The foundational principles outlined by Dame Cicely Saunders became, and continue to be, the basis for current end-of-life care approaches (Hadad, 2009; MacDonald et al., 2021; Saunders, 1984; 1995). Based on these origins, the term "palliative care" was coined around 1975 by Dr. Balfour Mount, who is commonly regarded as the "father of palliative care" (Hadad, 2009; Hui et al., 2013; Mount, 1978). Owing to the ground-breaking work of Dame Cicely Saunders and Dr. Balfour Mount, palliative care emerged as an approach to care that is not directly aimed to prolong life, but rather, seeks to relieve biopsychosocial symptoms and enhance the quality of the time remaining for individuals who are acutely dying (Hadad, 2009; MacDonald et al., 2021; Mount, 1978). This historical context conceptually supports the potential value of the principles of palliative care in heightening consideration of QoL and, in turn, improving individuals' perceived QoL.

As such, it is well established in the literature that the principles of palliative care have a proven history of maximizing QoL when quantity of life may be limited (Bakitas et al., 2009; Greer et al., 2012; Hanks, 2008; Temel et al., 2010; WHO, 2019). Therefore, as opposed to proposing a novel theoretical framework that may serve to better address QoL issues faced by HNCa survivors, it is suggested that the well-established foundational principles of palliative care may be of value in the context of HNCa survivorship. Admittedly, the provision of palliative care has been traditionally reserved for those individuals with a life-limiting illness and whose disease is no longer responsive to curative treatment (Rousseau, 2014; Strand et al., 2013). Nonetheless, consideration of the principles of palliative care in the context of HNCa survivorship may reveal the potential for these principles to be of value in efforts to better address survivors' QoL. Thus, a clear depiction of the foundational principles of palliative care is important in the context of the present treatise and will be addressed in the context of HNCa survivorship in the subsequent section.

The Central Principles of Palliative Care in the Context of HNCa Survivorship

The central principles of palliative care outline a set of precepts that are intended to guide care for individuals who are dying but are also theoretically applicable more broadly to HNCa survivors for whom death is not imminent (Gillick, 2005; MacDonald et al., 2021). If the principles of palliative care are not limited to the confines of end-of-life, the benefits offered by these principles may be realized in the context of HNCa survivorship (Gillick, 2005; MacDonald et al., 2021). In the context of HNCa survivorship, the principles of palliative care may serve to address challenges that may be engendered directly from disease management and/or the disease proper (Gillick, 2005; MacDonald et al., 2021). In turn, these principles may serve to fill gaps in care provision left by the discrepancy between the noble ideals that originally motivated the conception of survivorship and the provision of survivorship care that is typically enacted (Baker et al., 2020). The central principles of palliative care ultimately pertain to symptom management, patient-physician communication, respect for the patient's autonomy and dignity, the need to inform patients of what to expect in unfamiliar circumstances, the involvement of family and/or significant others, consideration of the patient's aspirations, and the value of interdisciplinary care (Hadad, 2009).

Symptom Management. Impeccable symptom management through the early identification and assessment of an individual's biopsychosocial problems and/or suffering is a benchmark of palliative care (WHO, 2019). Palliative care is an extension of the traditional biomedical model and, thus, its theoretical underpinnings and translation to practice do not exclude the management and relief of physical symptoms (Hadad, 2009; Strand et al., 2013; WHO, 2019). Rather, it is well established in the literature that palliative care is renowned for exemplary symptom management within the physical domain (Hui et al., 2013; Oliver, 2018; WHO, 2019). However, by *extending* the biomedical model, the theory and practice of palliative care also pertain to the management of deficits in the psychological domain of functioning (Gillick, 2005; Hadad, 2009; Strand et al., 2013). Therefore, care that addresses depression or distress experienced by a laryngectomee in relation to the non-normal sound of their new method of alaryngeal speech, for example, is advocated for by this principle of palliative care.

As part of biopsychosocial symptom management, this principle of palliative care also espouses the notion that individuals should be enabled to continue their social relationships and participation in their larger social networks (Hadad, 2009). As previously discussed, social isolation and/or social withdrawal are common following total laryngectomy (Eadie, 2003; Semple et al., 2004; Threats, 2007). Although social support and social engagement are correlated to positive adjustment to the experience of disease and improved QoL (Eadie & Bowker, 2012; McDonough et al., 1996), deficits in the social domain of functioning are beyond the current scope of the survivorship care that a laryngectomee may expect to receive (MacDonald et al., 2021). However, consideration of one's social functioning, along with support and assistance with social challenges are well within the scope of care that is guided by this principle of palliative care (e.g., providing support to enable the individual to participate fully in relationships, fulfill significant roles, and engage in meaningful activities of daily life) (Bruera & Hui, 2012; Ndetei et al., 2018; Oliver, 2018; WHO, 2019). Additionally, this principle of palliative care also permits consideration of wider aspects of care including existential and spiritual domains (Hadad, 2009; Hui et al., 2013; Oliver, 2018; WHO, 2019). Taken together, the consideration of physical, psychological, social, and existential/spiritual functioning dictated by this foundational principle of palliative care may serve to better address and/or promote QoL in HNCa survivorship.

By addressing functioning within domains beyond those that are solely physical, the principles of palliative care may promote a rebalancing of the disequilibrium that has allowed the dominant focus on the physical domain of functioning and biomedical aspects of disease in survivorship care (MacDonald et al., 2021). In turn, the biopsychosocial perspective promoted by this principle of palliative care may facilitate awareness of the interaction of the collective cascade of functional challenges and the reciprocal and interdependent nature of these challenges (Engel, 1977). Accordingly, the reductionist, disease-focused approach to care may be supplemented by this broader perspective, thereby minimizing the associated dehumanizing impact of care that is guided solely by consideration of the physical domain of functioning (Hitch et al., 2018; Ingram, 2014; Mount, 2013). In essence, the foundational principles of palliative care may promote a broader perspective that looks beyond the disease focus and encourages consideration of the individual's idiosyncratic illness experience and its consequential impact on their QoL (Knox, 2020).

Patient-Physician Communication. Comprehensive patient-physician communication is an additional principle of palliative care and is considered paramount in its provision (Bradley et al., 2000; Creutzfeldt et al., 2015; Davis et al., 2015; Gilewski, 2001; Johnson et al., 2008; Metzger et al., 2013; Oliver, 2018; Zhi & Smith, 2015; Zubkoff et al., 2018). Exceptional patient-physician communication is critical in the establishment a concrete understanding of the patient's goals of care, which is a central part of end-of-life discussions (Mack et al., 2012; Mady et al., 2018; Sinclair et al., 2017; Wright et al., 2008). Ascertaining the patient's goals of care allows the physician to align the provision of care with what is most meaningful and important to the patient (Bernacki & Block, 2014). Accordingly, it should come as no surprise that there exists a well-documented relationship between clearly defined goals of care and higher perceived QoL (Bernacki & Block, 2014; Puri, 2013). Therefore, the establishment of a survivors' ongoing goals of care based on what is meaningful to them as they navigate the posttreatment phase of survivorship may also serve to bolster efforts at improving QoL.

Autonomy and Dignity. Another principle of palliative care posits that patients should be enabled to live as autonomous and dignified individuals with continued control and independence in life (Ferrell et al., 2017; Hadad, 2009). The essence of this principle of palliative care encapsulates the notion that individuals are deserving of compassionate and respectful care that recognizes their autonomy and dignity (Randall & Downie, 2011). Illness related concerns, symptom distress, and breached privacy boundaries (e.g., openly discussed personal details, the need for assistance with private activities of daily living) have been documented to compromise dignity (Johnston et al., 2015). However, these concerns are also concomitant with one's survivorship experience postlaryngectomy. Thus, this principle of palliative care also may be relevant outside of the end-of-life context and may be poignantly included in the context of HNCa survivorship.

Moreover, the relevance of explicit consideration of autonomy and dignity to HNCa survivorship becomes further apparent upon reconsideration of the aforementioned example of communication loss secondary to total laryngectomy. The experience of communication loss distinguishes laryngeal cancer as a disease with a particularly profound impact on QoL since it leaves survivors incapable of using natural means of voice or speech to express their concerns, decisions, wishes, and/or aspirations (Doyle, 2005; Doyle & MacDonald, 2019; Ma & Yiu, 2001; MacDonald et al., 2021). It follows logically, that the loss of one's means of normal verbal communication secondary to total laryngectomy is concomitant with the loss of autonomy since self expression is inherently tied to an individuals' capacity to be independent and in control of one's own life (MacDonald et al., 2021; Schenck, 2002). Guided by this principle, palliative care upholds a patient's autonomy by respecting the individual's right to "self-rule" and promoting a sense of control over a situation in which one is likely to feel that control has been lost (Schenck, 2002, p. 412). This principle of palliative care promotes the notion that the individual has the right to self-governance even when typical means of exerting control are compromised by aspects of the dying process, in its traditional end-of-life context, or by total laryngectomy, as would be the case if applied in the context of HNCa survivorship (Schenck, 2002). In turn, inclusion of the principle of palliative care that promotes full consideration of one's autonomy and dignity may ultimately facilitate care for HNCa survivors that more fully addresses their QoL.

However, as was the case with the psychological and social domains, the current scope of traditional survivorship care may not include comprehensive consideration of one's loss of autonomy and the impact it is likely to have on one's perceived QoL (MacDonald et al., 2021). If the notion of autonomy is present in the current provision of disease-focused care, it is likely to manifest at the most basic level of voluntary decision making which takes the concrete form of informed consent and, thus, is likely quite clinical in nature (Schenck, 2002). Thus, comprehensive consideration of one's loss of autonomy may represent a gap in survivorship care as it is typically enacted, which may be filled by this principle of palliative care.

What to Expect. An additional principle of palliative care pertains to ensuring individuals are fully informed about their health status, beyond their physical diagnosis and prognosis, to ensure they are able to make informed decisions about their care (Hadad, 2009). As such this principle ultimately refers to the notion that a central role of palliative care is one of informational support (Metzger et al., 2013). The provision of such informational support is intended to fully inform the individual about what they can expect in regard to their biopsychosocial functioning and is not limited to disease related factors and prognostication. Concrete manifestations of informational support come in the form of providing information about what a patient can expect in regard to treatment/care options, likely outcomes of these options, and transitions in the clinical pathway (Metzger et al., 2013).

It must be noted that the provision of information is not unique to palliative care. Rather, it is the nature and scope of the information that is typically provided within the context of palliative care that distinguishes it from other sub-specialities of medicine and, by extension, typical survivorship care (Metzger et al., 2013). More specifically, while other sub-specialties of medicine and/or survivorship care convey critical and valuable information to patients, the approach taken in palliative care is characterized as more comprehensive and wide-ranging. As such, a larger breadth of topics may be discussed, a broader scope of available options may be offered, and discussions of what to expect may extend beyond physical prognostic information to include psychosocial domains in consideration of the individual patient's life circumstances (Metzger et al., 2013). Thus, this principle may be valuable in the context of HNCa survivorship owing to the unfamiliar and potentially uncertain trajectory of posttreatment survivorship care (Zhang, 2017).

Involvement of Family and/or Significant Others. Additionally, a central principle of palliative care pertains to the importance of involving the individual's family and/or significant others in their care (if deemed appropriate and/or requested by the individual) so they may participate in a meaningful way and also engage in discussions to ensure their concerns are addressed (Ferrell et al., 2017; Gillick, 2005; Hadad, 2009; Ingram, 2014; Strand et al., 2013). In the context of the provision of traditional palliative care, this principle is exemplified by the precept that palliative care does not end with the death of the individual since care is then extended to support the family and significant others through their grief and bereavement (Gillick, 2005; Hadad, 2009). Unfortunately, the current standard of survivorship care that is typically enacted is rarely extended to survivors' family members and/or significant others. However, the relevance of this principle of palliative care to HNCa survivorship may be delineated by considering it in the context of total laryngectomy. For instance, the laryngectomee's family members may have a preconceived notion of how the laryngectomee should behave and react following the completion of definitive treatment (i.e., laryngectomy with or without radiation therapy and/or chemotherapy) as dictated by narrowly defined societal expectations of survivorship (Little et al., 2002; Miller, 2015). In other words, there may exist a disconnect between family members' and/or significant others' expectations for a survivor's recovery posttreatment and the survivor's lived experience following treatment completion (Little et al., 2002).

For example, and guided by the above issues, the laryngectomee's family members and/or significant others may believe that there is no price too great for survival. Accordingly, the family members and/or significant others may expect endless gratitude from the laryngectomee, with little understanding of the ongoing existential tensions of surviving a life-threatening disease like laryngeal cancer and the concomitant loss of verbal expression and changes to social roles (Bickford et al., 2018; Knox, 2020; Little et al., 2002; Swore-Fletcher et al., 2012). Family members may believe the laryngectomee should simply be grateful for receiving curative treatment and, thus, that they should easily return back to the normalcy of their pre-cancer identity and behaviour, and resume their usual roles and responsibilities (Miller, 2015). Accordingly, the laryngectomee's family members may offer little recognition or sympathy to the laryngectomee's experience of the ongoing consequences of surviving laryngeal cancer and its treatment (Little et al., 2002). However, this disconnect between the family's societally defined expectations of legitimate responses to the existential state of survivorship and the laryngectomee's lived experience may heighten psychosocial distress experienced by the laryngectomee (Little et al., 2002; Miller, 2015). For instance, the laryngectomee may respond in any number of ways that may include any of the following: (1) the laryngectomee may act as though their life is indeed back to normal when this actually not the case, thereby adding additional pressure for the laryngectomee to conform to this fake normalcy; (2) if the laryngectomee is open about their ongoing experience of persistent challenges, their experience may be met with little understanding or compassion; and/or (3) the disconnect between the laryngectomee's lived experience of ongoing functional challenges and societal expectations may pose as a barrier to accessing support posttreatment (Little et al., 2002).

The current provision of survivorship care as it is typically enacted falls short of addressing these interconnected challenges that must be navigated by the survivor and their family. However, the aforementioned principle of palliative care pertaining to management of one's existential/spiritual concerns may offer guidance within the context of survivorship care in terms of addressing the existential tensions of survivorship (Hadad, 2009; Hui et al., 2013; Knox, 2020; Oliver, 2018; WHO, 2019). Moreover, the principle that advocates for familial involvement may serve to resolve the disconnect between the family's expectations and the survivor's ongoing lived experience. More specifically, application of this principle of palliative care to HNCa survivorship care may promote the notion that ongoing involvement and consideration of the survivor's family is beneficial to both the family members and the survivor. Guided by this principle of palliative care, continued support for the laryngectomee's family members may serve to establish greater congruence between the survivor's experience and their family's expectations by helping the family members to understand the profound and extensive range of biopsychosocial functional challenges secondary to surviving laryngeal cancer and its treatment. In turn, an enhanced understanding of the laryngectomee's lived experience may promote increased potential for empathy and compassion toward the laryngectomee. Accordingly, by filling the gap left by typically enacted survivorship care, this principle of palliative care may serve to solidify enhanced consideration of both the laryngectomees' and their family members' QoL.

Hopes and Dreams. Another principle of palliative care captures the precept that individuals deserve to be supported to reach their hopes, dreams, and aspirations so they may establish a sense of meaning and purpose in life (Hadad, 2009). The consideration of an individual's hopes and dreams is tremendously subjective in nature and, thus, this principle alludes to the willingness of palliative care to attend to potentially intangible topics and/or concerns. Unfortunately, the propensity of palliative care to deal within subjective dimensions insinuates that it is often only when death is imminent that consideration of the individual's idiosyncratic and subjective aspirations may be positioned more centrally in care provision. As such, these subjective notions pertaining to one's hopes and dreams are beyond the scope of medicalized survivorship care as it is typically enacted. However, Lee et al. (2017) suggested that "the failure by healthcare providers to identify, accept, and possibly exploit the potential influence of subjective factors and states relative to one's recovery and rehabilitation may restrict rather than optimize outcomes" (p. 1007). Therefore, inclusion of this principle of palliative care in survivorship care may, in part, promote increased acceptance of subjective factors outside of the end-of-life context and, in turn, optimize outcomes for HNCa survivors.

Interdisciplinary Care. Finally, palliative care is guided by an interdisciplinary approach to care provision, in which healthcare providers from different specialties work *together* as a *collaborative* team to contribute their expertise to the care delivered (Billings, 1998; Creutzfeldt et al., 2015; Ferrell et al., 2017; Gillick, 2005; Hui et al., 2012; Hui et al., 2013; Meghani, 2004; Strand et al., 2013). Conversely, as previously discussed, multidisciplinary care is the accepted approach to oncological and survivorship care (Loonen et al., 2018; Morgan, 2009). In multidisciplinary care healthcare providers from different specialties work *separately* from each other to *independently* contribute their expertise to the care delivered (Mitchell et al., 2008). A multidisciplinary care approach draws knowledge from different disciplines of healthcare but allows these healthcare providers to stay within their own boundaries. While a multidisciplinary approach permits healthcare providers to work in parallel, an interdisciplinary approach calls for more considerable integration of the expertise contributed by the healthcare providers involved. Although interdisciplinary and multidisciplinary approaches to care provision are not conceptually dissimilar, the nuanced difference between multidisciplinary and interdisciplinary care must not be overlooked in the context of survivorship versus palliative care.

As part of the interdisciplinary care approach that guides the provision of palliative care, it is important that the roles of the physicians and other clinicians involved in the team are clearly defined in order to foster teamwork and collaboration (Fadul et al., 2009; Messing et al., 2019). Interestingly, discrepancies in the perceived responsibilities of various clinicians commonly exist in the context of end-of-life care and issues pertaining to the definition of a physician's role is a prominent topic in the palliative care literature (Bradley et al., 2000; Cherny & Catane, 2003; Fadul et al., 2009; Johnson et al., 2008; Ward et al., 2009). However, coordination of the interdisciplinary team members through enhanced role definition may serve to improve the efficacy and reduce the redundancy of care, minimize costs, and enhance patient outcomes, including those related to QoL (Messing et al., 2019; Ritchie et al., 2016). Ultimately, when viewed together, these foundational principles of palliative care provide examples of methods through which consideration of QoL may be bolstered in HNCa survivorship.

Statement of Problem

The biomedically directed disease focus that prevails in both oncology and cancer survivorship generally relegates the consideration of QoL to end-of-life palliative care. Palliative care is often invoked only when biomedically driven curative treatment is deemed futile (Strand et al., 2013). As such, one’s QoL only becomes a central aspect of care when an individual’s quantity of life is appreciably diminished. Nevertheless, in consideration of the well documented detriments to QoL associated with HNCa survivorship, it is paradoxical to wait until individuals are at the end-of-life before addressing QoL (MacDonald et al., 2021). Unfortunately, the foundational principles of palliative care and disease-focused oncological care are commonly viewed as dichotomous doctrines on opposing ends of the continuum of care (Gillick, 2005; MacDonald et al., 2021). As such, in disease-focused oncological care, patients may find themselves in an “either-or” situation in which they feel they must choose between treatment that is directed toward either cure or comfort, or in essence, quantity of life or QoL (Gillick, 2005). Unfortunately, this overly reductionist dichotomy only serves to further remove consideration of QoL from disease-focused care and propagates the notion that the principles of palliative care must be reserved for those for whom death is imminent.

Through the consideration of the mechanisms of disease and physical domains of functioning the biomedically directed provision of disease-focused oncological care is extremely proficient at disease management (Hayden, 2019). As such, it must be acknowledged that disease-focused oncological care has delivered unparalleled advances in life prolonging treatment for HNCa survivors. However, with the quantitative extension of life, there exists the moral obligation to also consider and address the *quality* of these survivors’ lives. Put differently, “because as a modern society we have succeeded so well at prolonging lives, we have a moral obligation to increase the quality of those prolonged lives" (Zimmermann & Rodin, 2004, p. 127). Thus, it is imperative that survivorship care is expanded beyond the exclusive confines of the biomedical model (Heathcote et al., 2020). This may be promoted if the foundational principles of palliative care are implemented to guide the provision of survivorship care. More specifically, the principles of palliative care extend the mandate of care beyond the biomedical model to incorporate the broader scope that is required to more comprehensively address QoL issues that arise secondary to one's illness experience with HNCa (Hanks, 2008). Thus, if applied in the context of HNCa survivorship, the principles of palliative care may serve to bolster the focus on survivors' QoL, even when there is not a marked loss of quantity of life. Therefore, if HNCa survivorship care is guided by the principles of palliative care it may allow the factors that influence QoL to be more comprehensively addressed.

It is important to note, however, that it is not suggested that palliative care in its traditionally and historically bound context can be seamlessly translated into the context of HNCa survivorship care. Rather, it is recognized that a HNCa survivor who has completed definitive treatment and an individual for whom death is imminent are likely to have very different needs which may call for a different emphasis of care (Fadul et al., 2009). Thus, the distinction between palliative care and survivorship care that is based on need and clinical context must not be minimized (Fadul et al., 2009). However, acknowledging the well documented detriments to QoL associated with HNCa, and laryngeal cancer specifically, it is simply paradoxical to restrict the principles of palliative care to end-of-life care (MacDonald et al., 2021).

Given the potential advantages of examining the principles of palliative care in the context of HNCa survivorship, there is a need to understand physicians' and laryngectomees' perceptions of the utility of the principles of palliative care in bolstering the focus on QoL in HNCa survivorship. Since laryngectomees and physicians are integral stakeholders, their perceptions are essential to guiding survivorship care. Information pertaining to the perceptions of these stakeholders regarding aspects of survivorship care that are guided by the principles of palliative care and, thus, inherently support QoL, becomes an important area of clinical inquiry if QoL-related outcomes are to be optimized and laryngectomees are to return to as full a life as possible. As such, this study sought to identify and describe laryngectomees' and physicians' perceptions regarding the inclusion of principles of palliative care in the posttreatment care of HNCa survivors under ideal circumstances and in actual practice. By asking laryngectomees and physicians about their personal experience and opinions, a narrative about ideal circumstances and actual practice that comprises multiple viewpoints can be constructed. These data may offer insights into efforts that seek to better address the myriad detriments to QoL concomitant with HNCa survivorship. Thus, the specific objectives of the present study centred on the identification and description of:

1. Laryngectomees' and physicians' perceptions of whether principles of palliative care that ultimately support QoL *should* be present following HNCa treatment completion under *ideal circumstances*.
2. Laryngectomees' and physicians' perceptions of whether principles of palliative care that ultimately support QoL are present in *actual practice* following HNCa treatment completion.

CHAPTER 2

Methods

Design

The current study was a prospective, cross-sectional exploratory study that utilized a self-administered, web-based questionnaire to identify and describe laryngectomees' and physicians' perceptions of principles of palliative care that are believed to ultimately support QoL in the context of HNCa survivorship. Formal ethical approval was granted by the Western University Health Sciences Research Ethics Board before study commencement (REB #118374); copies of the initial approval and amendment approval for this study are provided in Appendices A and B, respectively.

Participants

This study sampled participants from two specific groups: 1) a laryngectomee population and 2) a physician population; these participants formed a Survivor Group and Physician Group, respectively. Individuals who had undergone total laryngectomy served as the primary population of interest for the Survivor Group. Physicians with direct involvement in the care of those diagnosed with HNCa served as the primary population of interest for the Physician Group of the current study. The recruitment strategies for both the Survivor and Physician Groups are delineated in subsequent sections of this chapter.

Inclusion Criteria

Survivor Group. Individuals over the age of 18 years who had previously undergone total laryngectomy for treatment of laryngeal cancer were invited to participate as part of the Survivor Group. Laryngectomees were required to be a minimum of 1-month posttreatment completion, including any treatment modalities received in addition to total laryngectomy (i.e., radiation therapy and/or chemotherapy). Participation was also limited to laryngectomees who identified as proficient in English.

Physician Group. Physicians with direct involvement in the care of those diagnosed with HNCa were invited to participate as part of the Physician Group. To be eligible for participation, potential physician participants also were required to identify as proficient in English.

Exclusion Criteria

Potential participants of both the Survivor and Physician Groups were excluded from participation if they were either unable or unwilling to submit the web-based questionnaire. Individuals whose English literacy was self-identified as being insufficient for participation were also excluded.

Questionnaire Development

The purpose of this study was to identify and describe laryngectomees’ and physicians’ perceptions regarding the frequency of the occurrence of aspects of HNCa survivorship care that are ultimately guided by the principles of palliative care. A questionnaire that assesses perceptions regarding such aspects of care in HNCa survivorship did not exist. Consequently, to fulfill the objectives of the present study, proprietary development of a questionnaire was required. As such, a multi-phase instrument-development process was undertaken. Based on a comprehensive review of the literature and expert review, a web-based questionnaire with two versions was developed: one version targeted to identify laryngectomees’ perceptions and one version targeted to identify physicians’ perceptions. Both the laryngectomee and physician versions contained consistent domains pertaining to the same subject matter. However, the questions within each domain were uniquely posed in each version to appropriately address and target the given participant group (i.e., laryngectomees or physicians).

More specifically, questionnaire development began with a comprehensive literature review of the principles of palliative care and QoL (see Chapter 1). This was followed by a review of clinical and empirical studies and questionnaires related to perceptions toward palliative care, early integration of palliative care in oncology, and referral barriers to palliative care (Abel & Kellehear, 2016; Bradley et al., 2000; Bradley et al., 2002; Bruera & Hui, 2012; Cherny & Catane, 2003; Creutzfeldt et al., 2015; Dalal et al., 2011; Davis et al., 2015; Fadul et al., 2009; Gilewski, 2001; Hui et al., 2012; Hui et al., 2013; Johnson et al., 2008; Metzger et al., 2013; Oliver, 2018; Turner et al., 2005; Ward et al., 2009; Zhi & Smith, 2015; Zubkoff et al., 2018). Based on this literature review, an initial pool of 42 targeted questions was developed by the Doctoral Candidate (C.M.).

These initial questions were then edited by members of the research team (J.T., P.C.D., C.M.) on the basis of their centrality to the underlying concepts and principles identified in the literature. This editing process was guided by the following considerations which were used to evaluate the proposed questions in the initial pool: relevance to the study objectives and purpose of the questionnaire, suitability for target populations, redundancy, and overall completeness of information. The resulting first draft of the questionnaire consisted of 19 questions. This draft was then reviewed for face and construct validity by members of the research team. Considerations of clarity and succinctness were also central. Based on this review, edits were made to the wording of the questions. Due to redundancy, one question was removed. One question that pertained to patients' global perception of posttreatment care was added.

The subsequent draft of the questionnaire then underwent content validation by five experts with diverse qualifications who were not directly involved with the study. These experts included an oncology nurse practitioner, a registered social worker and certified grief and bereavement counselor, two otolaryngologist/head and neck surgeons, and a laryngectomee. These experts, who each contributed valuable and unique expertise relative to the content, were instructed to provide feedback as to whether the questionnaire wholly represented and comprehensively captured its intended content. Based on the feedback provided by this expert review, the wording of the questions was further tailored to increase their applicability and suitability to the respective target audiences of the Survivor and Physician Versions of the questionnaire. The order in which certain questions were asked was also modified in response to expert feedback. Finally, two questions were added to the questionnaire as per expert guidance: one question that pertained to the opportunity for laryngectomees to meet with a fellow laryngectomee and an open-response question to offer participants the opportunity to share additional information. The revisions based on this expert review were implemented and the resultant Questionnaire was reviewed again and finalized by members of the research team (J.T., P.C.D., C.M.).

The finalized questionnaire consisted of 21 questions for both the Survivor Version (Appendix C) and the Physician Version (Appendix D). More specifically, 19 questions pertained to the frequency of the occurrence of given aspects of care, one question asked for a general judgement of how pleased patients were with posttreatment survivorship care, and one question was posed as an open-response question to collect any additional information participants may have felt to be relevant. The 19 questions related to frequency were rated on a 7-point Likert-type scale that ranged from “never” to “always”. Indices for each question were calculated by allocating a numerical score to each response category represented by the 7-point Likert-type scale: “never” (1), “almost never” (2), “less than half the time” (3), “half the time” (4), “more than half the time” (5), “almost always” (6), “always” (7). The question related to participants’ global perception of posttreatment care was also rated on a 7-point Likert-type scale, however, the response categories ranged from “not pleased” (1) to “very pleased” (7).

Readability

As part of the expert review of the questionnaire, the five experts were also instructed to assess and make recommendations regarding the readability (i.e., the ease of understanding or comprehension of the writing style) of both the Survivor and Physician Versions of the questionnaire in the context of each versions’ respective target participants’ reading level (Zhou et al., 2017). Careful consideration was taken to ensure the readability of the Survivor Version fell at the accepted readability level for average adults, as well as the average readability level of head and neck oncology patient-reported outcome measures (i.e., a grade eight reading level and a grade nine reading level, respectively) (Cooley et al., 1995; Lee, Farzal, et al., 2020). This was carefully balanced with consideration of the substantially higher level of accepted readability for the Physician Version for reasons related to this target population’s prerequisite education level. The language of the questions on each version of the questionnaire was carefully considered to accommodate the divergent reading levels required for each version while still maintaining consistency and parallel structure between both the Survivor and Physician Versions.

The Flesch-Kincaid Grade Level test was applied to rate the readability of each version of the questionnaire (i.e., using the Flesch-Kincaid Grade Level formula: [0.39 x average sentence length] + [11.8 x average number of syllables per word]) (Zhou et al., 2017). The Flesch-Kincaid Grade Level of the Survivor Version was calculated to be 8.0, which indicated a grade eight reading level and was, therefore, consistent with the target reading level. The Flesch-Kincaid Grade Level of the Physician Version was found to be 7.9, which also approximately indicated a grade eight reading level. Although a higher Flesch-Kincaid Grade Level would have been accepted for physician participants, this slightly lower level of readability likely reflected the need to maintain parallel structure between both versions and that fewer explanatory words were required in the Physician Version to clarify potentially complex concepts when compared to the level of clarification required in the Survivor Version.

Questionnaire Domains

The questionnaire was designed to address five domains conceptually related to the theory and practice of palliative care, as well as QoL: 1) Symptom Management, 2) Physician Role Definition, 3) Patient-Physician Communication, 4) Foundational Principles of Palliative Care, and 5) Global Perception of Care Provision. In addition to the five domains, the questionnaire also contained a short demographics section that sought to collect information such as age, sex, race, and other baseline characteristics that were deemed useful for describing the laryngectomee and physician samples. A full description of the demographics section of both the Survivor and Physician Versions of the questionnaire can be found in Tables 1 and 2, respectively.

Table 1

Demographics Section – Survivor Version

What is your age? Please provide your age in years and closest additional months.
How do you identify yourself? (i.e., self-identified sex)
Which race category best describes you?
What country do you live in?
What is the highest level of education you have achieved?
How many months has it been since the completion of your cancer treatment?
Which of the following cancer treatments (in addition to total laryngectomy) did you receive?
Which type of alaryngeal/postlaryngectomy speech do you use as your primary method?

Table 2

Demographics Section – Physician Version

What is your age? Please provide your age in years and closest additional months.
How do you identify yourself? (i.e., self-identified sex)
Which race category best describes you?
What country do you live in?
What is your medical sub-specialty?
How many years of experience do you have?
How would you categorize your site location/place of work?
What is your clinical background/training?

It is important to note that the domains included in the questionnaire contained questions that were conceptually grouped together, however, there was no a priori assumption that questions within these groupings were statistically associated. That is, the questions were grouped within one of the five domains based on the extensive literature review and expert feedback, and not based on statistical analysis. As such, the extent to which each question was statistically related to the domain in which it was grouped remains unknown. Accordingly, and given the content of the domains assessed, it is acknowledged that these domains are unlikely to be mutually exclusive. Nevertheless, a logical relationship existed between the questions grouped within each domain on the basis of the literature review and expert review of the questionnaire.

Although the lexical term “palliative care” was explicitly excluded from the wording of the questions in the questionnaire, each of the domains, and the questions represented in those domain groups, were tied to underlying principles of palliative care. Terminology that explicitly referenced palliative care was intentionally excluded in an attempt to minimize undue bias that may have existed toward the theory and practice of this subspeciality of medicine. More specifically, many physicians’ and patients’ perspectives of palliative care are related to myths (i.e., palliative care is a death service that hastens death), stigma, fear, anxiety, distress, and hopelessness (Bruera & Hui, 2012; Fadul et al., 2009; Hui et al., 2013; Oliver, 2018; Zhi & Smith, 2015). These negative perspectives are often accompanied by resistance to assessment for and/or involvement of palliative care, especially at earlier stages of the disease trajectory (Bruera & Hui, 2012; Oliver, 2018). Moreover, several studies have found that the term “palliative care” may be a deterrent, in and of itself, to early referral to palliative care services (Dalal et al., 2011; Fadul et al., 2009; Miyashita et al., 2008; Morstad Boldt et al., 2006). In essence, the term “palliative care” was not used because of the widely held assumption that it is a subspeciality of medicine that pertains solely to end-of-life concerns, rather than being tied to larger concepts that fall under the conceptualization of the construct of QoL. Thus, by removing all explicit reference to the term, the questionnaire was intended to assess perceptions of the underlying principles of palliative care within the context of HNCa survivorship, and subsequently, served to minimize the potential impact of any preconceived bias associated with direct use of the term as part of the questionnaire.

Symptom Management Domain. Three of the 21 questions were grouped in the *Symptom Management* domain (Questions 1-3, Table 3). The theory and practice of palliative care extends the biomedical model of care to include the consideration and management of biopsychosocial symptoms (Bruera & Hui, 2012; Hadad, 2009; Hui et al., 2013; Oliver, 2018; Strand et al., 2013; WHO, 2019). Accordingly, the consideration of what might typically be identified as “peripheral” domains of functioning, such as existential and/or spiritual functioning, is also a benchmark of palliative care theory and practice (Hui et al., 2013; Oliver, 2018; Turner et al., 2005; WHO, 2019). The first two questions in this domain were intended to measure participants’ perceptions regarding the frequency with which posttreatment symptom management addresses physical, psychological, social, and existential/spiritual functioning under ideal circumstances and in actual practice. The third question in the Symptom Management domain was posed to assess perceived comfort/approachability regarding topics related to physical, psychological, social, and existential/spiritual functioning. Although symptom management in these core domains is central to the theory and practice of palliative care, the relevance of consideration of symptoms within these domains of functioning is also inherent in the conceptualization of QoL (Gritz et al., 1999). That is, it should be explicitly noted that physical, psychological, social, and existential/spiritual functioning are consistent with the core domains of QoL (Gritz et al., 1999; Klein et al., 2014; Lawton, 2001).

Table 3

Symptom Management Domain Questions

#	Survivor Version	Physician Version
1.	Under **ideal circumstances**, cancer doctors should address:	Under **ideal circumstances** and exclusive of referrals I would make, the care that **I** provide should address survivors':
(i)	physical concerns.	physical symptoms.
(ii)	emotional (psychological) concerns.	psychological symptoms.
(iii)	social concerns.	social functioning.
(iv)	existential/spiritual concerns.	existential/spiritual concerns.
2.	Based on **my experience**, my cancer doctor attended to my:	In **actual practice** and exclusive of referrals I make, the care that **I** provide addresses survivors':
(i)	physical concerns.	physical symptoms.
(ii)	emotional (psychological) concerns.	psychological symptoms.
(iii)	social concerns.	social functioning.
(iv)	existential/spiritual concerns.	existential/spiritual concerns.
3.	I was comfortable using my follow-up appointments with my cancer doctor to discuss:	In **actual practice**, during follow-up appointments, I feel that I am approachable regarding topics related to a patient's:
(i)	physical concerns.	physical symptoms.
(ii)	emotional (psychological) concerns.	psychological symptoms.
(iii)	social concerns.	social functioning.
(iv)	existential/spiritual concerns.	existential/spiritual concerns.

Physician Role Definition Domain. The *Physician Role Definition* domain consisted of three of the 21 questions (Questions 5-7, Table 4). Issues pertaining to the definition of a physician's role is a prominent topic in the palliative care literature owing to discrepancies in the perceived responsibilities of physicians of various medical specialties in the context of end-of-life care (Bradley et al., 2000; Cherny & Catane, 2003; Fadul et al., 2009; Johnson et al., 2008; Ward et al., 2009). In the context of the current study, the questions provided in the Physician Role Definition domain were intended to identify participants' views of the perceived role of a physician in the context of HNCa survivorship. More specifically, Questions 5-7 pertained to a physician’s role in the context of HNCa survivorship care following the completion of definitive treatment and the first year of regular surveillance.

Table 4

Physician Role Definition Domain Questions

#	Survivor Version	Physician Version
5.	It was part of my cancer doctor’s role to provide care after my treatment.	Continuing to care for survivors following the first year of regular surveillance is part of my role.
6.	My cancer doctor’s time was too limited to provide adequate care after my treatment.	My time is too limited to provide ongoing care to survivors following the first year of regular surveillance.
7.	I would have preferred someone other than my cancer doctor to have taken over my care after my treatment.	I would prefer to have someone else take over the ongoing care of survivors following the first year of regular surveillance.

Patient-Physician Communication Domain. The theory and practice of palliative care pertain to the improvement of QoL, in part, by means of comprehensive communication with patients (Bradley et al., 2000; Creutzfeldt et al., 2015; Davis et al., 2015; Gilewski, 2001; Johnson et al., 2008; Metzger et al., 2013; Oliver, 2018; Zhi & Smith, 2015; Zubkoff et al., 2018). Questions included in the *Patient-Physician Communication* domain (Table 5) were intended to assess participants’ perceptions of patient-physician communication as it pertained to decision making, goal setting, and goals of care both under ideal circumstances and in actual practice (Questions 8, 9). The Patient-Physician Communication domain also included questions intended to index participants’ perceptions of patients’ desire to be informed of what to expect following definitive treatment, physicians’ understanding of survivorship issues and their confidence in handling difficult discussions, and the opportunity for patients to meet with a fellow laryngectomee to discuss rehabilitation (Questions 10-12, 19).

Table 5

Patient-Physician Communication Domain Questions

#	Survivor Version	Physician Version
8.(a)	Under **ideal circumstances**, cancer doctors should communicate with their patients about decision making and posttreatment goal setting.	Under **ideal circumstances**, I should communicate about decision making and goal setting with survivors.
(b)	Based on **my experience**, my cancer doctor communicated with me about decision making and posttreatment goal setting.	In **actual practice**, I communicate about decision making and goal setting with survivors.
9.(a)	Under **ideal circumstances**, cancer doctors should have discussions with their patients concerning the goals of care that involve consideration of the patient's personal values, beliefs, and preferences.	Under **ideal circumstances**, I should engage in discussions concerning the goals of care with survivors that solicit their personal values, beliefs, and preferences.
(b)	Based on **my experience**, my cancer doctor discussed goals of care with me that involved consideration of my personal values, beliefs, and preferences.	In **actual practice**, I engage in discussions concerning the goals of care with survivors that solicit their personal values, beliefs, and preferences.
10.	I wanted to know what to expect after treatment and what my "new normal" was going to look like.	In my experience, survivors want to know what to expect and what their "new normal" will look like following definitive treatment.
11.	My cancer doctor communicated with me in a way that made me feel like he/she understood survivorship issues and the posttreatment experience.	My understanding of HNCa survivorship is adequate enough to discuss survivorship issues and the posttreatment experience with HNCa patients.
12.	My cancer doctor adequately communicated about difficult topics and made me feel comfortable.	I am confident in my communication skills when discussing difficult topics with survivors.
19.(a)	Under **ideal circumstances**, either before or after surgery, cancer doctors should provide their patients with the opportunity to meet with a laryngectomized visitor to discuss posttreatment recovery and rehabilitation.	Under **ideal circumstances**, either before or after treatment, I should provide my patients with an opportunity to meet with a HNCa survivor to discuss their recovery and rehabilitation.
(b)	Based on **my experience**, either before or after surgery, my cancer doctor provided me with the opportunity to meet with a laryngectomized visitor to discuss my posttreatment recovery and rehabilitation.	In **actual practice**, either before or after treatment, I provide my patients with an opportunity to meet with a HNCa survivor to discuss their recovery and rehabilitation.

Foundational Principles of Palliative Care Domain. Seven questions were designed to measure perceptions concerning specific foundational principles of palliative care in the context of HNCa survivorship (Questions 4, 13-18, Table 6). For instance, since the central ethos of palliative care pertains to the improvement of QoL (Gillick, 2005; Geerse et al., 2018; Hadad, 2009; Strand et al., 2013), Question 13 was intended to address participants' perceptions of the frequency with which posttreatment care addresses QoL issues under ideal circumstances and in actual practice. Additionally, a central principle of palliative care pertains to the importance of involving the individual's family and/or significant others in their care if deemed appropriate and/or requested by the individual (Hadad, 2009). As such, Question 14 asked participants about their perceptions toward this principle in the context of HNCa survivorship care both under ideal circumstances and in actual practice.

Another principle of palliative care dictates that individuals deserve to be fully informed about their biopsychosocial health status through the provision of comprehensive informational support (Hadad, 2009; Metzger et al., 2013). This principle of palliative care is intended to ensure individuals are comprehensively informed about what to expect to enable them to make informed decisions about their ongoing care and life choices. Within the context of HNCa survivorship care, both under ideal circumstances and in actual practice, Question 15 was intended to assess participants perceptions of this principle of palliative care. Also within the context of ideal versus actual care provision in HNCa survivorship, Question 16 asked participants about their perceptions regarding the principle of palliative care which posits that individuals should be enabled to continue their social relationships and participation in their larger social networks (Hadad, 2009).

An additional principle of palliative care posits that individuals should be supported to reach their hopes, dreams, and aspirations so they may establish a sense of meaning and purpose in life (Hadad, 2009). Accordingly, Question 17 was intended to assess participants' perceptions of this principle of palliative care, within the context of HNCa survivorship care under ideal circumstances and in actual practice. Additionally, since palliative care is modeled on an interdisciplinary approach to care provision (Billings, 1998; Creutzfeldt et al., 2015; Ferrell et al., 2017; Gillick, 2005; Hui et al., 2012; Hui et al., 2013; Meghani, 2004; Strand et al., 2013), Question 18 asked participants about their perceptions toward interdisciplinary care (Question 18[a]), as well as their perceptions regarding whether the members of this team should be housed within the same clinic (Question 18[b]).

Finally, the essence of the principles of palliative care encapsulates the notion that individuals are deserving of compassionate and respectful care that recognizes their autonomy and dignity (Randall & Downie, 2011). Accordingly, Question 4 was developed with the intent of assessing participants' perceptions of the frequency with which care provision *should ideally* be or *actually* is guided by respect for patients' autonomy and dignity in the context of HNCa survivorship. Although Question 4 was conceptually grouped under the *Foundational Principles of Palliative Care* domain, it was deliberately asked closer to the outset of the questionnaire in an attempt to minimize any potential question order effects, or more specifically, any priming effects (Dillman et al., 2014). In other words, Question 4 was situated earlier in an attempt to minimize the potential influence of preceding questions on the participants' cognitive processing of subsequent questions (i.e., cognitive-based order effects) (Dillman et al., 2014). It is anticipated that most laryngectomees and physicians are likely to indicate that care should "always" or "almost always" respect the patient's autonomy and dignity. As such, to reduce exposure to questions that may further influence the participants' answers to skew toward the "always" anchor of the rating scale, Question 4 was asked before participants might be prompted to think about other issues while responding to this particular question. In turn, it was intended that by ordering the questions in this way, it may serve to minimize potential priming that could cause an assimilation effect in which responses across questions become more similar (Dillman et al., 2014). Moreover, since Question 4 was asked and formatted in a way that was structurally similar to the questions in the Symptom Management domain, it followed logically to position it directly following the three symptom management questions.

Table 6

Foundational Principles of Palliative Care Domain Questions

#	Survivor Version	Physician Version
4. (a)	Under **ideal circumstances**, cancer doctors should provide care that respects the patient's:	Under **ideal circumstances**, I should provide care that respects the patient's:
(i)	independence and autonomy.	independence and autonomy.
(ii)	self-worth and dignity.	self-worth and dignity.
(b)	Based on **my experience**, my cancer doctor provided me with care that respected my:	In **actual practice**, I provide care that respects the patient's:
(i)	independence and autonomy.	independence and autonomy.
(ii)	self-worth and dignity.	self-worth and dignity.
13.(a)	Under **ideal circumstances**, the care provided by cancer doctors should address "quality of life" issues.	Under **ideal circumstances**, my care of survivors should address "quality of life" issues.
(b)	Based on **my experience**, my cancer doctor provided care that addressed "quality of life" issues.	In **actual practice**, my care of survivors addresses "quality of life" issues.
14.(a)	Under **ideal circumstances**, and at the patient's request, cancer doctors should meet with and address the concerns of family members and/or significant others.	Under **ideal circumstances**, and at the patient's request, my care for survivors should include meeting with and addressing the concerns of family members and/or significant others.
(b)	Based on **my experience**, and at my request, my cancer doctor met (or would have met) with and addressed the	In **actual practice**, and at the patient's request, I meet with and address the concerns of family members and/or significant others.

	concerns of my family members and/or significant others.	
15.(a)	Under **ideal circumstances**, cancer doctors should inform their patients about what to expect posttreatment to help them make informed decisions about their continuing care.	Under **ideal circumstances**, I should inform survivors about what to expect posttreatment to help them make informed decisions regarding their care.
(b)	Based on **my experience**, my cancer doctor informed me about what to expect posttreatment to help me make informed decisions about my continuing care.	In **actual practice**, I inform survivors about what to expect posttreatment to help them make informed decisions regarding their care.
16.(a)	Under **ideal circumstances**, cancer doctors should provide care that helps their patients continue personal relationships since they are part of larger social networks.	Under **ideal circumstances**, my care for survivors should address helping them to continue their relationships since they are part of larger social networks.
(b)	Based on **my experience**, my cancer doctor recognized that I was part of larger social networks and provided me with care that helped me to continue those relationships.	In **actual practice**, I recognize that survivors are part of larger social networks and I provide care that helps them to continue their relationships.
17.(a)	Under **ideal circumstances**, cancer doctors should provide their patients with opportunities to reach their hopes and dreams of whatever is most meaningful to them.	Under **ideal circumstances**, I should consider patients' posttreatment aspirations (avocational, vocational, etc.) and what is most meaningful to them.
(b)	Based on **my experience**, my cancer doctor provided me with opportunities to reach my hopes and dreams of what was most meaningful to me.	In **actual practice**, I consider patients' posttreatment aspirations (avocational, vocational, etc.) and what is most meaningful to them.
18.(a)	It is beneficial when healthcare providers from different specialties work together as a team to contribute their expertise to the care delivered after treatment.	An interdisciplinary care approach where healthcare providers from different specialties work together as a team to contribute their expertise to the care delivered following treatment completion is beneficial in the care of survivors.
(b)	A collaborative care approach that allows patients to access healthcare providers from different specialties which are housed within the same clinic is beneficial in the care of survivors after treatment.	A collaborative care approach that allows patients to access healthcare providers from different specialties housed within the same clinic is beneficial in the care of survivors following treatment completion.

Global Perception of Care Provision Domain. The last domain consisted of the single question which asked participants to provide an overall judgement of the care received following definitive treatment (Question 20, Table 7). As previously mentioned, Question 20 was also rated on a 7-point Likert-type scale, however, it is important to note that the response categories ranged from "not pleased" to "very pleased". The questionnaire concluded with an opportunity for respondents to share any other information they felt to be relevant via an open text response question (Question 21, Table 7).

Table 7

Global Perception of Care Provision Domain Questions

#	Survivor Version	Physician Version
20.	Overall, how pleased were you with the care you received from your cancer doctor after your cancer treatment?	Overall, how would you rate your patients' judgement of how pleased they are with your care following definitive treatment?
21.	Is there any other information you would like to tell the researchers?	Is there any other information you would like to offer the researchers?

Procedures

Participant Recruitment

Survivor Group Recruitment Strategy. Convenience sampling was used to recruit participants for both the Survivor and Physician Groups. Potential laryngectomee participants were initially contacted through a single mass email that was sent to the mailing list of WebWhispers, an international online support group for laryngectomee survivors. The email provided potential laryngectomee participants with a brief introduction to the study and the hyperlink to the web-based questionnaire (Appendix E). This mass email was sent by an administrator from WebWhispers and followed a recruitment script approved by the Research Ethics Board. WebWhispers members who were on the mailing list received a follow up email two months after the initial email. Since members of the research team did not have access to the mailing list there was no record of potential participants' or consenting participants' email addresses. Thus, the WebWhispers administrator sent the reminder email to all individuals on the mailing list, and those who had not yet participated were able to consider doing so if they wished. An administrator from WebWhispers also posted a brief statement about the study, including a call for participants, the letter of information, and the hyperlink to the web-based questionnaire on the WebWhispers "Member's Area" webpage of their website. The Letter of Information was also posted on the WebWhispers general webpage which could be optionally accessed by potential laryngectomee participants.

Physician Group Recruitment Strategy. A call for participants was sent to the department chairs of specifically identified academic training centres (14 Canadian institutions and five high volume American institutions) via email following a recruitment script approved by the Research Ethics Board (Appendix F). These centres, as well as the department chairs, were identifiable by public domain information. Since HNCa care is regionalized to larger centres, particularly in Canada, these institutions were identified to ensure participants were sampled from a group of physicians known to provide posttreatment care to a high-volume of patients. The email sent to department chairs provided a brief overview of the study and asked the department chair to distribute the call for participants to appropriate personnel who met the inclusion criteria outlined in the email. This call for participants also provided the hyperlink to the web-based questionnaire. One reminder email was sent to the identified department chairs three weeks after the initial email. The reminder email invited the department chairs to distribute the call for participation again to the eligible physicians in their department. Since the identity of consenting physician participants was not tied to their completed questionnaire responses, the reminder email invited department chairs to resend the call for participants to the email addresses of all potential physician participants that were originally identified.

As a more direct physician recruitment strategy, whereby the questionnaire was accessible directly instead of going through a middle-person (i.e., a department chair), a call for participants was also sent out by the Canadian Society of Otolaryngology – Head & Neck Surgery (CSO). This call for participants was sent by a CSO administrator to CSO members via email using a recruitment script approved by the Research Ethics Board (Appendix G). This email provided a brief overview of the study and invited physicians who are actively involved in the follow-up care of those treated for HNCa to participate. This email also contained the hyperlink to the web-based questionnaire. As per CSO protocol for electronic survey distribution, one reminder email was sent to CSO members three weeks after the initial email. The identity of consenting physician participants was not tied to their completed questionnaire responses. Therefore, the reminder email was offered to all CSO members regardless of previous participation. Those who had not yet participated were able to consider doing so if they wished.

Data Collection

Upon clicking the hyperlink to the web-based questionnaire, laryngectomee and physician participants were directed to either the Survivor or Physician Version of the questionnaire, respectively. The respective Letter of Information was located on the landing page of each version of the questionnaire (Appendices H and I). A downloadable hyperlink for the Letter of Information was also included on the landing page to permit participants to print a copy for their records. The Letter of Information informed participants that submission of the questionnaire served as their provision of informed consent to participate in the study. Thus, upon reading the Letter of Information and proceeding to the questionnaire, implied consent was obtained for both laryngectomee and physician participants as per questionnaire submission. As such, participation was voluntary following informed consent. After three months (April, 2021 to June, 2021 inclusive) the questionnaire website was closed, and the data was analysed. Hyperlinks to access the questionnaire on Qualtrics have been provided in Appendices C and D. However, samples of both versions of the questionnaire as they appeared to participants, are also provided for reference in Appendix J.

Data Analysis

Descriptive Statistics. SPSS Statistics Software (version 25) was used in the statistical analyses of the data (IBM Corp, 2017). To describe the laryngectomee and physician samples demographic information was summarized using descriptive statistics. It is important to note that it was anticipated that the study would not be powered sufficiently to distinguish differences in the participants' perceptions on the basis of demographic variables. For this reason, demographic information was used for descriptive purposes in order to better understand the background characteristics of the participants.

Frequencies of the participants' responses to each of the 20 questions rated on Likert-type scales were tabulated to describe the raw data. Additionally, measures of central tendency including the mean, median, and mode were used to analyze the data collected from individual questions. Measures of dispersion including the range and standard deviation (SD) were also calculated to describe the variability around the measures of central tendency. Objective one aimed to gather information regarding laryngectomees' and physicians' perceptions of the frequency with which principles of palliative care that ultimately support QoL *should* be present following HNCa treatment completion under *ideal circumstances*. Thus, for objective one, descriptive statistics were used to analyze the data collected from questions posed to laryngectomees and physicians in the context of ideal circumstances[2]. Objective two sought to collect information regarding laryngectomees' and physicians' perceptions of the frequency with which principles of palliative care that ultimately support QoL are present in *actual practice* following HNCa treatment completion. For objective two the aforementioned descriptive statistics were calculated to analyze the data collected from questions posed in the context of actual practice on both the Survivor and Physician Versions of the questionnaire[3]. To further contextualize laryngectomees' and physicians' perceptions regarding the inclusion of principles of palliative care that support QoL in HNCa survivorship care, the mean, median, mode, SD, and range were also calculated for the unpaired questions that were not bound to the context of ideal circumstances or actual practice[4].

It is important to note that while the mean and SD values were calculated as part of the descriptive statistics used to summarize the participants' perceptions, these values must be interpreted with caution owing to the level of measurement and the anticipated distribution of the data. More specifically, the mode and median values were the most appropriate measures of central tendency, and the range was the most appropriate measure of dispersion for correct analysis of the data since the Likert-type scale collected discrete (ordinal) data (McCormick & Salcedo, 2015). Moreover, it was not anticipated that the data would cluster around the middle

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[2] Data pertaining to participants' perceptions regarding how frequently aspects of palliative care *should* be included in HNCa survivorship care under *ideal circumstances* were collected using Questions 1 (i, ii, iii, iv), 4 (a, i), 4 (a, ii), 8 (a), 9 (a), 13 (a), 14 (a), 15 (a), 16 (a), 17 (a), 19 (a) of the Survivor and Physician Versions of the questionnaire.

[3] Data pertaining to participants' perceptions regarding how frequently aspects of palliative care are included in HNCa survivorship care in *actual practice* were collected using Questions 2 (i, ii, iii, iv), 4 (b, i), 4 (b, ii), 8 (b), 9 (b), 13 (b), 14 (b), 15 (b), 16 (b), 17 (b), 19 (b) of both the Survivor and Physician Versions of the questionnaire.

[4] Data to further contextualize participants' perceptions toward principles of palliative care were collected using Questions 3 (i, ii, iii, iv), 5, 6, 7, 10, 11, 12, 18 (a, b), 20. These questions are considered "unpaired" since their subject matter was asked in a singular context (i.e., not ideal circumstances or actual practice).

response anchors of the Likert-type scale utilized in the questionnaire and, thus, a normal distribution was unlikely to occur (Daniel & Cross, 2013; Evans, 2014). However, acknowledging these precautions, careful consideration of the mean values may still augment the pursuit of a thorough understanding of the clustering of the responses and trends related to "directionality" in these responses.

Inferential Statistics. ***Within Group Cross-Sectional Comparisons.*** Potential differences between laryngectomees' perceptions of the frequency with which principles of palliative care *should* be included under ideal circumstances and their experience of the frequency with which principles of palliative care were *actually* included in their survivorship care were analyzed. The potential differences between physicians' perceptions of the frequency with which the principles of palliative care *should* be included under ideal circumstances and the frequency with which they include these principles in their *actual practice* were also analyzed[5]. Both analyses were completed using the Wilcoxon Signed-Rank Test. The Wilcoxon Signed-Rank Test was selected since a non-normal distribution of the data was anticipated. Moreover, a non-parametric statistical test, like the Wilcoxon Signed-Rank Test was indicated since the scale collected discrete (ordinal) data. Accordingly, since the general assumptions of Cohen's d formula for effect size would be violated by the data of the current study, effect sizes were calculated using the formula $r = Z/\sqrt{N}$ (Rosenthal, 1994)[6].

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[5] Differences were assessed between participants' perceptions toward paired questions (i.e., 1[i, ii, iii, iv] and 2[i, ii, iii, iv], 4[a] and 4[b], 8[a] and 8[b], 9[a] and 9[b], 13[a] and 13[b], 14[a] and 14[b], 15[a] and 15[b], 16[a] and 16[b], 17[a] and 17[b], and 19[a] and 19[b]).

[6] To calculate effect sizes in data which are not normally distributed, the formula $r = Z/\sqrt{N}$ is indicated for use, in which "Z" represents the Z-value calculated by the Wilcoxon Signed-Rank Test and "N" represents the number of observations being compared (i.e., 2 x number of participants) (Rosenthal, 1994).

Correlational Analysis. Potential correlations between the perceptions of the laryngectomees and physicians toward equivalent questions across the Survivor and Physician Versions of the questionnaire were examined using the Spearman's correlation coefficient[7]. Correlational analysis was also used to identify any underlying relationships between the aspects of care featured in each question and one's global perception of posttreatment care. More specifically, Spearman's correlation coefficient was utilized to test for correlations between the participants' responses to the Global Perception of Care Provision domain (i.e., Question 20), and all other questions on the questionnaire. Spearman's correlation coefficient was utilized in both of these correlational analyses since it is a non-parametric measure of rank correlation that is appropriate for discrete (ordinal) variables (Daniel & Cross, 2013; Evans, 2014). Moreover, as previously stated, the distribution of the current data was anticipated to be non-normal and, thus, the general assumptions of a parametric test could not be met (Daniel & Cross, 2013; Evans, 2014).

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[7] Correlational analysis of equivalent questions across the Survivor and Physician Versions of the questionnaire pertained to the questions that concerned the same subject matter but are posed slightly differently to appropriately target the given participant group (i.e., 1 [i] on the Survivor Version and 1 [i] on the Physician Version, 1 [ii] on the Survivor Version and 1 [ii] on the Physician Version, etc.).

CHAPTER 3

Results

This chapter presents the results of the current study in relation to its objectives which were to identify and describe:

1. Laryngectomees’ and physicians’ perceptions of whether principles of palliative care that ultimately support QoL *should* be present following HNCa treatment completion under *ideal circumstances*.
2. Laryngectomees’ and physicians’ perceptions of whether principles of palliative care that ultimately support QoL are present in *actual practice* following HNCa treatment completion.

To begin, the response rates of the Survivor and Physician Groups will be presented. Subsequently, demographic information to describe the survivor and physician samples will be outlined. To address the stated objectives, frequencies and descriptive statistics for the questions posed in the context of ideal circumstances and actual practice will be presented to summarize the Survivor and Physician Groups’ responses. Frequencies and descriptive statistics calculated for the unpaired questions that were not bound to the context of ideal circumstances or actual practice will also be presented to further contextualize the participants’ perceptions. Next, the differences between the participants’ perceptions of the inclusion of the principles of palliative care under ideal circumstances and in actual practice in HNCa survivorship care will be presented. Then, the results of the correlational analyses between the laryngectomees’ and physicians’ perceptions toward the equivalent questions across the Survivor and Physician Versions of the questionnaire will be provided. Lastly, the results of the correlational analyses performed between the Global Perception of Care Provision domain and all other questions on the questionnaire will be presented.

Response Rates

Survivor Group

A total of 2922 individuals are on the WebWhispers mailing list and thus, potentially received the call for participants via the mass email; however, it is noteworthy that not all of these members are considered active. That is, some individuals may utilize WebWhispers resources, but do not regularly engage in other types of active participation. Of the individuals on the WebWhispers mailing list, 240 consented to participate. However, nine of these consenting participants did not meet eligibility criteria and their completed questionnaires were excluded. Reasons for the exclusion of these nine questionnaires included treatment that was ongoing and total laryngectomy secondary to a diagnosis other than laryngeal carcinoma. Overall, a conservative response rate of 7.9% was estimated (n = 231).

Physician Group

Fourteen academic training centres and five high volume cancer care institutions were identified for physician recruitment in Canada and the United States, respectively. Approximately 176 otolaryngologists who practice at these 19 institutions were identified as likely to have direct involvement in the care of HNCa survivors (55 at the Canadian institutions and 121 at the American institutions). Additionally, physician recruitment involved a call for participants via the CSO. The CSO's mailing list consists of 493 otolaryngologists, not all of whom would be involved in head and neck oncology. Assuming the 55 physicians practicing at the identified Canadian institutions were also members of the CSO, approximately 614 physicians were potential participants. In total, completed questionnaires were collected from 32 consenting and eligible physicians, resulting in a conservative response rate estimate of 5.2%. This estimate may be conservative since it is possible for physician members of the CSO to no longer be in practice.

Demographic Information

Survivor Group

Of the 231 participants in the Survivor Group, a total of 168 were male (72.7%), 60 were female (26.0%), and 2 identified as non-binary (0.9%). The mean age of consenting laryngectomees was 70.1 years (range = 37.0-92.0); male laryngectomees had a mean age of 71.2 years (range = 37.0-92.0), female laryngectomees had a mean age of 67.1 years (range = 45.8-83.8), and non-binary laryngectomees had a mean age of 69.2 years (range = 67.3-71.0). The majority of participating laryngectomees (94.4%) indicated that they were White (European descent). Most of the participants of the Survivor Group (85.3%) resided in the United States. Among the Survivor Group, high school was the most common level of education achieved (31.6%). Complete demographic information for the Survivor Group is presented in Table 8.

Table 8

Demographic Information of Survivor Group Participants

Demographic Variable	n	%
Sex		
Male	168	72.7
Female	60	26.0
Non-binary	2	0.9
Mean Age (Range), in years	70.1 (37.0-92.0)	N.A.
Race		
White (European descent)	218	94.4
Black (African American descent/African Canadian descent/Afro-Caribbean)	6	2.6
Latino	2	0.9
East/Southeast Asian	1	0.4
First Nations, Mixed Ancestry, Metis, Inuit, Native American	1	0.4
Middle Eastern	1	0.4
South Asian	1	0.4
Country of Residence		
United States	197	85.3
Canada	18	7.8
Australia	5	2.2
Mexico	3	1.3
UK	2	0.9
Ireland	1	0.4
Netherlands	1	0.4
New Zealand	1	0.4
Scotland	1	0.4
South Africa	1	0.4
Highest Level of Education Achieved		
Did not complete high school	5	2.2
Completed high school	73	31.6
Did not complete college	16	6.9
Completed college	50	21.6
Undergraduate university degree	38	16.5
Post-graduate university degree	46	19.9
Prefer not to answer	3	1.3

On average, the participants in the Survivor Group completed their treatment for laryngeal cancer 8.1 years prior to study participation (97.6 months, range = 2 months-516 months). Laryngectomees most commonly reported (30.3%) that they had received radiation therapy before undergoing total laryngectomy. The primary method of alaryngeal speech reported was TE speech (65.4%). Complete data pertaining to disease- and treatment-related variables for the Survivor Group are presented in Table 9.

Table 9

Disease- and Treatment-Related Data of Survivor Group Participants

Variable	n	%
Years since Treatment Completion		
<5 years	99	42.9
5-9 years	49	21.2
10-14 years	34	14.7
15-19 years	23	10.0
20-24 years	8	3.5
25-29 years	5	2.16
30-34 years	5	2.16
35-39 years	0	0
40-45 years	1	0.43
Modality of Treatment (in addition to laryngectomy)		
Radiation therapy (before surgery)	70	30.3
Radiation therapy (after surgery)	58	25.1
Radiation therapy (before and after surgery)	3	1.3
Radiation therapy (before surgery), chemotherapy	34	14.7
Radiation therapy (after surgery), chemotherapy	23	10.0
Radiation therapy (before and after surgery), chemotherapy	6	2.6
Prefer not to answer	5	2.2
Primary method of alaryngeal speech		
Esophageal speech	11	4.8
Tracheoesophageal speech	151	65.4
Electrolaryngeal speech	55	23.8
Tablet app/writing	12	5.2
Effective in more than one method	2	0.9

Physician Group

The Physician Group (n = 32) consisted of 29 male (90.6%) and 3 female (9.4%) participants. The mean age of the physician participants was 48.6 years (range = 30.0-76.9), with a mean age of 49.8 years for males (range = 30.0-76.9) and 37.2 years for females (range = 31.5-44.0). The predominant race category in the Physician Group was White (European descent)

(81.3%). The majority of the physician participants indicated that their country of residence was Canada (84.4%). Most participating physicians practiced in the sub-speciality of Head and Neck Surgery (65.6%). On average, the physician participants had 15.7 years of experience (range = 1.0-45.0). Participants in the Physician Group indicated that they were predominantly practicing in cancer centres (59.4%). The majority of the Physician Group's clinical background/training was in otolaryngology (75.0%). Complete demographic information for the Physician Group is presented in Table 10.

Table 10

Demographic Information of Physician Group Participants

Demographic Variable	n	%
Sex		
Male	29	90.6
Female	3	9.4
Mean Age	48.6 (30.0-76.9)	N.A.
Race		
White (European descent)	26	81.3
Black (African American descent/African Canadian descent/Afro-Caribbean)	0	0
First Nations, Mixed Ancestry, Metis, Inuit, Native American	0	0
East/Southeast Asian	2	6.3
South Asian	1	3.1
Middle Eastern	1	3.1
Latino	0	0
Country of Residence		
Canada	27	84.4
United States	4	12.5
Medical Sub-Specialty		
Otology and Neurotology	1	3.1
Head and Neck Surgery	21	65.6
Pediatric Otolaryngology	0	0.0
Rhinology and Sinus	1	3.1
Skull Base Surgery	0	0
Facial Plastics and Reconstructive Surgery	1	3.1
Laryngology	2	6.3
Sleep Surgery	0	0
General ENT	6	18.8
Mean Years of Experience	15.7 (1.0-45.0)	N.A.
Category of Site Location/Place of Work		
Cancer Centre	19	59.4
Teaching Hospital	6	18.8
Community Hospital	7	21.9
Clinical Background/Training		
Otolaryngology	24	75.0
Oncology	5	15.6
Facial Plastics/Reconstructive Surgery	2	6.3

Note: Parenthetical values present the range.

Perceptions of the Inclusion of Principles of Palliative Care in HNCa Survivorship

Frequencies of the survivors’ and physicians’ responses to the questions on the questionnaire were tabulated (see Tables 11 and 12, respectively). A frequency table that displays both the survivors’ and physicians’ responses is provided in Appendix K. The frequencies are also presented graphically; Figures 1-3 display the frequencies for the questions in the Symptom Management domain, Figure 4 displays those for the questions in the Physician Role Definition domain, Figure 5 displays those for the questions in the Patient-Physician Communication domain, Figure 6 displays those for the questions in the Foundational Principles of Palliative Care domain, and Figure 7 displays those for the questions in the Global Perception of Care Provision domain.

Table 11

Frequency Table for Survivor Group Responses to Individual Questions on the Questionnaire

Question Number	Question Content	Never	Almost Never	Less than Half the Time	Half the Time	More than Half the Time	Almost Always	Always
1(i)	Ideal - Physical	1 (0.4)	1 (0.4)	2 (0.9)	8 (3.5)	9 (3.9)	52 (22.5)	153 (66.2)
1(ii)	Ideal - Psychological	2 (0.9)	3 (1.3)	10 (4.3)	12 (5.2)	11 (4.8)	53 (22.9)	134 (58.0)
1(iii)	Ideal – Social	6 (2.6)	10 (4.3)	15 (6.5)	25 (10.8)	17 (7.4)	52 (22.5)	100 (43.3)
1(iv)	Ideal – Existential	34 (14.7)	43 (18.6)	12 (5.2)	23 (10.0)	18 (7.8)	48 (20.8)	46 (19.9)
2(i)	Actual – Physical	4 (1.7)	11 (4.8)	6 (2.6)	19 (8.2)	22 (9.5)	49 (21.2)	113 (48.9)
2(ii)	Actual – Psychological	27 (11.7)	33 (14.3)	25 (10.8)	28 (12.1)	28 (12.1)	33 (14.3)	50 (21.6)
2(iii)	Actual – Social	50 (21.6)	48 (20.8)	22 (9.5)	23 (10.0)	17 (7.4)	30 (13.0)	34 (14.7)
2(iv)	Actual – Existential	109 (47.2)	45 (19.5)	18 (7.8)	11 (4.8)	8 (3.5)	17 (7.4)	15 (6.5)
3(i)	Approachability – Physical	7 (3.0)	13 (5.6)	3 (1.3)	12 (5.2)	18 (7.8)	44 (19.0)	124 (53.7)
3(ii)	Approachability – Psychological	34 (14.7)	47 (20.3)	12 (5.2)	23 (10.0)	12 (5.2)	33 (14.3)	62 (26.8)
3(iii)	Approachability – Social	52 (22.5)	39 (16.9)	19 (8.2)	17 (7.4)	15 (6.5)	28 (12.1)	51 (22.1)
3(iv)	Approachability – Existential	108 (46.8)	45 (19.5)	10 (4.3)	13 (5.6)	8 (3.5)	11 (4.8)	24 (10.4)
4(a)(i)	Ideal – Autonomy	2 (0.9)	1 (0.4)	1 (0.4)	5 (2.2)	13 (5.6)	43 (18.6)	151 (65.4)

4(b)(i)	Actual – Autonomy	5 (2.2)	11 (4.8)	7 (3.0)	13 (5.6)	15 (6.5)	59 (25.5)	107 (46.3)
4(a)(ii)	Ideal – Dignity	2 (0.9)	3 (1.3)	2 (0.9)	6 (2.6)	10 (4.3)	37 (16.0)	155 (67.1)
4(b)(ii)	Actual – Dignity	6 (2.6)	19 (8.2)	9 (3.9)	10 (4.3)	16 (6.9)	42 (18.2)	114 (49.4)
5	Physician’s Role Posttreatment	9 (3.9)	11 (4.8)	13 (5.6)	11 (4.8)	21 (9.1)	53 (22.9)	98 (42.4)
6	Physician’s Time Limitations	80 (34.6)	49 (21.2)	20 (8.7)	18 (7.8)	15 (6.5)	22 (9.5)	11 (4.8)
7	Transfer of Care Preference	124 (53.7)	31 (13.4)	7 (3.0)	15 (6.5)	8 (3.5)	19 (8.2)	9 (3.9)
8(a)	Ideal – Decisions, Goals		1 (0.4)	1 (0.4)	7 (3.0)	10 (4.3)	44 (19.0)	151 (65.4)
8(b)	Actual – Decisions, Goals	12 (5.2)	18 (7.8)	16 (6.9)	18 (7.8)	18 (7.8)	47 (20.3)	86 (37.2)
9(a)	Ideal – Values, Preferences	5 (2.2)	9 (3.9)	7 (3.0)	12 (5.2)	12 (5.2)	51 (22.1)	116 (50.2)
9(b)	Actual – Values, Preferences	19 (8.2)	34 (14.7)	21 (9.1)	20 (8.7)	19 (8.2)	36 (15.6)	62 (26.8)
10	Desire to Know What to Expect	2 (0.9)	2 (0.9)	4 (1.7)	8 (3.5)	12 (5.2)	34 (14.7)	151 (65.4)
11	Survivorship Knowledge	7 (3.0)	21 (9.1)	11 (4.8)	21 (9.1)	18 (7.7)	51 (22.1)	82 (35.5)
12	Difficult Topics	9 (3.9)	18 (7.8)	13 (5.6)	21 (9.1)	15 (6.5)	51 (22.1)	85 (36.8)
13(a)	Ideal - QoL		2 (0.9)	3 (1.3)	8 (3.5)	6 (2.6)	48 (20.8)	142 (61.5)
13(b)	Actual - QoL	9 (3.9)	20 (8.7)	18 (7.8)	19 (8.2)	15 (6.5)	51 (22.1)	78 (33.8)
14(a)	Ideal – Family Involvement	4 (1.7)	2 (0.9)	4 (1.7)	11 (4.8)	15 (6.5)	39 (16.9)	135 (58.4)

14(b)	Actual – Family Involvement	13 (5.6)	17 (7.4)	6 (2.6)	11 (4.8)	17 (7.4)	43 (18.6)	102 (44.2)
15(a)	Ideal – What to Expect	1 (0.4)	1 (0.4)	4 (1.7)	3 (1.3)	4 (1.7)	27 (11.7)	168 (72.1)
15(b)	Actual – What to Expect	9 (3.9)	16 (6.9)	14 (6.1)	18 (7.8)	20 (8.7)	48 (20.8)	84 (36.4)
16(a)	Ideal – Social Networks	12 (5.2)	18 (7.8)	6 (2.6)	18 (7.8)	18 (7.8)	47 (20.3)	86 (37.2)
16(b)	Actual – Social Networks	30 (13.0)	37 (16.0)	13 (5.6)	23 (10.0)	18 (7.8)	33 (14.3)	51 (22.1)
17(a)	Ideal – Hopes and Dreams	16 (6.9)	20 (8.7)	7 (3.0)	12 (5.2)	20 (8.7)	47 (20.3)	81 (35.1)
17(b)	Actual – Hopes and Dreams	35 (15.2)	34 (14.7)	9 (3.9)	24 (10.4)	20 (8.7)	35 (15.2)	44 (19.0)
18(a)	Interdisciplinary Care				3 (1.3)	2 (0.9)	26 (11.3)	176 (76.2)
18(b)	Location of Clinicians	2 (0.9)	4 (1.7)	1 (0.4)	6 (2.6)	3 (1.3)	40 (17.3)	151 (65.4)
19(a)	Ideal –Visit from Survivor		3 (1.3)		1 (0.4)	5 (2.2)	55 (23.8)	141 (61.0)
19(b)	Actual – Visit from Survivor	78 (33.8)	7 (3.0)	6 (2.6)	8 (3.5)	6 (2.6)	23 (10.0)	79 (34.2)
20	Perception of Care	6 (2.6)	4 (1.7)	3 (1.3)	13 (5.6)	17 (7.4)	36 (15.6)	128 (55.4)

Note: Parenthetical values represent percentages of the total laryngectomee sample (n = 231). Empty cells indicate a frequency of zero.

Table 12

Frequency Table for Physician Group Responses to Individual Questions on the Questionnaire

Question Number	Question Content	Never	Almost Never	Less than Half the Time	Half the Time	More than Half the Time	Almost Always	Always
1(i)	Ideal - Physical					2 (6.3)	7 (21.9)	23 (71.9)
1(ii)	Ideal - Psychological			2 (6.3)	2 (6.3)	6 (18.8)	8 (25.0)	14 (43.8)
1(iii)	Ideal – Social		2 (6.3)	3 (9.4)	2 (6.3)	8 (25.0)	5 (15.6)	12 (37.5)
1(iv)	Ideal – Existential	1 (3.1)	6 (18.8)	7 (21.9)	3 (9.4)	2 (6.3)	5 (15.6)	7 (21.9)
2(i)	Actual – Physical					3 (9.4)	7 (21.9)	21 (65.6)
2(ii)	Actual – Psychological			5 (15.6)	5 (15.6)	9 (28.1)	9 (28.1)	3 (9.4)
2(iii)	Actual – Social		3 (9.4)	9 (28.1)	4 (12.5)	5 (15.6)	7 (21.9)	3 (9.4)
2(iv)	Actual – Existential	2 (6.3)	15 (46.9)	5 (15.6)	3 (9.4)	3 (9.4)	3 (9.4)	
3(i)	Approachability – Physical						5 (15.6)	24 (75.0)
3(ii)	Approachability – Psychological				3 (9.4)	2 (6.3)	13 (40.6)	12 (37.5)
3(iii)	Approachability – Social	1 (3.1)			4 (12.5)	7 (21.9)	9 (28.1)	9 (28.1)
3(iv)	Approachability – Existential	1 (3.1)	3 (9.4)	6 (18.8)	4 (12.5)	4 (12.5)	6 (18.8)	6 (18.8)
4(a)(i)	Ideal – Autonomy					2 (6.3)	3 (9.4)	24 (75.0)

4(b)(i)	Actual – Autonomy					1 (3.1)	12 (37.5)	16 (50.0)
4(a)(ii)	Ideal – Dignity					1 (3.1)	2 (6.3)	26 (81.3)
4(b)(ii)	Actual – Dignity					2 (6.3)	8 (25.0)	19 (59.4)
5	Physician's Role Posttreatment			1 (3.1)		1 (3.1)	3 (9.4)	24 (75.0)
6	Physician's Time Limitations	24 (75.0)	3 (9.4)	1 (3.1)				1 (3.1)
7	Transfer of Care Preference	16 (50.0)	11 (34.4)	1 (3.1)		1 (3.1)		
8(a)	Ideal –Decisions, Goals	1 (3.1)				3 (9.4)	8 (25.0)	17 (53.1)
8(b)	Actual – Decisions, Goals	1 (3.1)	2 (6.3)	1 (3.1)	1 (3.1)	6 (18.8)	8 (25.0)	10 (31.3)
9(a)	Ideal – Values, Preferences	1 (3.1)	1 (3.1)			2 (6.3)	6 (18.8)	19 (59.4)
9(b)	Actual – Values, Preferences	1 (3.1)	2 (6.3)	2 (6.3)	2 (6.3)	6 (18.8)	9 (28.1)	7 (21.9)
10	Desire to Know What to Expect			1 (3.1)	1 (3.1)	2 (6.3)	12 (37.5)	13 (40.6)
11	Survivorship Knowledge			2 (6.3)	1 (3.1)	6 (18.8)	11 (34.4)	8 (25.0)
12	Difficult Topics				1 (3.1)	4 (12.5)	14 (43.8)	10 (31.3)
13(a)	Ideal - QoL					2 (6.3)	6 (18.8)	21 (65.6)
13(b)	Actual - QoL			2 (6.3)	1 (3.1)	4 (12.5)	14 (43.8)	8 (25.0)
14(a)	Ideal – Family Involvement				2 (6.3)	3 (9.4)	8 (25.0)	16 (50.0)

14(b)	Actual – Family Involvement		1 (3.1)	2 (6.3)	2 (6.3)	5 (15.6)	12 (37.5)	7 (21.9)
15(a)	Ideal – What to Expect		1 (3.1)				6 (18.8)	22 (68.8)
15(b)	Actual – What to Expect		1 (3.1)				15 (46.9)	13 (40.6)
16(a)	Ideal – Social Networks	1 (3.1)	1 (3.1)	3 (9.4)		4 (12.5)	5 (15.6)	15 (46.9)
16(b)	Actual – Social Networks	1 (3.1)	4 (12.5)	3 (9.4)	5 (15.6)	6 (18.8)	6 (18.8)	4 (12.5)
17(a)	Ideal – Hopes and Dreams	1 (3.1)	1 (3.1)			5 (15.6)	4 (12.5)	18 (56.3)
17(b)	Actual – Hopes and Dreams	1 (3.1)	1 (3.1)	2 (6.3)	3 (9.4)	5 (15.6)	9 (28.1)	8 (25.0)
18(a)	Interdisciplinary Care						9 (28.1)	20 (62.5)
18(b)	Location of Clinicians		2 (6.3)		1 (3.1)	3 (9.4)	10 (31.3)	12 (37.5)
19(a)	Ideal –Visit from Survivor		1 (3.1)	3 (9.4)	2 (6.3)	3 (9.4)	8 (25.0)	11 (34.4)
19(b)	Actual – Visit from Survivor	2 (6.3)	9 (28.1)	8 (25.0)	4 (12.5)		4 (12.5)	1 (3.1)
20	Perception of Care	1 (3.1)				8 (25.0)	13 (40.6)	7 (21.9)

Note: Parenthetical values represent percentages of the total physician sample (n = 32). Empty cells indicate a frequency of zero.

Figure 1

Symptom Management Domain: Ideal Circumstances

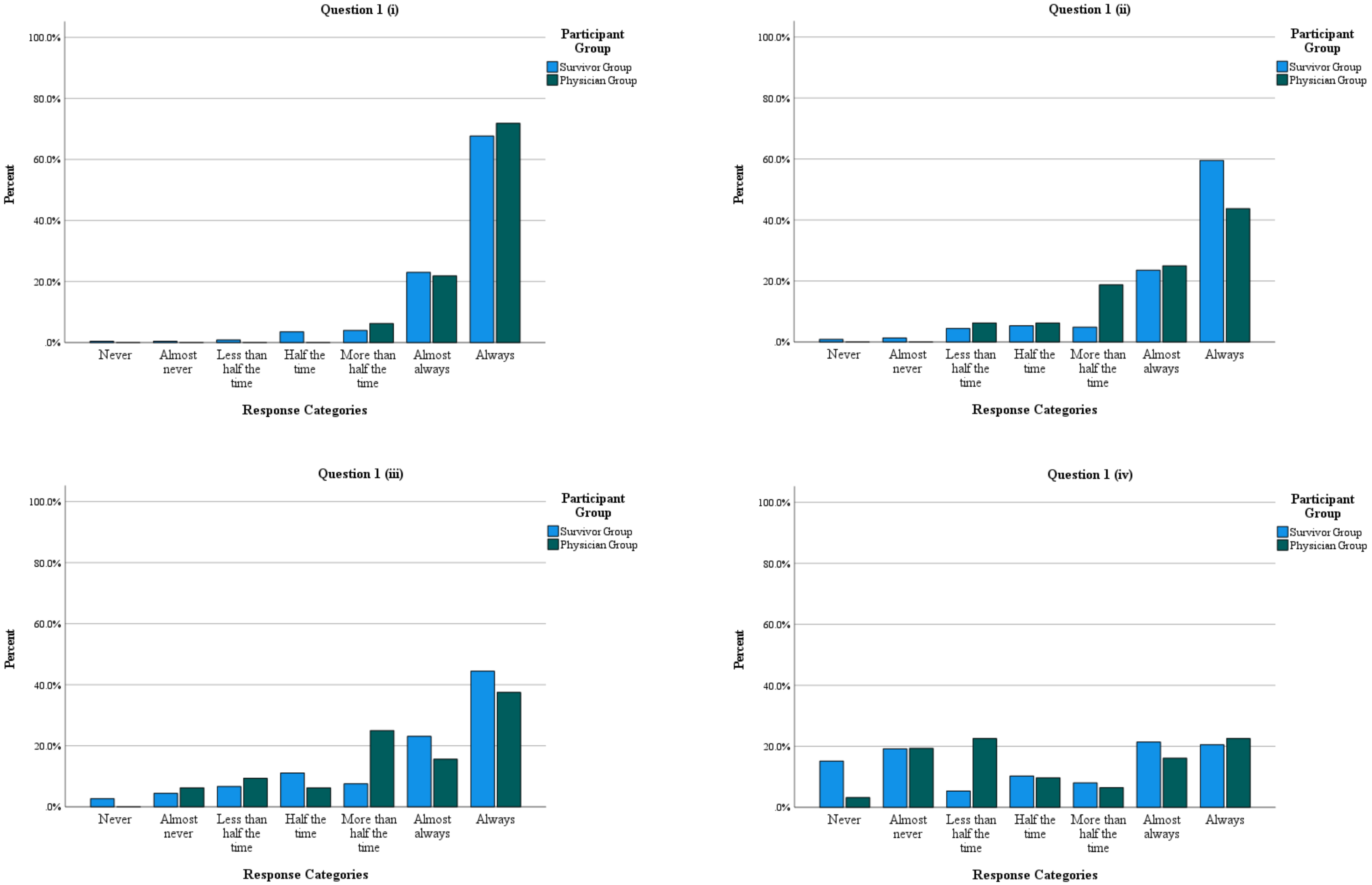


Figure 2

Symptom Management Domain: Actual Practice

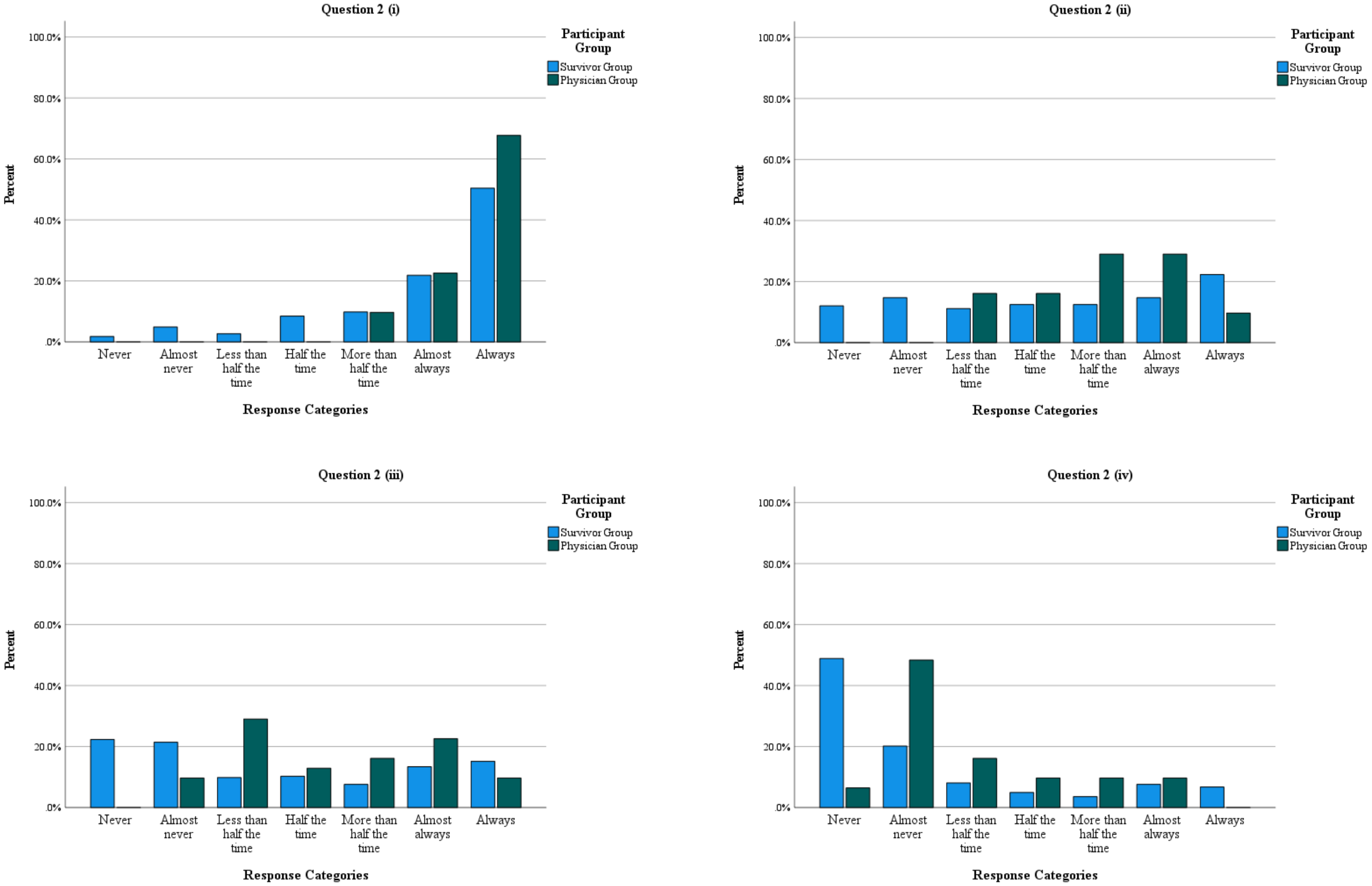


Figure 3

Symptom Management Domain: Approachability

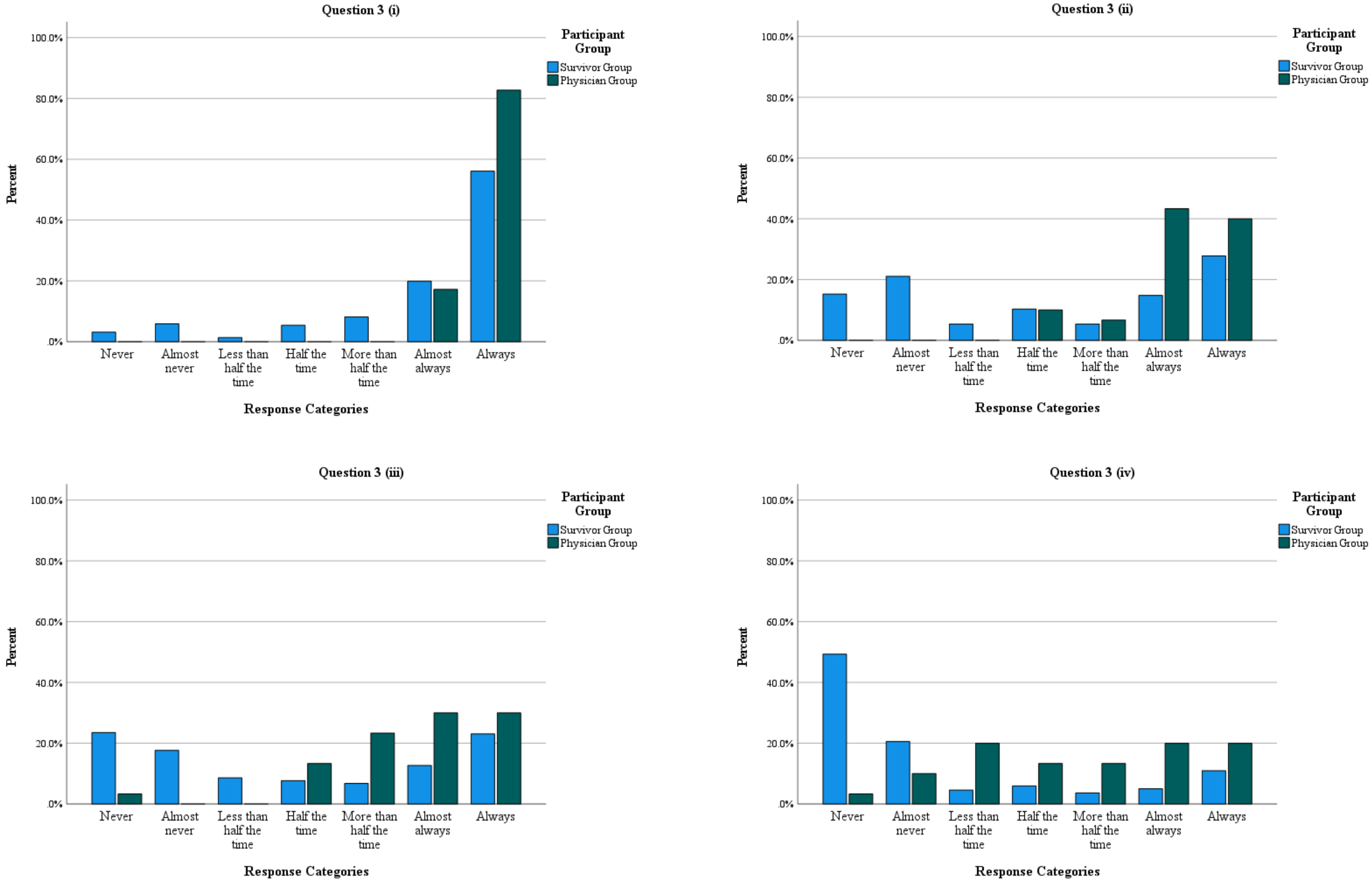


Figure 4

Physician Role Definition Domain

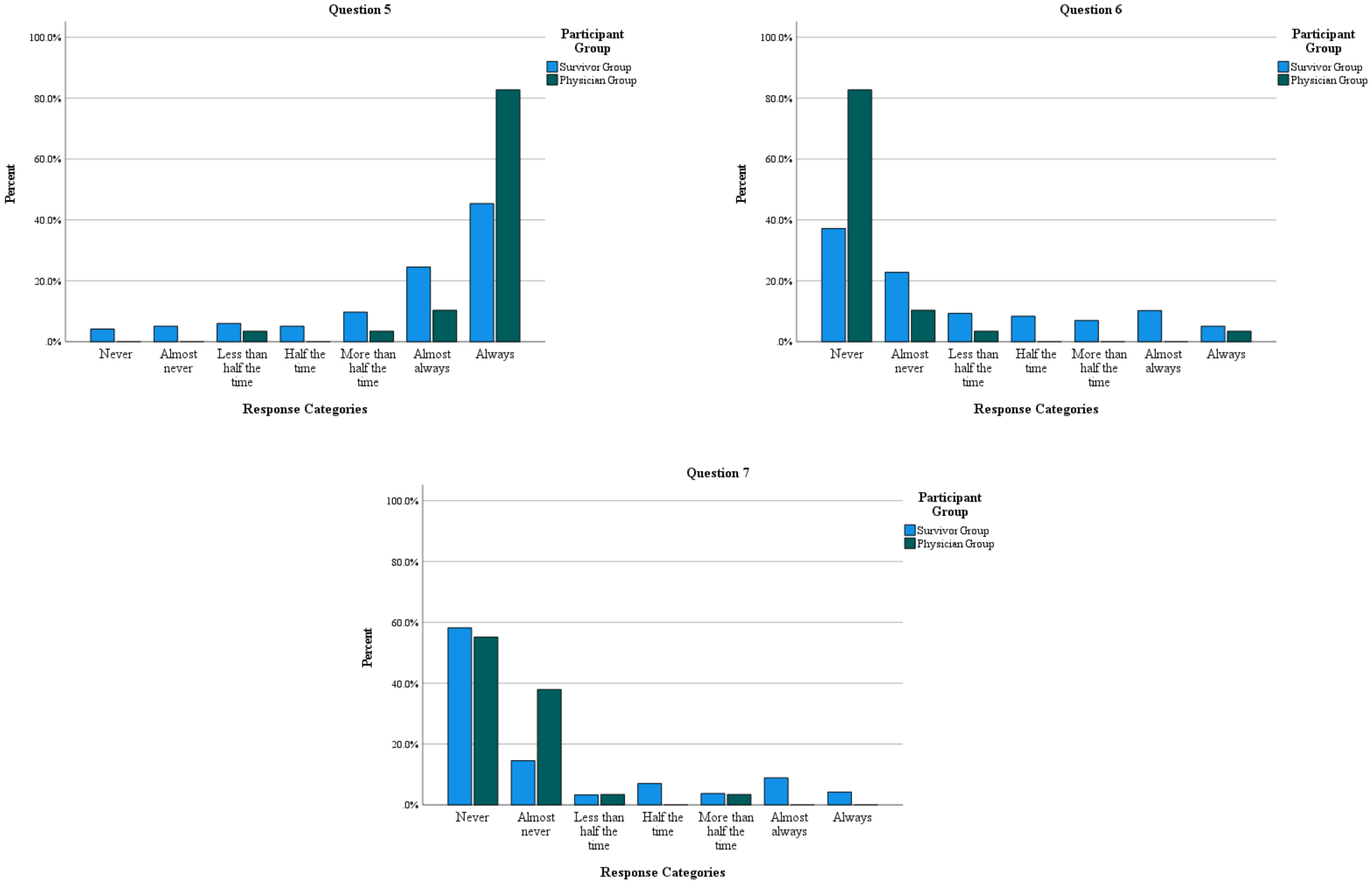


Figure 5

Patient-Physician Communication Domain

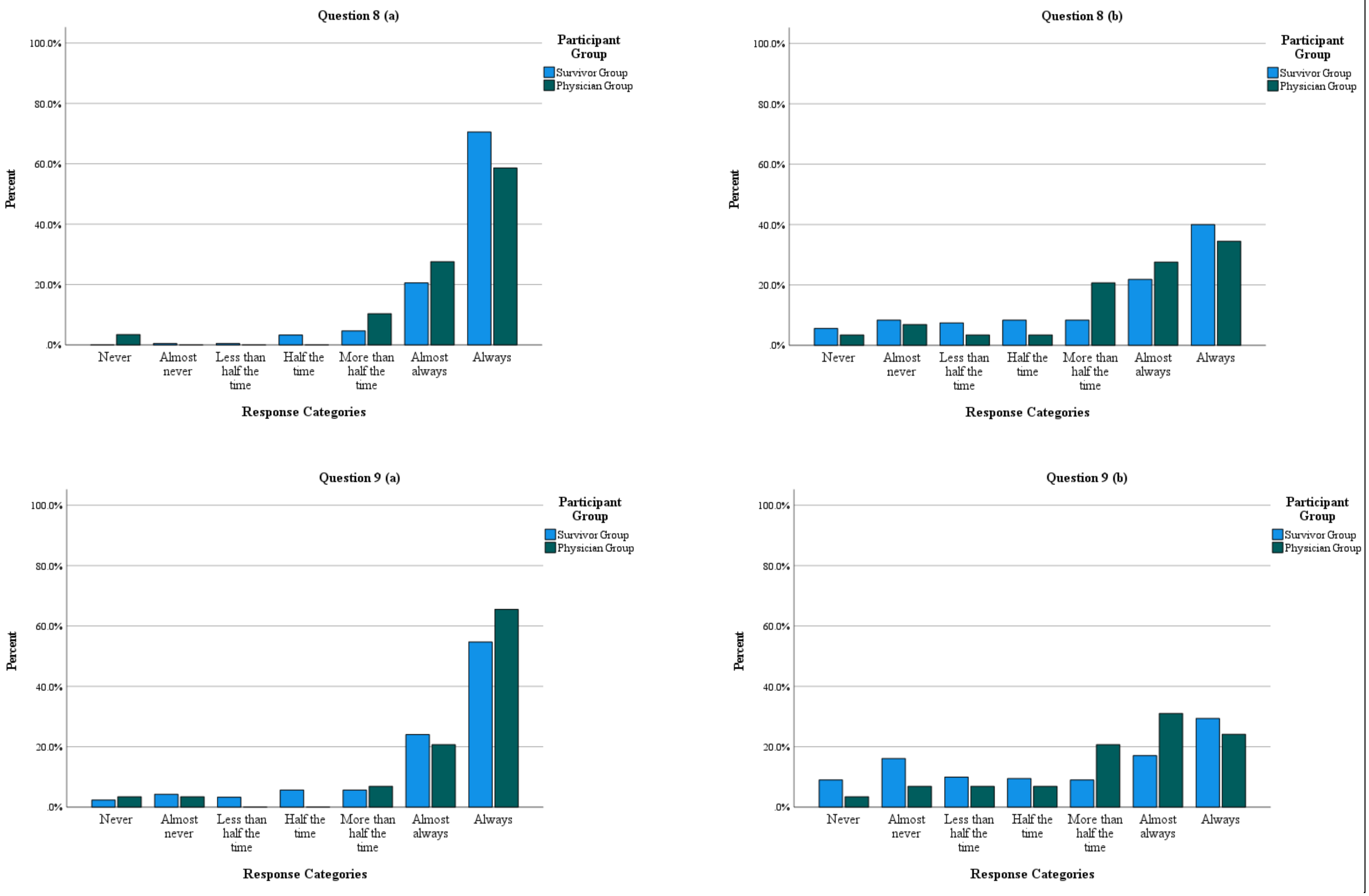
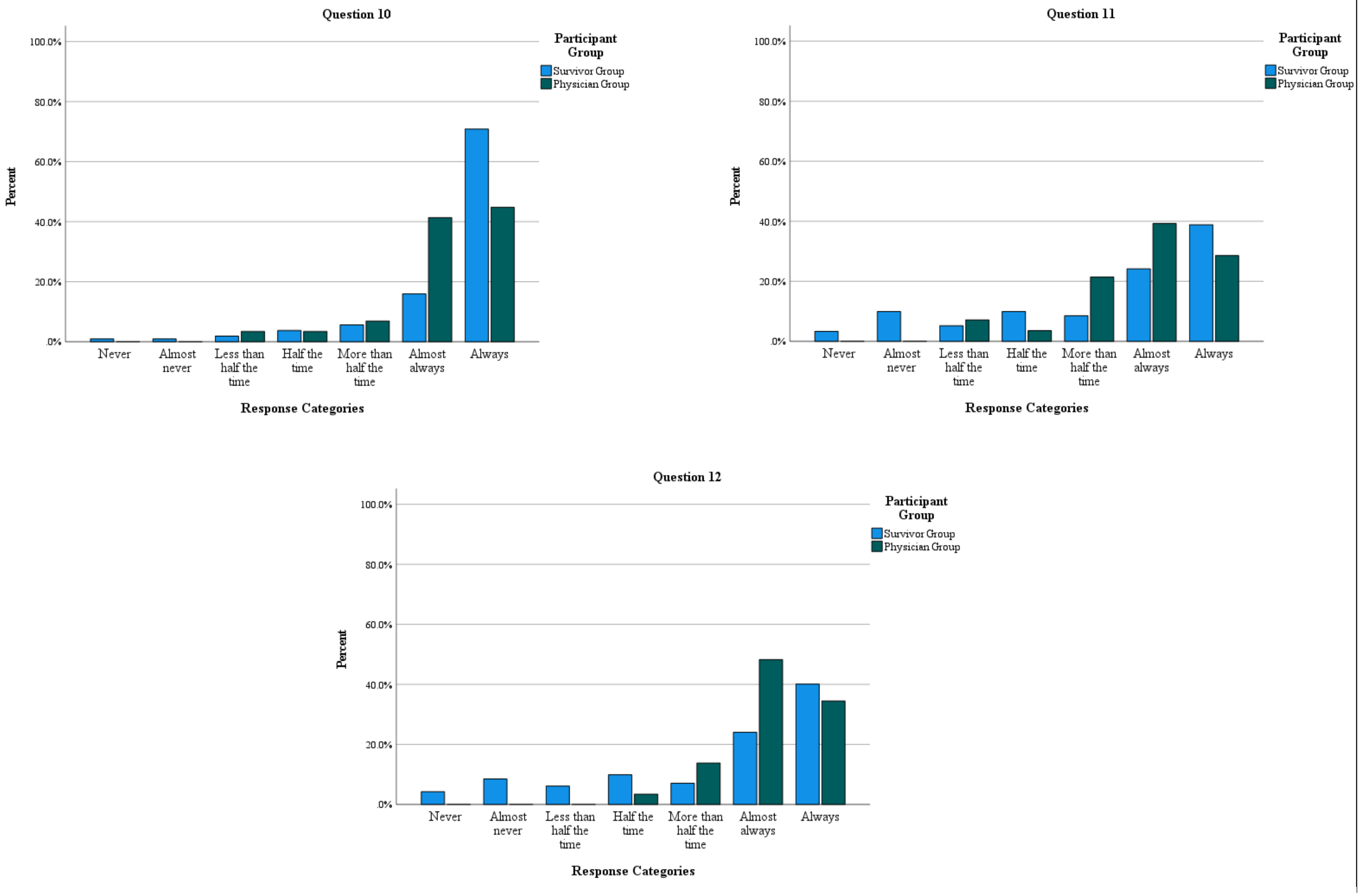


Figure 5, continued



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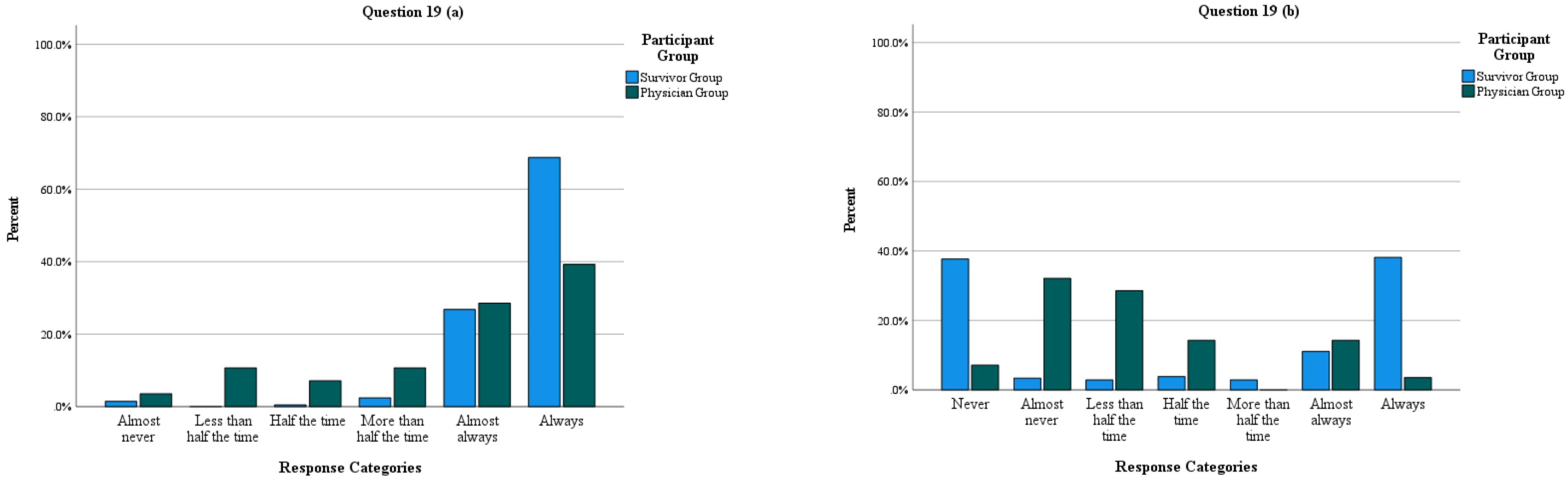


Figure 6

Foundational Principles of Palliative Care Domain

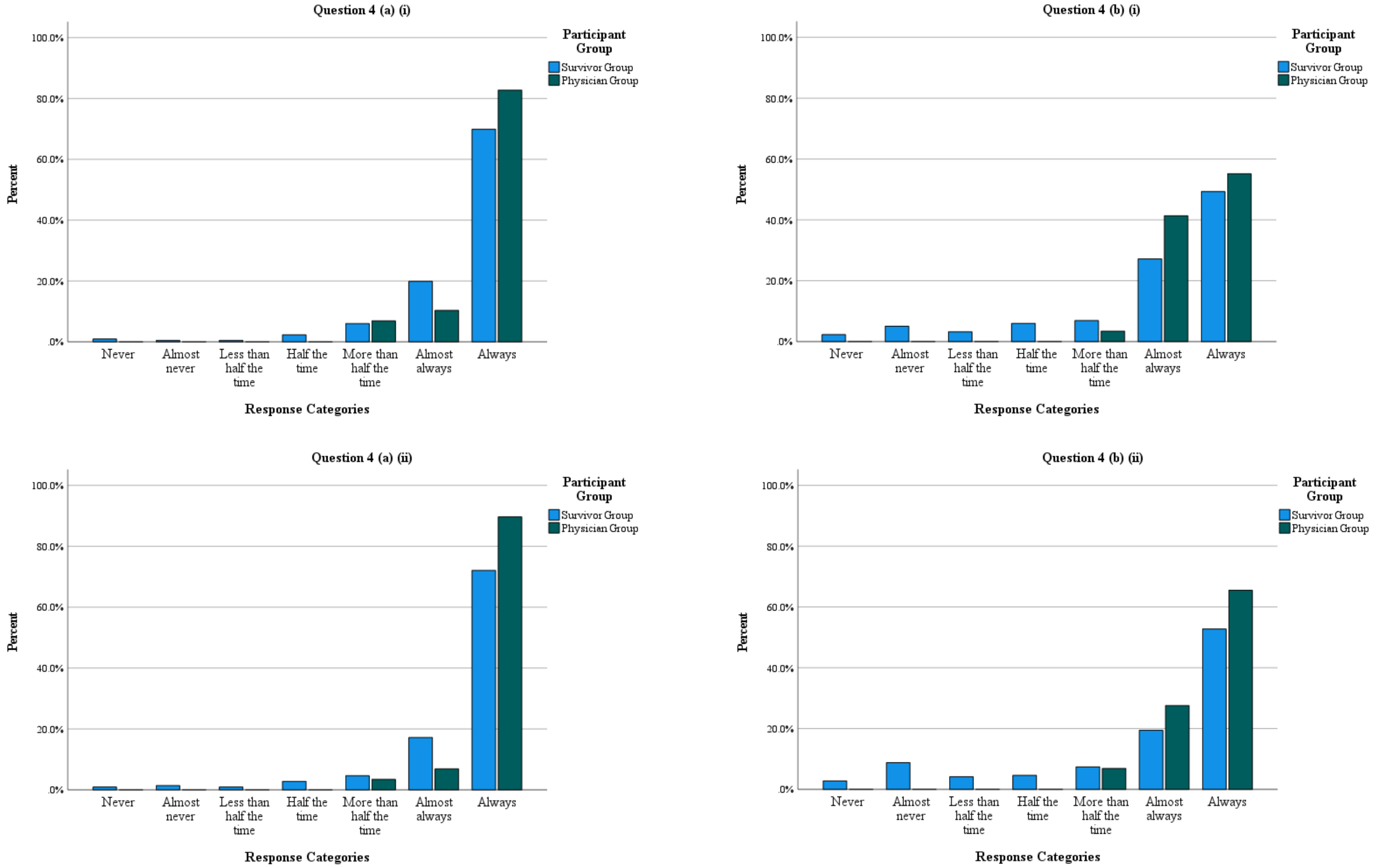


Figure 6, continued

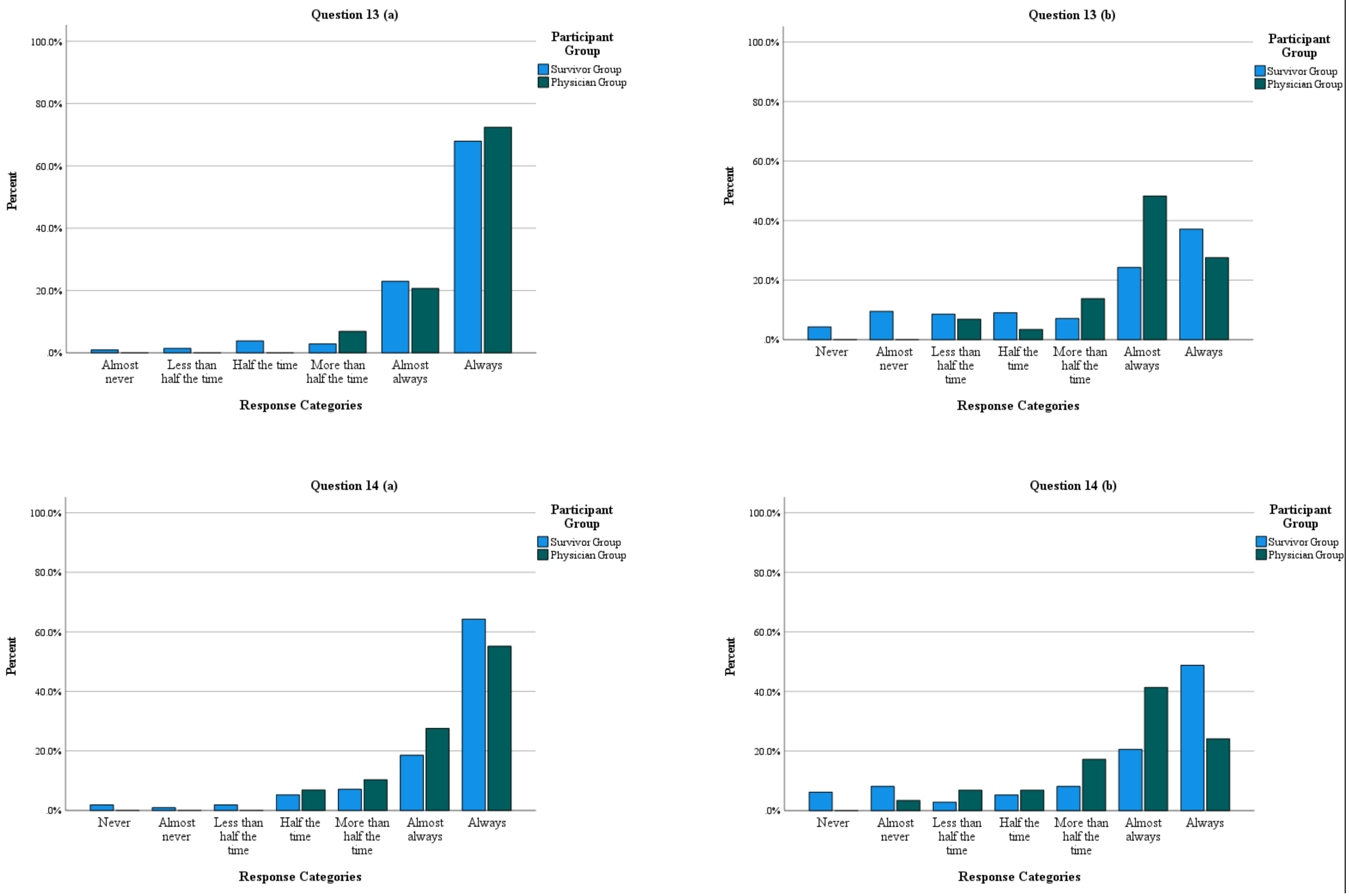
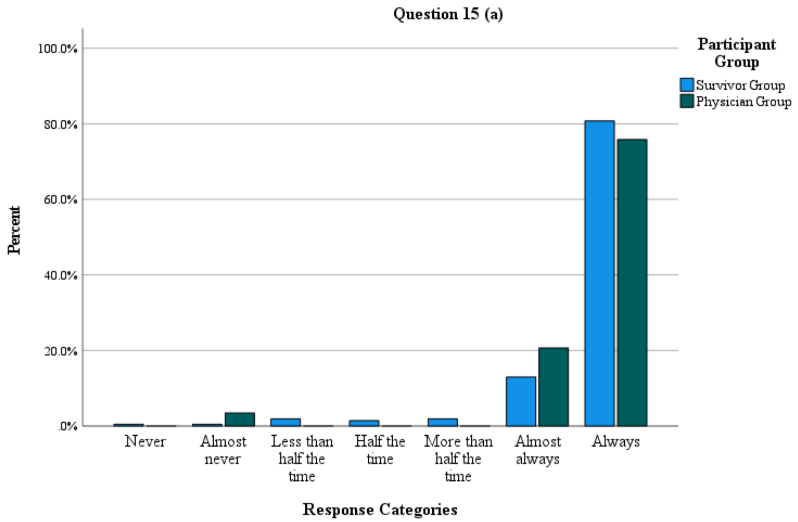
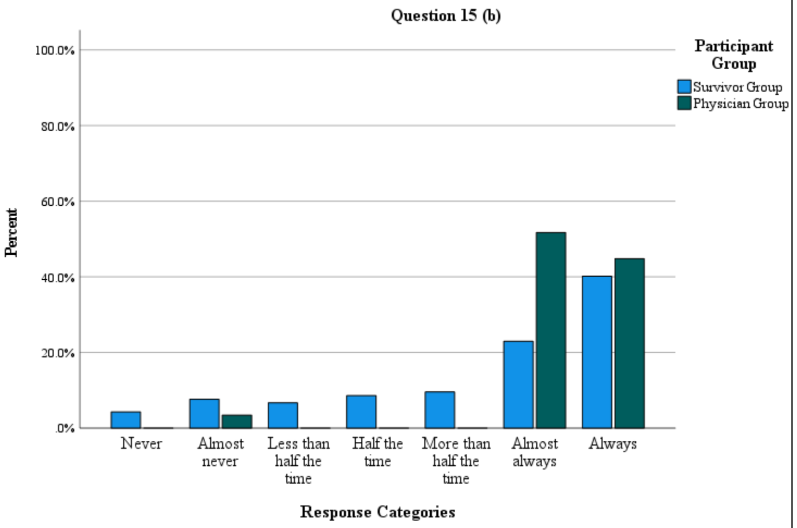
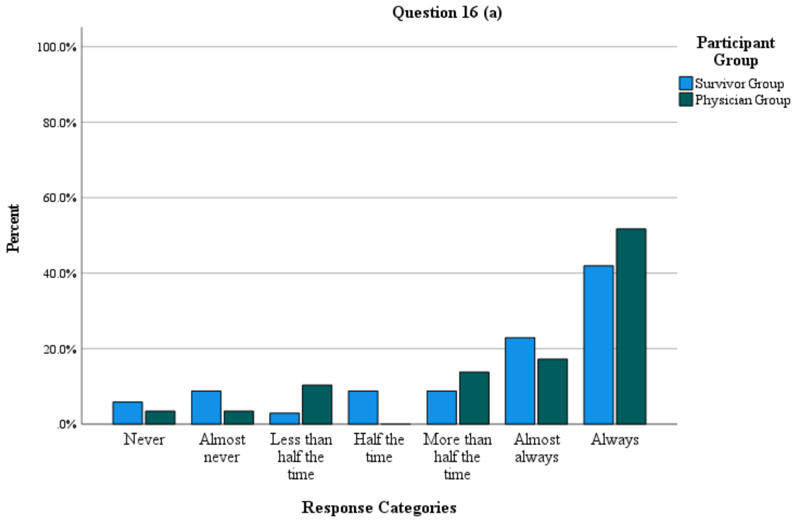


Figure 6, continued


Question 15 (a)


Question 15 (b)


Question 16 (a)

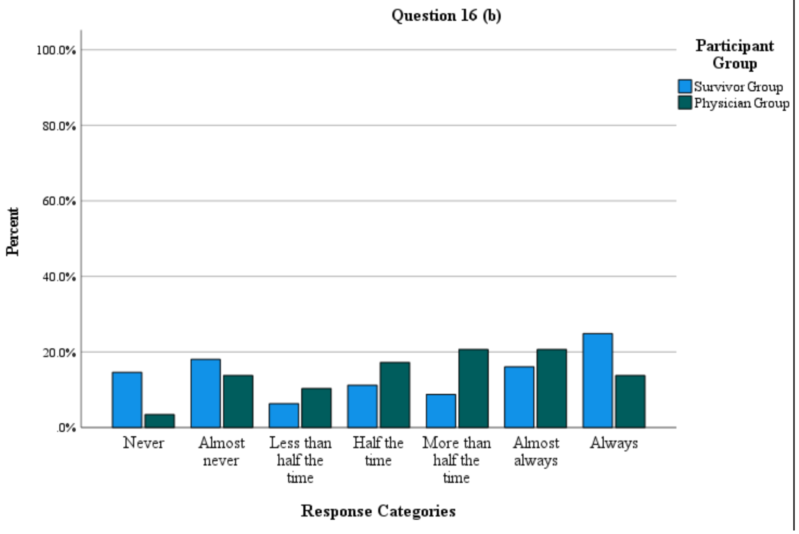

Question 16 (b)

Figure 6, continued

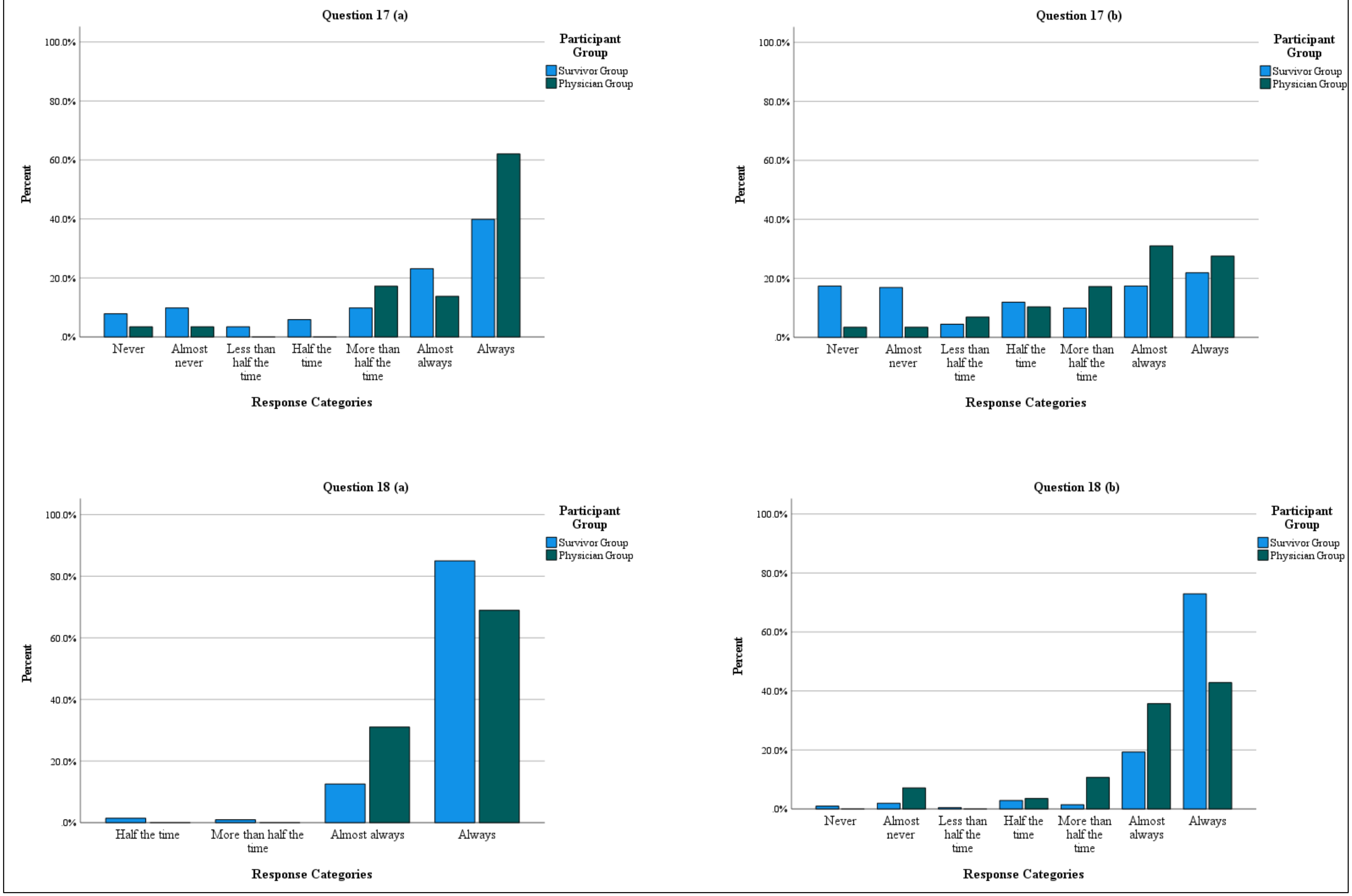
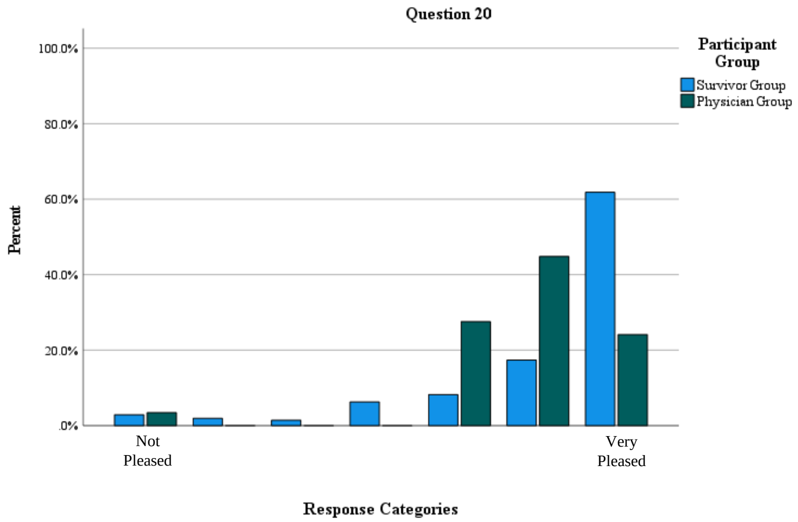


Figure 7

Global Perception of Care Provision Domain



Objective One: Perceptions of Principles of Palliative Care in Ideal Circumstances

Objective one sought to describe laryngectomees' and physicians' perceptions regarding the frequency with which the principles of palliative care that support QoL *should* be present in the care delivered following HNCa treatment completion under ideal circumstances. Thus, measures of central tendency (mean, median, mode) and dispersion (range, SD) were calculated for the questions posed to laryngectomees and physicians in the context of ideal circumstances[8].

Objective One: Survivor Group. Fourteen questions pertained to the laryngectomees' perceptions of the inclusion of the principles of palliative care under ideal circumstances (see Table 13). While 13 of 14 questions exhibited a mode of 7, this response was most common for Question 15 (a) (*"Under ideal circumstances, cancer doctors should inform their patients about what to expect posttreatment to help them make informed decisions about their continuing care."*) (mode = 7, number of responses = 168). Question 1 (iv) was the only question posed to

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[8] Questions 1 (i, ii, iii, iv), 4 (a, i), 4 (a, ii), 8 (a), 9 (a), 13 (a), 14 (a), 15 (a), 16 (a), 17 (a), 19 (a)

laryngectomees in the context of ideal circumstances that demonstrated a mode other than 7 *(“Under ideal circumstances, cancer doctors should address existential/spiritual concerns.”*) (mode = 6). The mode for Question 1 (iv) also represented the fewest modal responses in this question set (number of responses = 48). In addition, Question 1 (iv) demonstrated the lowest median (median = 4.5), while the other questions exhibited medians of 6.0 or 7.0. Responses to Question 1 (iv) also demonstrated the most variability in the laryngectomees’ responses to questions posed in the context of ideal circumstances (see Figure 1, Question 1 [iv]). Careful review of Table 13 reveals that mean scores across this question set ranged from a low of 4.23 (Question 1 [iv]) to a high of 6.66 (Question 15 [a]).

Table 13

Measures of Central Tendency and Dispersion for Questions in the Context of Ideal Circumstances – Survivor Group

Question	N	Mean	Median	Mode	Range	SD
1(i)	226	6.50	7.0	7(153)	1-7	0.94
1(ii)	225	6.21	7.0	7(134)	1-7	1.29
1(iii)	225	5.64	6.0	7(100)	1-7	1.68
1(iv)	224	4.23	4.5	6(48)	1-7	2.22
4(a)(i)	216	6.51	7.0	7(151)	1-7	0.97
4(a)(ii)	215	6.49	7.0	7(155)	1-7	1.09
8(a)	214	6.56	7.0	7(151)	2-7	0.83
9(a)	212	5.99	7.0	7(116)	1-7	1.55
13(a)	209	6.49	7.0	7(142)	2-7	0.95
14(a)	210	6.28	7.0	7(135)	1-7	1.29
15(a)	208	6.66	7.0	7(168)	1-7	0.91
16(a)	205	5.42	6.0	7(86)	1-7	1.92
17(a)	203	5.29	6.0	7(81)	1-7	2.03
19(a)	205	6.60	7.0	7(141)	2-7	0.78

Note: Parenthetical values represent number of responses.

Objective One: Physician Group. Table 14 summarizes the descriptive statistics for the 14 questions posed to physicians in the context of ideal circumstances. While all questions in this set exhibited a mode of 7, this response was most common for Question 4 (a) (ii) (*"Under ideal circumstances, I should provide care that respects the patient's self-worth and dignity."*) (mode = 7, number of responses = 26). Additionally, Question 4 (a) (ii) had one of the narrowest ranges in this question set (range = 5-7). Although multiple modes existed for Question 1 (iv) (*"Under ideal circumstances and exclusive of referrals I would make, the care that I provide should address survivor's existential/spiritual concerns."*), it was the only question posed to physicians in the context of ideal circumstances that demonstrated a mode other than 7 (modes = 3, 7; number of responses = 7). The multiple modes for Question 1 (iv) also represented the fewest modal responses in this question set. In addition, Question 1 (iv) was noted to have the lowest median (median = 4.0), a wide range (range = 1-7), and the most variability in the physicians' responses to questions asked in the context of ideal circumstances (see Figure 1, Question 1 [iv]). Careful review of Table 14 reveals that mean scores across the questions posed to physicians in this set ranged from a low of 4.35 (Question 1 [iv]) to a high of 6.86 (Question 4 [a] [ii]). Except for Question 1 (iv), all other questions in this set exhibited medians of 6.0 or 7.0.

Table 14

Measures of Central Tendency and Dispersion for Questions in the Context of Ideal Circumstances – Physician Group

Question	N	Mean	Median	Mode	Range	SD
1(i)	32	6.66	7.0	7(23)	5-7	0.60
1(ii)	32	5.94	6.0	7(14)	3-7	1.22
1(iii)	32	5.47	6.0	7(12)	2-7	1.59
1(iv)	31	4.35	4.0	3,7(7)*	1-7	2.01
4(a)(i)	29	6.76	7.0	7(24)	5-7	0.58
4(a)(ii)	29	6.86	7.0	7(26)	5-7	0.44
8(a)	29	6.31	7.0	7(17)	1-7	1.23
9(a)	29	6.28	7.0	7(19)	1-7	1.46
13(a)	29	6.66	7.0	7(21)	5-7	0.61
14(a)	29	6.31	7.0	7(16)	4-7	0.93
15(a)	29	6.62	7.0	7(22)	2-7	0.98
16(a)	29	5.76	7.0	7(15)	1-7	1.75
17(a)	29	6.14	7.0	7(18)	1-7	1.51
19(a)	28	5.68	6.0	7(11)	2-7	1.52

*Multiple modes exist, all are presented.

Note: Parenthetical values represent number of responses.

Objective Two: Perceptions of Principles of Palliative Care in Actual Practice

Objective two sought to describe laryngectomees' and physicians' perceptions regarding the frequency with which the principles of palliative care that support QoL are present in the care delivered following HNCa treatment completion in *actual practice*. Thus, the mean, median, mode, range, and SD were calculated for the questions posed to laryngectomees and physicians in the context of actual practice[9].

Objective Two: Survivor Group. Fourteen questions pertained to the laryngectomees' perceptions of the presence of the principles of palliative care in actual practice (see Table 15). In this question set, the greatest number of modal responses occurred on Question 4 (b) (ii)

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[9] Questions 2 (i, ii, iii, iv), 4 (b, i), 4 (b, ii), 8 (b), 9 (b), 13 (b), 14 (b), 15 (b), 16 (b), 17 (b), 19 (b)

(*“Based on my experience, my cancer doctor provided me with care that respected my self-worth and dignity.”*) (mode = 7, number of responses = 114). The lowest numeric mode that was selected with the highest frequency of modal responses was found for Question 2 (iv) (*“Based on my experience, my cancer doctor attended to my existential/spiritual concerns.”*) (mode = 1, number of responses = 109). The mode for Question 17 (b) (*“Based on my experience, my cancer doctor provided me with opportunities to reach my hopes and dreams of what was most meaningful to me.”*) represented the fewest responses for a mode value in this question set (mode = 7, number of responses = 44). Considerable variability also was observed within the survivors’ responses to Question 17 (b) and the observed median value fell on the midway mark of the response scale (see Figure 6, Question 17 [b]; median = 4.0]). Additionally, considerable variability was noted for Questions 2 (ii) (*“Based on my experience, my cancer doctor attended to my emotional [psychological] concerns.”*) and 16 (b) (*“Based on my experience, my cancer doctor recognized that I was part of larger social networks and provided me with care that helped me to continue those relationships.”*) (see Figure 2, Question 2 [ii] and Figure 6, Question 16 [b]). In addition, the median values of Question 2 (ii) and 16 (b) fell directly on the midway mark of the 7-point Likert-type response scale (medians = 4.0).

Although the median value for Question 2 (iii) (*“Based on my experience, my cancer doctor attended to my social concerns.”*) reflected a slight trend toward the “Never” anchor of the response scale (median = 3.0), the data for Question 2 (iii) were also reflective of considerable variability (see Figure 2, Question 2[iii]). Variability was also noted for Question 9 (b) (*“Based on my experience, my cancer doctor discussed goals of care with me that involved consideration of my personal values, beliefs, and preferences*.”) (see Figure 5, Question 9 [b]).

However, the median value observed for Question 9 (b) reflected the slight trend toward the "Always" anchor of the response scale (median = 5.0).

Laryngectomees' opinions were polarized regarding Question 19 (b) (*"Based on my experience, either before or after surgery, my cancer doctor provided me with the opportunity to meet with a laryngectomized visitor to discuss my posttreatment recovery and rehabilitation."*); 33.8% of laryngectomees selected the response category "never", while 34.2% of laryngectomees selected the response category "always" (see Table 11 and Figure 5: Question 19 [b]). Careful consideration of Table 15 reveals that mean scores across the questions posed to laryngectomees in the context of actual practice ranged from a low of 2.44 (Question 2 [iv]) to a high of 5.89 (Question 4 [b] [i]; *"Based on my experience, my cancer doctor provided me with care that respected my independence and autonomy."*). Questions in this set exhibited medians that ranged from 2.0 (Question 2 [iv]) to 7.0 (Questions 2 [i] [*"Based on my experience, my cancer doctor attended to my physical concerns."*] and 4 [b] [ii]).

Table 15

Measures of Central Tendency and Dispersion for Questions in the Context of Actual Practice – Survivor Group

Question	N	Mean	Median	Mode	Range	SD
2(i)	224	5.87	7.0	7(113)	1-7	1.55
2(ii)	224	4.32	4.0	7(50)	1-7	2.10
2(iii)	224	3.60	3.0	1(50)	1-7	2.19
2(iv)	223	2.44	2.0	1(109)	1-7	1.95
4(b)(i)	217	5.89	6.0	7(107)	1-7	1.57
4(b)(ii)	216	5.75	7.0	7(114)	1-7	1.79
8(b)	215	5.31	6.0	7(86)	1-7	1.94
9(b)	211	4.62	5.0	7(62)	1-7	2.15
13(b)	210	5.27	6.0	7(78)	1-7	1.91
14(b)	209	5.58	6.0	7(102)	1-7	1.93
15(b)	209	5.41	6.0	7(84)	1-7	1.85
16(b)	205	4.29	4.0	7(51)	1-7	2.24
17(b)	201	4.20	4.0	7(44)	1-7	2.25
19(b)	207	4.17	5.0	7(79)	1-7	2.73

Note: Parenthetical values represent number of responses.

Objective Two: Physician Group. Table 16 summarizes the descriptive statistics for the 14 questions posed to physicians in the context of actual practice. In this question set, the greatest number of modal responses occurred on Question 2 (i) (*"In actual practice and exclusive of referrals I make, the care that I provide addresses survivors' physical symptoms."*) (mode = 7, number of responses = 21). Additionally, a narrow range was observed for Question 2 (i) (range = 5-7). In the context of actual practice, the lowest numeric mode that was selected with the highest frequency of responses was found for Question 2 (iv) (*"In actual practice and exclusive of referrals I make, the care that I provide addresses survivors' existential/spiritual concerns."*) (mode = 2, number of responses = 15). Multiple modes existed for Question 16 (b) (*"In actual practice, I recognize that survivors are part of larger social networks and I provide care that helps them to continue their relationships."*). These multiple modes for Question 16 (b) represented the fewest responses for a mode value in this question set (modes = 5, 6; number of responses = 6). A wide range also was observed for Question 16 (b) (range = 1-7) and, accordingly, considerable variability was identified within the physicians' responses (see Figure 6, Question 16 [b]).

Variability in the physicians' responses was found for Questions 2 (ii) (*"In actual practice and exclusive of referrals I make, the care that I provide addresses survivors' psychological symptoms."*) and Question 2 (iii) (*"In actual practice and exclusive of referrals I make, the care that I provide addresses survivors' social functioning."*) (see Figure 2, Question 2 [ii], Question 2 [iii]). Careful review of Table 16 reveals that mean scores across the questions posed to physicians in the context of actual practice ranged from a low of 2.97 (Question 2 [iv]) to a high of 6.59 (Question 4 [b] [ii]; *"In actual practice, I provide care that respects the patient's self-worth and dignity."*). Median values ranged from a low of 2.0 (Question 2 [iv]) to a high of 7.0 (Questions 2 [i], 4 [b] [i] [*"In actual practice, I provide care that respects the patient's independence and autonomy."*], and 4 [b] [ii]).

Table 16

Measures of Central Tendency and Dispersion for Questions in the Context of Actual Practice – Physician Group

Question	N	Mean	Median	Mode	Range	SD
2(i)	31	6.58	7.0	7(21)	5-7	0.67
2(ii)	31	5.00	5.0	5,6(9)*	3-7	1.24
2(iii)	31	4.42	4.0	3(9)	2-7	1.59
2(iv)	31	2.97	2.0	2(15)	1-6	1.47
4(b)(i)	29	6.52	7.0	7(16)	5-7	0.57
4(b)(ii)	29	6.59	7.0	7(19)	2	0.63
8(b)	29	5.52	6.0	7(10)	1-7	1.68
9(b)	29	5.24	6.0	6(9)	1-7	1.68
13(b)	29	5.86	6.0	6(14)	3-7	1.09
14(b)	29	5.59	6.0	6(12)	2-7	1.32
15(b)	29	6.31	6.0	6(15)	2-7	0.97
16(b)	29	4.55	5.0	5,6(6)*	1-7	1.74
17(b)	29	5.38	6.0	6(9)	1-7	1.61
19(b)	28	3.25	3.0	2(9)	1-7	1.62

Note: Parenthetical values represent number of responses.

*Multiple modes exist, all are presented.

Perceptions of Principles of Palliative Care in Unpaired Questions

To further contextualize laryngectomees' and physicians' perceptions regarding the frequency of the inclusion of principles of palliative care in HNCa survivorship care, the mean, median, mode, SD, and range were calculated for the questions that were not bound to the context of ideal circumstances or actual practice[10].

Unpaired Questions: Survivor Group. Table 17 summarizes the descriptive statistics for the 13 unpaired questions posed to laryngectomees. In this question set, the greatest number of modal responses occurred on Question 18 (a) (*"It is beneficial when healthcare providers from different specialties work together as a team to contribute their expertise to the care*

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[10] Questions 3 (i, ii, iii, iv), 5, 6, 7, 10, 11, 12, 18 (a, b), 20

delivered after treatment.") (mode = 7, number of responses = 176). Question 18 (a) also was identified as having the smallest range in this question set (range = 4-7). The lowest numeric mode value that was selected with the highest frequency of responses was identified for Question 7 (*"I would have preferred someone other than my cancer doctor to have taken over my care after my treatment."*) (mode = 1, number of responses = 124). The mode of Question 3 (iii) (*"I was comfortable using my follow-up appointments with my cancer doctor to discuss social concerns."*) represented the fewest responses for a mode value in this question set (mode = 1, number of responses = 52). Moreover, laryngectomees' opinions were polarized regarding Question 3 (iii); 22.5% of laryngectomees selected the response category "never", while 22.1% of laryngectomees selected the opposing response category "always" (see Table 11 and Figure 3: Question 3 [iii]).

Variability in the laryngectomees' responses was observed for Question 3 (ii) (*"I was comfortable using my follow-up appointments with my cancer doctor to discuss emotional [psychological] symptoms."*) (see Figure 3, Question 3 [ii]). Careful review of Table 17 reveals that mean scores across the unpaired questions posed to laryngectomees ranged from a low of 2.27 (Question 7) to a high of 6.81 (Question 18 [a]). Median values ranged from a low of 1.0 (Question 7) to a high of 7.0 (Questions 3 [i] [*"I was comfortable using my follow-up appointments with my cancer doctor to discuss physical concerns."*], 10 [*"I wanted to know what to expect after treatment and what my 'new normal' was going to look like."*], 18 [a], 18 [b] [*"A collaborative care approach that allows patients to access healthcare providers from different specialties which are housed within the same clinic is beneficial in the care of survivors after treatment."*], 20 [*"Overall, how pleased were you with the care you received from your cancer doctor after your cancer treatment?"*]).

Table 17

Measures of Central Tendency and Dispersion for Unpaired Questions – Survivor Group

Question	N	Mean	Median	Mode	Range	SD
3(i)	221	5.94	7.0	7(124)	1-7	1.65
3(ii)	223	4.25	4.0	7(62)	1-7	2.32
3(iii)	221	3.87	4.0	1(52)	1-7	2.36
3(iv)	219	2.53	2.0	1(108)	1-7	2.10
5	216	5.66	6.0	7(98)	1-7	1.75
6	215	2.76	2.0	1(80)	1-7	1.94
7	213	2.27	1.0	1(124)	1-7	1.91
10	213	6.44	7.0	7(151)	1-7	1.13
11	211	5.38	6.0	7(82)	1-7	1.84
12	212	5.40	6.0	7(85)	1-7	1.87
18(a)	207	6.81	7.0	7(176)	4-7	0.51
18(b)	207	6.52	7.0	7(151)	1-7	1.09
20	207	6.14	7.0	7(128)	1-7	1.45

Note: Parenthetical values represent number of responses.

Unpaired Questions: Physician Group. Thirteen unpaired questions were posed to physicians. The descriptive statistics for this question set are summarized in Table 18. In this question set, the highest numeric mode that was most frequently selected occurred for Questions 3 (i) (*"In actual practice, during follow-up appointments, I feel that I am approachable regarding topics related to a patient's physical symptoms."*) and 5 (*"Continuing to care for survivors following the first year of regular surveillance is part of my role."*) (mode = 7, number of responses = 24). Question 3 (i) also was found to have the narrowest range of responses, along with Question 18 (a) (*"An interdisciplinary care approach where healthcare providers from different specialties work together as a team to contribute their expertise to the care delivered following treatment completion is beneficial in the care of survivors."*) (ranges = 6-7). The lowest numeric mode that was most frequently selected was found for Question 6 (*"My time is too limited to provide ongoing care to survivors following the first year of regular surveillance."*) (mode = 1, number of responses = 24).

The multiple modes that existed for Question 3 (iv) (*“In actual practice, during follow-up appointments, I feel that I am approachable regarding topics related to a patient’s existential/spiritual concerns.”*) represented the fewest modal responses in this question set (modes = 3, 6, 7; number of responses = 6). Additionally, the range of responses for Question 3 (iv) was wide (range = 1-7). Moreover, the median value found for Question 3 (iv) was noted to be the most proximal to the midway mark of the 7-point Likert type response scale, although it denotes a slight skew toward the “always” response anchor (median = 5.0). As such, considerable variability was identified for Question 3 (iv) (see Figure 3, Question 3 [iv]). Careful consideration of Table 18 reveals that mean scores across the unpaired questions posed to physicians ranged from a low of 1.38 (Question 6) to a high of 6.83 (Question 3 [i]). Median values ranged from a low of 1.0 (Questions 6 and 7 [*“I would prefer to have someone else take over the ongoing care of survivors following the first year of regular surveillance.”*]) to a high of 7.0 (Questions 3 [i], 5, and 18 [a]).

Table 18

Measures of Central Tendency and Dispersion for Unpaired Questions – Physician Group

Question	N	Mean	Median	Mode	Range	SD
3(i)	29	6.83	7.0	7(24)	6-7	0.38
3(ii)	30	6.13	6.0	6(13)	4-7	0.94
3(iii)	30	5.63	6.0	6,7(9)*	1-7	1.35
3(iv)	30	4.63	5.0	3,6,7(6)*	1-7	1.83
5	29	6.69	7.0	7(24)	3-7	0.85
6	29	1.38	1.0	1(24)	1-7	1.18
7	29	1.59	1.0	1(16)	1-5	0.87
10	29	6.21	6.0	7(13)	3-7	0.98
11	28	5.79	6.0	6(11)	3-7	1.13
12	29	6.14	6.0	6(14)	4-7	0.79
18(a)	29	6.69	7.0	7(20)	6-7	0.47
18(b)	28	5.96	6.0	7(12)	2-7	1.37
20	29	5.79	6.0	6(13)	1-7	1.18

Note: Parenthetical values represent number of responses.

*Multiple modes exist, all are presented.

Differences Between Perceptions in Ideal Circumstances and Actual Practice

Potential differences between the participants' perceptions of the inclusion of the principles of palliative care under ideal circumstances and their inclusion in actual practice in the posttreatment care of HNCa survivors were assessed[11]. The full Wilcoxon Signed-Rank Test statistics tables are provided for the Survivor and Physician Groups in Appendices L and M, respectively.

Survivor Group

Statistically significant differences between the laryngectomees' perceptions of the inclusion of principles of palliative care in ideal circumstances and actual practice were observed

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[11] Differences were assessed between participants' perceptions toward paired questions (i.e., 1[i, ii, iii, iv] and 2[i, ii, iii, iv], 4[a] and 4[b], 8[a] and 8[b], 9[a] and 9[b], 13[a] and 13[b], 14[a] and 14[b], 15[a] and 15[b], 16[a] and 16[b], 17[a] and 17[b], and 19[a] and 19[b]).

for all comparisons within the Survivor Group data. The greatest statistically significant difference between the laryngectomees' perceptions of the inclusion of the principles of palliative care in ideal circumstances and actual practice was observed between Question 1 (ii) (*"Under ideal circumstances, cancer doctors should address emotional [psychological] concerns."*) (median = 7.0, 95% CI = [7.0, 7.0]) and Question 2 (ii) (*"Based on my experience, my cancer doctor attended to my emotional [psychological] concerns."*) (median = 4.0, 95% CI = [4.0, 5.0]) (Z = -10.36, p < 0.001, r = -0.491; see Figure 1, Question 1[ii] and Figure 2, Question 2[ii]). The smallest statistically significant difference between the laryngectomees' perceptions of the inclusion of the principles of palliative care in ideal circumstances and actual practice was observed between Question 14 (a) (*"Under ideal circumstances, and at the patient's request, cancer doctors should meet with and address the concerns of family members and/or significant others."*) (median = 7.0, 95% CI = [7.0, 7.0]) and Question 14 (b) (*"Based on my experience, and at my request, my cancer doctor met [or would have met] with and addressed the concerns of my family members and/or significant others."*) (median = 6.0, 95% CI = [6.0, 7.0]) (Z = -5.70, p < 0.001, r = -0.279; see Figure 6, Question 14[a] and Question 14[b]). Table 19 presents the differences identified between the laryngectomees' perceptions of care in ideal circumstances and actual practice, along with the effect sizes of these differences.

Table 19

Wilcoxon Signed-Rank Test Results – Survivor Group

Questions	n	Z	Effect Size (r)
Q1(i) – Q2(i)	224	-5.94***	-0.281
Q1(ii) – Q2(ii)	223	-10.36***	-0.491
Q1(iii) – 2(iii)	223	-10.33***	-0.489
Q1(iv) – Q2(iv)	221	-9.74***	-0.463
Q4(a)(i) – Q4(b)(i)	216	-6.17***	-0.297
Q4(a)(ii) – Q4(b)(ii)	215	-5.94***	-0.286
Q8(a) – Q8(b)	213	-8.44***	-0.409
Q9(a) – Q9(b)	211	-8.89***	-0.433
Q13(a) – Q13(b)	209	-8.39***	-0.410
Q14(a) – Q14(b)	209	-5.70***	-0.279
Q15(a) – Q15(b)	208	-8.64***	-0.424
Q16(a) – Q16(b)	202	-7.06***	-0.351
Q17(a) – Q17(b)	201	-6.86***	-0.342
Q19(a) – Q19(b)	205	-9.32***	-0.460

***$p < 0.001$

Physician Group

A statistically significant difference was found for all comparisons between physicians' perceptions regarding the inclusion of principles of palliative care in ideal circumstances and actual practice except for one; the difference between the physicians' perceptions of Question 1 (i) (*"Under ideal circumstances and exclusive of referrals I would make, the care that I provide should address survivors' physical symptoms."*) (median = 7.0, 95% CI = [7.0, 7.0]) and Question 2 (i) (*"In actual practice and exclusive of referrals I make, the care that I provide addresses survivors' physical symptoms."*) (median = 7.0, 95% CI = [6.0, 7.0]) was not found to be statistically significant ($Z = -0.51$, $p > 0.05$, $r = -0.065$; see Figure 1, Question 1[i] and Figure 2, Question 2[i]). The greatest statistically significant difference between the physicians' perceptions of the inclusion of the principles of palliative care in ideal circumstances and actual practice was observed between Question 19 (a) (*"Under ideal circumstances, either before or* *after treatment, I should provide my patients with an opportunity to meet with a HNCa survivor to discuss their recovery and rehabilitation."*) (median = 6.0, 95% CI = [5.0, 7.0]) and Question 19 (b) (*"In actual practice, either before or after treatment, I provide my patients with an opportunity to meet with a HNCa survivor to discuss their recovery and rehabilitation."*) (median = 3.0, 95% CI = [2.0, 4.0]) (Z = -3.95, p < 0.001, r = -0.528; see Figure 5, Question 19[a] and Question 19[b]). The smallest statistically significant difference between the physicians' perceptions of the inclusion of the principles of palliative care in ideal circumstances and actual practice was found between Question 4 (a) (i) (*"Under ideal circumstances, I should provide care that respects the patient's independence and autonomy."*) (median = 7.0, 95% CI = [7.0, 7.0]) and Question 4 (b) (i) (*"In actual practice, I provide care that respects the patient's independence and autonomy."*) (median = 7.0, 95% CI = [6.0, 7.0]) (Z = -2.33, p < 0.05, r = -0.306; see Figure 6, Question 4[a][i] and Question 4[b][i]). Table 20 displays the differences identified between the physicians' perceptions of care in ideal circumstances and actual practice, along with the effect sizes of these differences.

Table 20

Wilcoxon Signed-Rank Test Results – Physician Group

Questions	n	Z	Effect Size (r)
Q1(i) – Q2(i)	31	-0.51	-0.065
Q1(ii) – Q2(ii)	31	-3.98***	-0.505
Q1(iii) – 2(iii)	31	-3.81***	-0.484
Q1(iv) – Q2(iv)	30	-3.45***	-0.445
Q4(a)(i) – Q4(b)(i)	29	-2.33*	-0.306
Q4(a)(ii) – Q4(b)(ii)	29	-2.53*	-0.332
Q8(a) – Q8(b)	29	-3.46***	-0.454
Q9(a) – Q9(b)	29	-3.86***	-0.507
Q13(a) – Q13(b)	29	-3.88***	-0.509
Q14(a) – Q14(b)	29	-2.51**	-0.330
Q15(a) – Q15(b)	29	-3.0**	-0.394
Q16(a) – Q16(b)	29	-3.57***	-0.469
Q17(a) – Q17(b)	29	-3.40***	-0.446
Q19(a) – Q19(b)	28	-3.95***	-0.528

*$p < 0.05$, **$p < 0.01$, ***$p < 0.001$

Correlational Analyses

Relationships Between Perceptions of the Laryngectomees and Physicians

No statistically significant correlations were identified between the perceptions of the laryngectomees and physicians toward the equivalent questions across the Survivor and Physician Versions of the questionnaire[12].

Relationships Between Global Perception of Care and All Other Specific Aspects of Care

Survivor Group. Correlational analysis was also performed between the laryngectomees' global perception of care (i.e., Question 20; *"Overall, how pleased were you with the care you received from your cancer doctor after your cancer treatment?"*), and their perceptions of all of the specific aspects of care featured in each question on the Survivor

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[12] Question 1 [i] on the Survivor Version and Question 1 [i] on the Physician Version, Question 1 [ii] on the Survivor Version and Question 1 [ii] on the Physician Version, etc.

Version of the questionnaire. The statistically significant correlations identified within the Survivor Group's data are presented in Table 21. The strongest statistically significant correlation was identified between the Global Perception of Care Provision domain and the survivors' perceptions of Question 12 (*"My cancer doctor adequately communicated about difficult topics and made me feel comfortable."*) ($r_s = 0.731$, $p < 0.01$). The second strongest statistically significant correlation was found between the Global Perception of Care Provision domain and the survivors' perceptions of Question 13 (b) (*"Based on my experience, my cancer doctor provided care that addressed "quality of life" issues."*) ($r_s = 0.716$, $p < 0.01$).

Table 21

Statistically Significant Correlations Between the Global Perception of Care Provision Domain (Question 20) and Questions 1-19 – Survivor Group

	Question	Spearman's Coefficient (r_s)
Question 20	2(i)	0.549**
	2(ii)	0.543**
	2(iii)	0.455**
	2(iv)	0.230**
	3(i)	0.469**
	3(ii)	0.445**
	3(iii)	0.417**
	3(iv)	0.253**
	4(a)(i)	0.146*
	4(b)(i)	0.574**
	4(a)(ii)	0.165*
	4(b)(ii)	0.633**
	5	0.323**
	6	-0.492**
	7	-0.565**
	8(b)	0.649**
	9(b)	0.538**
	10	0.140*
	11	0.710**
	12	0.731**
	13(a)	0.142*
	13(b)	0.716**
	14(a)	0.253**
	14(b)	0.594**
	15(a)	0.154*
	15(b)	0.712**
	16(b)	0.549**
	17(b)	0.492**
	18(a)	0.150*
	18(b)	0.288**
	19(b)	0.363**

* $p < 0.05$, ** $p < 0.01$

Physician Group. Fewer statistically significant correlations were identified between the physicians' rating of their patients' global perception of care (i.e., Question 20; *"Overall, how would you rate your patients' judgement of how pleased they are with your care following* *definitive treatment?"*), and their own perceptions of the specific aspects of care featured in each question on the Physician Version of the questionnaire (see Table 22). The strongest statistically significant relationship was found between the Global Perception of Care Provision domain and the physicians' perceptions of Question 11 (*"My understanding of HNCa survivorship is adequate enough to discuss survivorship issues and the posttreatment experience with HNCa patients."*) ($r_s = 0.492$, $p < 0.01$).

Table 22

Statistically Significant Correlations Between the Global Perception of Care Provision Domain (Question 20) and Questions 1-19 – Physician Group

	Question	Spearman's Coefficient (r_s)
Question 20	2(iii)	0.423*
	11	0.492**
	12	0.418*
	18(b)	0.479**

* $p < 0.05$, ** $p < 0.01$

CHAPTER 4

Discussion

This study was designed to identify and describe the perceptions of laryngectomees and physicians regarding the inclusion of principles of palliative care in the posttreatment care of HNCa survivors. More specifically, the objectives of the study centred on the identification and description of laryngectomees' and physicians' perceptions of the inclusion of principles of palliative care that ultimately serve to support QoL under ideal circumstances, as well as the presence of these principles in actual practice in posttreatment HNCa survivorship care. To address these objectives, a proprietary, web-based questionnaire was developed to collect data pertaining to the perceptions of laryngectomees and physicians toward these principles of palliative care. This chapter provides a comprehensive discussion of these data on the basis of the findings within each of the questionnaire's domains. As such, the participants' perceptions of aspects of care grouped within the Symptom Management domain will be discussed, followed by their perceptions of aspects of care in the Physician Role Definition domain, Patient-Physician Communication domain, Foundational Principles of Palliative Care domain, and Global Perception of Care Provision domain. The discussion for each domain will also incorporate the relevant differences identified between the participants' perceptions of the principles of palliative care in the context of ideal circumstances versus actual practice, as well as notable correlations identified between certain aspects of care and the Global Perception of Care Provision domain. Finally, limitations of the present study, clinical implications of the findings, and directions for future research will be offered.

Perceptions of Principles of Palliative Care in HNCa Survivorship Care

Symptom Management Domain

Physical Symptoms. The questions within the Symptom Management domain asked laryngectomees and physicians for their perceptions regarding physical symptoms, psychological symptoms, social functioning, and existential/spiritual concerns in various contexts (i.e., ideal circumstances, actual practice, approachability). In each of these three contexts, elements of care that pertained to physical symptoms were consistently identified as occurring at the highest frequency in HNCa survivorship care by the greatest proportion of both laryngectomees and physicians. More specifically, out of these four domains of functioning, the greatest proportion of laryngectomees and physicians perceived that care *should* "always" address physical symptoms, the care they received/provided "always" did address their physical symptoms, and they were "always" comfortable/approachable regarding topics related to physical symptoms. Moreover, out of all questions posed to physicians related to the context of actual practice, addressing physical symptoms was the aspect of care that the greatest proportion of physicians indicated was "always" included in the care they provided (65.6%).

The dominance of the physical domain of functioning in HNCa survivorship care as described in the current study, is consistent with the findings of previous research (Cassell, 2004; Cherny & Catane, 2003; Reading, 1977; Seely & Mount, 1999; Ward et al., 2009). For example, Cherny and Catane (2003) and Ward et al. (2009) also found that care provided by oncologists more commonly involves the management of physical symptoms than the management of psychosocial symptoms or existential/spiritual concerns. When these past reports are paired with the findings of the present study, it can be suggested that the management of physical symptoms is dominant in the provision of survivorship care as it is typically enacted. Not surprisingly, the only comparison between the physicians’ perceptions of elements of care in ideal circumstances and actual practice that was *not* found to be significantly different pertained to the provision of care that involved the management of physical symptoms. More specifically, 71.9% of physicians indicated that the frequency with which care addressed survivors’ physical symptoms was equal under ideal circumstances and in actual practice (see Appendix M). Although a statistically significant difference was found between laryngectomees’ perceptions of the inclusion of care that addresses physical symptoms in ideal circumstances and actual practice, it was one of the smallest differences identified. These findings are interesting, but not surprising.

The dominance of the physical domain of functioning in disease-focused oncological care has encouraged the longstanding myopic denial of the inevitability of death (Becker, 1973). Although death is an inevitable and natural fact of life, it is often viewed by medical professionals as a form of failure which may test a physician’s sense of competence (Economist Intelligence Unit, 2010; Hadad, 2009; Kleinman, 1988). By prioritizing the physical domain of functioning through the provision of life prolonging disease-focused treatment, physicians are increasingly able to avoid the confrontation of this failure (Cassell, 1974; Economist Intelligence Unit, 2010). However, in the context of illness and its increasingly comprehensive management, care aimed at postponing death and care aimed at enhancing QoL should not be regarded as dichotomous extremes (Gillick, 2005; MacDonald et al., 2021; Zimmermann & Rodin, 2004). Nevertheless, the findings of the current study support the notion that when disease management is achievable, care is inevitably guided by a disease focus that pertains predominantly to the physical aspects of the disease (Frank, 1995; Hayden, 2019; Kubler-Ross, 1969; MacDonald et al., 2021). Therefore, it is often only when disease management is deemed futile and care shifts to the provision of palliative care that the denial of death wanes. Physical functioning is still likely to remain paramount to ensure individuals are physically comfortable during end-of-life care (WHO, 2019). However, since efforts at evading the "failure" of death can subside, consideration of psychological, social, and existential concerns can be more consistently included in care provision (Hui et al., 2013; Oliver, 2018; Turner et al., 2005; WHO, 2019).

Psychological and Social Symptoms. For elements of care that pertained to *physical* functioning, considerable skew was observed toward the "always" anchor of the response scale in the context of ideal circumstances, actual practice, and perceived comfort/approachability. However, the same cannot be said for elements of care that pertained to *psychological* or *social* functioning. For both the laryngectomees and physicians, considerable skew toward the "always" anchor of the response scale was observed in their perceptions of how frequently aspects of care that pertain to psychological and social functioning *should* be included in ideal circumstances (see Figure 1). However, both the laryngectomees' and physicians' responses were much more varied regarding how frequently aspects of care that pertained to psychological and social functioning were included in *actual* practice (see Figure 2). Considerable variability was also observed in the laryngectomees' perceptions regarding how comfortable they were using their follow-up appointments to discuss their psychological concerns with their physician (see Figure 3). The laryngectomees appeared to be somewhat polarized toward their comfort levels with using their follow-up appointments to discuss their social concerns with their physicians (see Figure 3). That is, laryngectomees responses were clustered around dichotomous ends of the response scale (i.e., 34.2% were "always" or "almost always" comfortable, while 39.4 % were "never" or "almost never" comfortable). Conversely, the physicians' perceptions of how approachable they were regarding topics related to their patients' psychological and social concerns were skewed in the direction of the “always” anchor of the response scale (see Figure 3).

Taken together, these results may indicate that the dominance of the physical domain of functioning may translate into the perception of a higher level of acceptance and validation of physical symptoms compared to psychological or social concerns. This is in line with previous research that reported that HNCa survivors seldom self-report concerns related to their psychological or social functioning (Lee, Goo-Yoshino, et al., 2020; MacDonald et al., 2020). It has been suggested that psychosocial dysfunction is often overlooked in posttreatment care “due to pressing pathophysiologic problems and the lack of clinical tools” to collect data to measure and, ultimately, address such subjective psychosocial concerns (Lee, Goo-Yoshino, et al., 2020, p. 906). Thus, the underrepresentation of the consideration of psychosocial concerns may be inherently related to the largely subjective nature of psychosocial domains of functioning which may clash with the predominant focus on objective and easily measurable physical domains in disease-focused care provision.

As such, HNCa survivors may feel reticent to raise psychosocial concerns with their physicians. Physicians in the present study perceived care to frequently include consideration of psychological and social symptomology. However, if survivors are variably raising psychosocial concerns, they may perceive this to be an area of unmet need that is unbeknownst to physicians. Concerningly, these psychosocial domains of functioning are the domains that are correlated to HNCa survivors’ capacity for adjustment and coping (Blood et al., 1992). While imperative, *exclusive* consideration of the physical impact of HNCa is likely to be insufficient owing to the interdependent and reciprocal relationships that exist between a survivor’s physical, psychological, and social functioning (Doyle, 2005; Doyle & MacDonald, 2019; Engel, 1977). If psychosocial domains are left unaddressed in HNCa survivorship care, and physical aspects of disease are considered primary, a survivor’s “holistic” illness experience may not be comprehensively addressed by the scope of survivorship care. In turn, this is likely to influence HNCa survivors’ QoL since it is one’s valuation of these interrelated domains of functioning that contributes to one’s perceived QoL.

Of all the comparisons within the Survivor Group’s data, the largest disparities existed between the laryngectomees’ perceptions of the frequency with which care should address psychological symptoms and social symptoms in ideal circumstances and the frequency with which care addressed these symptoms in actual practice. That is, 64.9% and 68.8% of laryngectomees indicated the care they received considered their psychological and social symptoms, respectively, less frequently than what they believed was ideal (see Appendix L). Large statistically significant differences also were found between the physicians’ perceptions of the frequency with which care should address psychological symptoms and social symptoms in ideal circumstances and the frequency with which these symptoms are addressed their actual practice. More specifically, 59.4% and 56.3% of physicians indicated the care they actually provided considered their patients’ psychological and social symptoms, respectively, less than what they believed was ideal (see Appendix M). Taken together, the findings suggest that laryngectomees and physicians believed consideration of psychological and social functioning *should* be included in HNCa survivorship care under ideal circumstances. However, consideration of psychological and social functioning was also perceived by laryngectomees and physicians to be inconsistently included within survivorship care. The disparity between the participants’ perceptions of care that addresses psychological and social functioning under ideal circumstances and in actual practice is particularly concerning owing to the substantial impact of laryngectomy on psychosocial domains (i.e., depression, distress, anxiety, social withdrawal/isolation secondary to modified capacity for speech and/or swallowing) (Bornbaum et al., 2012; Doyle, 1994; Jacobs & Shulman, 2017; MacDonald et al., 2021; Maclean et al., 2009; Nekhlyudov et al., 2017; Nguyen et al., 2004; Threats, 2007). However, by identifying this gap in the provision of survivorship care, the utility of incorporating principles of palliative care that specifically advocate for the consideration of psychological and social functioning becomes evident (Bruera & Hui, 2012; Gillick, 2005; Hadad, 2009; Oliver, 2018; Strand et al., 2013; WHO, 2019).

Existential/Spiritual Concerns. Despite considerable variation, both laryngectomees and physicians tended to perceive that even in ideal circumstances addressing existential/spiritual concerns *should not* be a primary concern in HNCa survivorship care (see Figure 1). Relatedly, in the context of actual practice, the laryngectomees' and the physicians' perceptions regarding care that addressed existential/spiritual concerns were characterized by considerable skew toward the "never" anchor of the scale (see Figure 2). This trend was mirrored in the laryngectomees' perceived comfort in discussing existential/spiritual concerns with their physicians. However, considerable variability characterized the physicians' perception of their approachability regarding their patients' existential/spiritual concerns (see Figure 3). Moreover, among the questions posed within the Symptom Management domain, addressing existential functioning was consistently identified by both the laryngectomees and physicians as having the lowest frequency of occurrence.

Accordingly, although statistically significant differences were identified between the contexts of ideal circumstances and actual practice for participants' perceptions of the occurrence of care that addresses existential/spiritual functioning, the differences were among the smallest identified. These small differences were likely indicative of the participants' ambivalence toward the inclusion of care that addresses existential/spiritual functioning under ideal circumstances (Winkelman et al., 2011). This ambivalence may be related to a fundamental difference between the traditional end-of-life context of palliative care and the context of the posttreatment phase of HNCa survivorship. More specifically, existential concerns may be more relevant in the end-of-life context owing to the omnipresent salience of the confrontation of one's own mortality. Although HNCa is likely to create circumstances that will prompt an individual to confront their own mortality (Knox, 2020), this may be more likely to occur in closer proximity to the time of diagnosis rather than the time that follows the completion of definitive treatment (Miller & Shuman, 2016). This may account for the laryngectomees' and physicians' perceptions that existential/spiritual functioning should be addressed with less frequency in posttreatment HNCa survivorship care even in ideal circumstances.

Nevertheless, previous research has identified noteworthy existential themes in HNCa survivorship that go beyond the experience of living through a life-threatening disease (Knox, 2020; Liao et al., 2017; Schenck, 2002; Swore-Fletcher et al., 2012). Although the confrontation of mortality is likely to be prominent at the time of diagnosis (Miller & Shuman, 2016), *surviving* HNCa does not automatically eliminate existential concerns (Deimling et al., 2006). More specifically, beyond the confrontation of one's own mortality, existential concerns may arise for HNCa survivors secondary to the experience of alterations to one's self-identity and loss of self-expression related to modifications to verbal expression and changes to social roles (Bickford et al., 2018; Little et al., 2002; Schenck, 2002; Swore-Fletcher et al., 2012). As such, it is important to note that the domains of functioning are unlikely to be mutually exclusive and their collective impact on QoL should not be overlooked. The considerable variability in the participants’ responses to questions related to care that addresses existential/spiritual concerns in ideal circumstances may ultimately denote that the relevance of such care may be highly individualized and personal. More specifically, the illness experience of HNCa is likely to be internalized or interpreted differently by different individuals and the existential or spiritual interpretation of the illness experience is likely to be variably identified (Knox, 2020). Thus, owing to the personal nature of existential/spiritual beliefs and/or convictions, the provision of care that centres on such concerns should be guided by survivors’ needs and desires and made available as requested.

Physician Role Definition Domain

Issues pertaining to the definition of a physician’s role and discrepancies in the perceived responsibilities of various clinicians commonly exist in the context of end-of-life care; for example, the appropriateness and/or timing of transfers of care or the desire to stay involved to circumvent perceived abandonment (Bradley et al., 2000; Cherny & Catane, 2003; Fadul et al., 2009; Johnson et al., 2008; Ward et al., 2009). Interestingly, in the context of HNCa survivorship care, 75% percent of physicians indicated that they “always” perceived the ongoing care for survivors following the first year of regular surveillance to be part of their role. Accordingly, 75% of the physician participants “never” perceived their time to be too limited to provide ongoing care. Interestingly, 50% of physicians indicated that they would “never” prefer to have some one else take over the ongoing care of survivors following the first year of regular surveillance.

Of the laryngectomees who participated in the current study, 53.7% indicated that they would have “never” preferred someone other than their “cancer doctor” to have taken over their care after treatment completion. However, less than half (42.4%) indicated that they “always” perceived that it was part of their “cancer doctor’s” role to provide care after treatment completion. While 75% of physicians “never” perceived their time to be too limited to provide ongoing care, only 34.6% of laryngectomees “never” perceived that their physician’s time was too limited to provide adequate care posttreatment (see Figure 4).

Taken together the participants’ perceptions toward questions in the Physician Role Definition domain suggest that there exists some contradiction between the physicians’ and laryngectomees’ perceptions regarding the role of physicians in posttreatment HNCa survivorship care. Although physicians indicated they are able to manage the posttreatment survivorship care that extends beyond regular surveillance, laryngectomees indicated that the care provided by their physician posttreatment did not always meet their expectations. These apparently contradictory perceptions are supported by previous research that found that 88.4% of participating oncologists endorsed the belief that medical oncologists’ role *should* include care at all stages of disease (Cherny & Catane, 2003). However, only 43% of oncologists actually had the time to be involved in this manner (Cherny & Catane, 2003).

These collective findings suggest role clarification may be needed to promote increased understanding of the physicians’ role in HNCa survivorship. HNCa survivors also may benefit from a greater understanding of constraints in the physicians’ role so they can adjust their expectations to more realistically align with these inherent limitations. Similarly, physicians may benefit from a greater understanding of the broad range of HNCa survivors’ posttreatment needs so they may more realistically assess their capacity to comprehensively provide care. Increased alignment between survivors’ and physicians’ perceptions of physicians’ role definition may ultimately serve to improve satisfaction with survivorship care (Eide et al., 2003; Moreno et al., 2018). In turn, it has been suggested that enhanced role definition may ultimately serve to improve patient outcomes, including those related to QoL (Messing et al., 2019; Ritchie et al., 2016).

Patient-Physician Communication Domain

Decision Making and Goals of Care. Comprehensive patient-physician communication is in part the means through which the theory and practice of palliative care serve to improve QoL (Bradley et al., 2000; Creutzfeldt et al., 2015; Davis et al., 2015; Gilewski, 2001; Johnson et al., 2008; Metzger et al., 2013; Oliver, 2018; Zhi & Smith, 2015; Zubkoff et al., 2018). For the most part, considerable skew toward the “always” anchor of the response scale was observed for both the laryngectomees’ and physicians’ perceptions of patient-physician communication as it pertained to decision making and goals of care, both under ideal circumstances and in actual practice (see Figure 5). However, it is important to note that the skew toward the “always” response anchor was somewhat less defined for the participants’ perceptions of patient-physician communication that pertained to decision making in the context of *actual* practice. Moreover, in regard to patient-physician communication that pertained to goals of care, although the physicians’ perceptions were still slightly skewed toward the “always” response anchor in the context of actual practice, the laryngectomees’ perceptions were quite varied. As such, significant differences were identified between the contexts of ideal circumstances and actual practice in the data from both the Survivor and Physician Groups.

It is interesting to note that when patient-physician communication pertains to end-of-life discussions, involving the patient in decision making and establishing goals-of-care is essential (Mady et al., 2018; Metzger et al., 2013; Sinclair et al., 2017). In essence, when death is imminent, the provision of care shifts to offer heightened consideration of how the individual would like to spend their final days based on what is most meaningful to them. Involvement of the survivor in decision making and establishing their goals of care were perceived by both laryngectomees and physicians as aspects of care that *should* be included in HNCa survivorship care. Yet, the findings of the current study also suggest that survivor involvement in decision making, as well as the establishment of goals of care, are variably included in actual practice. These findings are concerning given that previous research has described a relationship between clearly established goals of care and improved perceptions of QoL (Bernacki & Block, 2014; Puri, 2013). Therefore, conversations that include the survivor in decision making and pertain to their goals of care, as dictated by the foundational principles of palliative care, may serve to bolster the focus on QoL in HNCa survivorship care.

Physicians' Understanding of Survivorship Issues and Discussion of Difficult Topics. The Patient-Physician Communication domain also included questions intended to index participants' perceptions of physicians' understanding of survivorship issues and their confidence in handling difficult discussions. Again, considerable skew toward the "always" anchor of the response scale was observed for both the laryngectomees' and physicians' perceptions of physicians' understanding of survivorship issues and physicians' aptitude in handling difficult discussions (see Figure 5). Interestingly, laryngectomees' global perception of care was found to be most strongly correlated with their perceptions of how adequately their physician communicated about difficult topics. The physicians' global perception of their patients' judgement of care was found to be most strongly correlated with the physicians' perceptions of their command of HNCa survivorship issues in discussions with their patients.

The finding that these two aspects of patient-physician communication are related to survivors' overall judgement of their care is consistent with previous studies. Bredart et al. (2005) reported that increased patient satisfaction with care was associated with effective communication between oncologists and cancer patients. Eide et al. (2003) found that cancer patients' satisfaction with care was predicted by the quality of patient-physician communication. Moreover, Adams et al. (2016) suggested that patient satisfaction with care is, in large part, driven by the patients' perceptions of patient-physician communication. Thus, to enhance patient satisfaction with HNCa survivorship care, efforts should be taken to ensure patient-physician communication continues to be held as paramount and its value cannot be underestimated (Adams et al., 2016; Clever et al., 2008).

Support from a Fellow Laryngectomee. In the context of ideal circumstances, considerable skew toward the "always" anchor of the response scale was observed within the laryngectomees' perceptions regarding the opportunity to meet with a fellow laryngectomee (see Figure 5). However, the laryngectomees' were quite polarized regarding whether or not they were actually given this opportunity. This finding likely reflects the largely binary nature of this question: in actual practice either the laryngectomee had the opportunity or not. Interestingly, a statistically significant difference was found between the laryngectomees' perceptions toward meeting with a fellow laryngectomee under ideal circumstances and in actual practice. Ultimately, the laryngectomees seemed to perceive the opportunity to meet with a fellow laryngectomee to be a valuable aspect of survivorship care, but in actual practice the inclusion of this opportunity is less frequent and variable.

In the context of both ideal circumstances and actual practice, the physicians' perceptions toward providing their patients with the opportunity to meet with a previously laryngectomized individual were more variable than the laryngectomees'. Nevertheless, the general inclination among the physicians reflected a slight trend toward the "always" anchor in ideal circumstances and the "never" anchor of the response scale in actual practice (see Figure 5). Accordingly, one of the largest significant differences was found between the physicians' perceptions toward providing laryngectomees' with an opportunity to meet with a previously laryngectomized individual in the context of ideal circumstances and actual practice.

Interestingly, in previous research the opportunity for patients to meet with a fellow laryngectomee to discuss the HNCa illness experience and recovery process has been found to have a positive effect on biopsychosocial functioning following total laryngectomy (Mathieson et al., 1990; Richardson et al., 1989). More specifically, Mathieson et al. (1990) found that preoperative visits by a fellow laryngectomee had a positive influence on survivors' long-term adjustment. Richardson et al. (1989) reported that support provided by another laryngectomee contributed to improved communication adaptation, and to a lesser but still noteworthy extent, decreased biopsychosocial dysfunction. Moreover, the opportunity to meet with a fellow laryngectomee preoperatively has been found to predict higher QoL (Stam et al., 1991). Thus, if the laryngectomees' desire for the opportunity to meet with a fellow laryngectomee is more frequently fulfilled in HNCa survivorship care, improved outcomes may result. However, the findings from the current study suggest that despite being positively regarded by both the laryngectomees and physicians, this opportunity is inconsistently offered in actual practice.

Foundational Principles of Palliative Care Domain

Respect for Autonomy. The laryngectomees' and physicians' perceptions regarding care that recognizes patients' autonomy trended toward the "always" anchor of the response scale, both within the context of ideal circumstances and actual practice (see Figure 6). Moreover, the smallest statistically significant difference identified in the Physician Group's data was found between perceptions toward the frequency with which care is respectful of survivors' autonomy in the context of ideal circumstances and actual practice. In fact, despite the identified difference, 62.5% of physicians indicated that the occurrence of care that respects survivors' autonomy was actually equal under ideal circumstances and in actual practice (see Appendix M). The laryngectomees' perceptions mirrored the physicians' perceptions of a minimal disparity between care that respects autonomy in ideal circumstances and actual practice. Only 31.6% of laryngectomees indicated that their expectations for care that respects autonomy in ideal circumstances were higher than what they experienced in reality, while 7.8% of laryngectomees reported that their experience of care that respected their autonomy exceeded their expectations (see Appendix L).

Taken together, the results pertaining to both the laryngectomees' and physicians' perceptions toward care that recognizes survivors' autonomy reflect a trend in the provision of healthcare in which the ethical principle of autonomy has come to occupy a prominent place the patient-physician relationship and ethical decision making (Myers, 2005; Schenck, 2002). In essence, "where decisions in healthcare were once largely in the hands of the beneficent healer, they are now thought to be more appropriately in the hands of the autonomous patient" (Schenck, 2002, p. 413). With this shift away from medical paternalism, enhanced regard for the individuals' values, concerns, and/or needs may be achieved, and considerations of their autonomy can be bolstered in the provision of care (MacDonald et al., 2021; Schenck, 2002). It follows logically that this finding is of particular relevance in the context of HNCa since the disease and the consequences of its treatment generate unique problems related to one's capacity to verbally express such values, concerns and/or needs (Doyle, 2005; Liao et al., 2017; Ma & Yiu, 2001).

The experience of communication loss secondary to total laryngectomy exerts a particularly profound impact on autonomy since HNCa survivors are rendered incapable of using normal means of voice or speech to express self-governance (Doyle & MacDonald, 2019; MacDonald et al., 2021; Schenck, 2002). Thus, it is encouraging that the current findings suggest that the principle of palliative care which dictates the need for consideration of autonomy (Ferrell et al., 2017; Hadad, 2009; Randall & Downie, 2011) also resonated with laryngectomees and physicians outside of the end-of-life context. Survivorship care as it is typically enacted may not exclude consideration of one's loss of autonomy to the extent originally suggested in the current treatise. Thus, the results from the present study suggest that this principle of palliative care may be readily accepted by physicians and survivors alike in the context of HNCa survivorship care.

Respect for Dignity. For both the laryngectomees and physicians, considerable skew toward the "always" anchor of the response scale was observed in their perceptions of the frequency with which compassionate and respectful care that recognizes survivors' dignity *should* be included in survivorship care under ideal circumstances. The trend toward the "always" anchor of the response scale was also observed in both groups' responses in the context of actual practice (see Figure 6). In other words, both laryngectomees and physicians felt quite strongly and affirmatively about the inclusion of care that recognizes the patients' dignity. Of all questions posed to physicians in the context of ideal circumstances, the aspect of care that the largest proportion of physicians (81.3%) indicated should "always" be included was the recognition of survivors' dignity. There was also considerable consensus among the physicians' regarding their perceptions of care that recognizes their patients' dignity, both in the context of ideal circumstances and actual practice. Interestingly, out of all questions posed to laryngectomees in the context of actual practice, the aspect of care that the largest proportion of laryngectomees (49.4%) indicated was "always" included was recognition of dignity. However, compared to the physicians' responses, somewhat greater variability among the laryngectomees' perceptions was observed. Nevertheless, although statistically significant differences were found between the participants' perceptions of care that recognizes patients' dignity under ideal circumstances and actual practice, these differences were notably small.

It was anticipated that most laryngectomees would indicate that care should always respect the patient's dignity since it is widely regarded as a basic ethical right (Johnston et al., 2015; Randall & Downie, 2011). Similarly, owing to the assumed strong moral and ethical behaviour of physicians, the finding that most physicians indicated that care should always respect the patient's dignity was also anticipated. It is encouraging to note that the laryngectomees and physicians indicated that dignity is indeed a frequently included element in the provision of HNCa survivorship care. This finding suggests that the principle of palliative care which advocates for compassionate and respectful care that recognizes survivors' dignity is already a central element in survivorship care. By extension, it may be proposed that the dichotomy between disease-focused care and palliative care may be less extreme when it comes to certain moral aspects of care. Thus, there may be increased acceptance regarding the inclusion of principles of palliative care if these principles are framed outside of the end-of-life context as aspects that are already customary in physicians' typical provision of survivorship care.

Quality of Life. The central ethos of palliative care pertains to the consideration and improvement of QoL (Gillick, 2005; Geerse et al., 2018; Hadad, 2009; Strand et al., 2013). Data from the current study suggest that both laryngectomees and physicians quite strongly believe that posttreatment survivorship care *should* "always" consider QoL issues under ideal circumstances (see Figure 6). By extension, the participants affirmatively indicated that the central ethos of palliative care *should* also be central in survivorship care. However, paired with the findings from the Symptom Management domain, the trends in the laryngectomees' and physicians’ perceptions suggest that the survivorship care that is actually provided aligns more closely with the biomedical model than the central ethos of palliative care (see Figure 2). As such, both laryngectomees and physicians indicated that the care they respectively received or provided in actual practice included the consideration of QoL issues less regularly than they believed such considerations *should* be included (see Figure 6). This is further evidenced by the significant differences identified between the participants’ perceptions of the frequency with which posttreatment care addresses QoL issues in ideal circumstances versus actual practice.

This disparity between ideal and actual care provision is noteworthy in light of the large positive correlation identified between the laryngectomees’ perceptions of the frequency with which their care actually addressed QoL issues and their global perception of how pleased they were with the care they received. In other words, the more that laryngectomees believed that their care considered QoL issues, the more pleased they were with that care. It is important to note, however, that this positive relationship does not suggest causality, but rather, that these two factors vary together. Nevertheless, this finding is complemented by previous studies that found improved QoL is correlated with increased satisfaction with care (Moreno et al., 2018; Nguyen et al., 2014). Taken together, the consideration of QoL as per the central ethos of palliative care, is perceived by both laryngectomees and physicians as an important area of HNCa survivorship care.

What to Expect Posttreatment. Of all questions posed in the context of ideal circumstances, the greatest proportion of laryngectomees (72.1%) indicated that being informed about what to expect posttreatment to aid in ongoing informed decision making *should* “always” be included in HNCa survivorship care (Question 15 [a]). Moreover, the laryngectomees also affirmatively indicated that they wanted to know what to expect of their “new normal” after treatment completion (Question 10). In the context of ideal circumstances, the physicians' perceptions toward informing patients about what to expect posttreatment, as well as their perceptions regarding patients' desire to be informed of what to expect, mirrored those of the laryngectomees' (see Figures 5 and 6). Additionally, in the context of actual practice, the laryngectomees' and physicians' perceptions toward informing patients about what to expect were also skewed toward the "always" anchor of the response scale. However, the laryngectomees' responses were characterized by more variability in the context of actual practice than ideal circumstances. The foundational principle of palliative care that was the target of Question 15 ultimately refers to the notion that a central role of palliative care is one of informational support (Metzger et al., 2013). A key element of informational support is patient-physician communication (Messing et al., 2019). As such, it is not surprising that the laryngectomees' and physicians' perceptions of Question 10, which was grouped within the Patient-Physician Communication domain, are aligned with their perceptions of Question 15 which pertained to informational support.

Owing to the uncertain nature of death and dying, addressing uncertainty through the provision of comprehensive informational support is central to this principle of palliative care (Hadad, 2009). In the context of end-of-life care, the notions of death and dying are at the foreground. Since these notions are often considered to be representative of the ultimate unknown, it follows logically that individuals for whom death is imminent would value and appreciate being prepared and informed on what they might expect in the dying process. The data from the current study suggest that the principle of palliative care that dictates that individuals deserve to be fully informed about what to expect (Hadad, 2009) also resonated with laryngectomees outside of the end-of-life context. High levels of uncertainty typically characterize the posttreatment period of HNCa survivorship (Coughlin, 2008; Doyle, 1994; Howren et al., 2012). As such, informational support should also be offered to HNCa survivors since posttreatment survivorship is often a period that is likely to be largely unknown and uncharted territory (Zhang, 2017).

Previous research has demonstrated that high levels of uncertainty, unmet informational needs, and low informational support negatively correlate to cancer patients' perceived QoL (Germino et al., 2013; Hsu et al., 2003; Kazer et al., 2011; Kim et al., 2012; Mishel et al., 2005, 2009; Sharour et al., 2019). Conceptually, the relationship between uncertainty and QoL is not surprising. Uncertainty is characterized as the "inability to determine the meaningfulness of illness-related events" (Mishel, 1988, p. 225). QoL denotes the perception that "life is worth living and that living has meaning" (p. 445) and captures the perceived meaningfulness of one's life (Doyle & MacDonald, 2019). It follows that QoL is likely to be impacted by the experience of uncertainty in HNCa survivorship. No one is in a better position to evaluate one's perceived QoL than the individual who experiences the disease; however, the individual must be given sufficient information with which to make this evaluation (Myers, 2005). Thus, this principle of palliative care that dictates that individuals should be informed about what to expect may serve as an element in HNCa survivorship care that ultimately supports QoL. In the present study, a disparity was identified between the participants' perceptions regarding the frequency with which survivorship care *should* inform patients about what to expect posttreatment and the frequency with which survivorship care *actually* informs patients about what to expect posttreatment. Therefore, the findings of the current study suggest that laryngectomees and physicians endorse the inclusion of this principle of palliative care in HNCa survivorship care. However, the inclusion of this principle remains variable if not limited in actual practice.

Involvement of Survivors' Family Members and/or Significant Others. Another central principle of palliative care pertains to the importance of involving the individual's family members and/or significant others in their care (Ferrell et al., 2017; Gillick, 2005; Hadad, 2009; Ingram, 2014; Strand et al., 2013). The laryngectomees' and physicians' perceptions toward the inclusion of this principle in HNCa survivorship care were skewed toward the "always" anchor of the response scale both within the context of ideal circumstances and actual practice (see Figure 6). Accordingly, the statistically significant differences identified between both the laryngectomees' and physicians' perceptions of the inclusion of family members and/or significant others in HNCa survivorship care in ideal circumstances and actual practice were small.

In HNCa survivorship there is the potential for a disconnect between family members' and/or significant others' expectations for a survivor's recovery posttreatment and the survivor's lived experience following treatment completion (Little et al., 2002). More specifically, the laryngectomee's family members may have a preconceived notion of how the survivor should respond after they have completed definitive treatment (Little et al., 2002; Miller, 2015). Greater congruence between the survivor's experience and their family's expectations may be facilitated by involving family members in an attempt to help them to understand the profound range of biopsychosocial functional challenges secondary to surviving laryngeal cancer and its treatment. For this reason, it is encouraging that although both the laryngectomees' and physicians' responses suggest there is some room for increased inclusion of survivors' family members and/or significant others, this principle of palliative care may not be far beyond the scope of survivorship care provision. Therefore, the inclusion of survivors' family members and/or significant others in the provision of survivorship care, as guided by this principle of palliative care, may be feasible with minimal infrastructural changes.

Recognition of Survivors' Social Networks. The functional challenges associated with total laryngectomy exert a wide-ranging influence on social functioning. Several of the physical sequelae of HNCa treatments, including dysphagia, xerostomia, dysgeusia, and mucositis can impair individuals' ability to engage in shared mealtimes in social settings which can lead to isolation (Pateman et al., 2015; Threats, 2007). Given the central role of verbal communication in social interaction, speech and voice deficits further inhibit a survivor's desire and/or capacity to engage socially (Eadie et al., 2015; Semple et al., 2004). The potential for social withdrawal and the extensive range of social challenges faced by individuals who have undergone total laryngectomy is particularly concerning since it is well documented that social support is correlated with positive adjustment to the experience of disease and improved QoL (Eadie & Bowker, 2012; McDonough et al., 1996). Acknowledging these substantial deficits within the social domain of functioning, the potential utility of the principle of palliative care that suggests that individuals should be enabled to continue their social relationships and participation in their larger social networks (Hadad, 2009) is not insignificant in the context of HNCa survivorship.

For both the laryngectomees and physicians, considerable skew toward the "always" anchor of the response scale was observed in their perceptions of how frequently this principle *should* be included in ideal circumstances (see Figure 6). However, both the laryngectomees' and physicians' responses were much more varied regarding the frequency of its inclusion in actual practice. Correspondingly, statistically significant differences were found between the frequency with which care that supports survivors' social functioning *should* be included and the frequency with which such care is actually included in HNCa survivorship care in both the Survivor and

Physician Groups' data. These findings mirror the participants' perceptions pertaining to social functioning identified within the Symptom Management domain.

Overall, these findings suggest that the principle of palliative care that dictates that individuals should be enabled to continue their social relationships and participation in their larger social networks is perceived by laryngectomees and physicians to be somewhat beyond the scope of survivorship care as it is typically enacted. However, if this principle of palliative care is utilized to guide HNCa survivorship care, physicians' awareness of the importance of survivors' social functioning and its impact on QoL may be increased. In essence, if this principle serves to enhance physicians' awareness of the wide-ranging impact of social functioning, physicians may be more likely to deliver care to survivors that supports their social functioning and, ultimately, QoL.

Hopes, Dreams, and Aspirations. Another principle of palliative care dictates that individuals deserve to be supported to reach their hopes and dreams so they may establish a sense of meaning and purpose in life (Hadad, 2009; Lee et al., 2017). For both the laryngectomees and physicians, considerable skew toward the "always" anchor of the response scale was observed in their perceptions of the frequency with which care that considers survivors' hopes, dreams, and aspirations *should* be included in ideal circumstances (see Figure 6). However, both the laryngectomees' and physicians' responses were much more varied regarding the frequency with which care considers survivors' hopes, dreams, and aspirations in actual practice (see Figure 6). Unsurprisingly, significant differences were observed between both groups' perceptions of the inclusion of care that centres on helping a survivor to achieve their hopes and dreams in ideal circumstances and actual practice.

It was expected that the participants would think that consideration of one’s hopes and dreams was a good idea in theory, but that it would be minimally included as part of typical survivorship care provision. These findings were anticipated owing to the highly subjective nature of the principle of palliative care featured in this question. That is, since subjective data are regarded as difficult to quantify, contextualize, and interpret, disease management has become largely driven by consideration of objective data (Lee et al., 2017; Ueda & Okawa, 2003). The potential dichotomy that has formed between the objective and subjective factors in an individual’s illness experience also serves to further contextualize the findings within the Symptom Management domain of functioning. More specifically, the objectivity with which physical symptoms can be measured and treated makes them more tangible to address (Lee et al., 2017; Ueda & Okawa, 2003).

While these objective data have undoubtedly delivered profound advancements in disease management, a by-product of such advancements has been the desire for “banishing the uncertainties of subjectivism” from care provision (Cassell, 2004, p. 20). As such, the management of physical symptoms is paramount, while the consideration of psychological, social, and existential/spiritual concerns, as well as one’s hopes and dreams, may be considered incidental. However, while critical, exclusive consideration of objective data is likely to limit the breadth with which care can address one’s holistic illness experience (Doyle & MacDonald, 2019; Lee et al., 2017; MacDonald et al., 2021; Ueda & Okawa, 2003). For this reason, although the consideration of a survivors’ hopes, dreams, and aspirations is a highly subjective endeavour, inclusion of this principle of palliative care may serve to more comprehensively address survivors’ illness experiences.

Interdisciplinary Care. Interdisciplinary care is the accepted approach to enacting palliative care (Billings, 1998; Ferrell et al., 2017; Gillick, 2005; Hui et al., 2012). In interdisciplinary care, healthcare providers from different specialties work together as a collaborative team to contribute their expertise to patient care (Creutzfeldt et al., 2015; Hui et al., 2013; Meghani, 2004; Strand et al., 2013). An interdisciplinary care approach brings together knowledge from different disciplines of healthcare by encouraging considerable integration of the expertise contributed by the healthcare providers involved. Question 18 (a) was considered an Unpaired Question that was grouped within the Foundational Principles of Palliative Care domain in order to ask participants about their perceptions toward interdisciplinary care. Interestingly, among the Unpaired Questions the highest proportion of laryngectomees indicated that interdisciplinary care is “always” beneficial in HNCa survivorship care (76.2%). Moreover, the laryngectomees’ perceptions were tightly clustered around the “always” anchor of the response scale, thereby indicating high consensus among responses. These trends are mirrored in the physicians’ perceptions toward interdisciplinary care: their responses were tightly clustered and skewed toward the “always” anchor of the response scale. Interestingly, whether or not the members of the interdisciplinary team are located within the same clinic seemed to matter slightly less to both laryngectomees and physicians as evidenced by more tempered responses with less considerable skew and much wider response ranges for Question 18 (b).

Owing to the complexity and highly interdependent nature of the biopsychosocial deficits experienced by laryngectomees, it follows logically that the laryngectomees in the current study perceived an approach to HNCa survivorship care that is characterized by integrated and highly connected healthcare provision to be beneficial. Moreover, due to the reciprocal and interdependent nature of the relationships that exist between the domains that influence perceived QoL (Doyle & MacDonald, 2019; Perry et al., 2015), an interdisciplinary approach to HNCa survivorship care may further serve to bolster comprehensive consideration of QoL. As such, the principle of palliative care that dictates that end-of-life care should be guided by an interdisciplinary approach is also of particular relevance in HNCa survivorship, irrespective of the patients' proximity to death.

If applied outside of the end-of-life context of traditional palliative care, an interdisciplinary approach may facilitate heightened awareness of the collective cascade of functional challenges which is indicative of the interdependent and reciprocal relationships between domains of functioning (Doyle & MacDonald, 2019; Engel, 1977). That is, if a healthcare provider with expertise in one discipline observes a deficit in one domain, it is likely that a reciprocal impact is being experienced in other domains of functioning that may not be within the realm of that particular healthcare provider's expertise. In such instances another team member can seamlessly contribute their unique expertise without the need for any formal transfer of care. In turn, the requirement for a direct transfer of care can be avoided which may mitigate survivors' potential sense of "abandonment" (Ward et al., 2009). Through the heightened integration and collaboration provided by an interdisciplinary approach to HNCa survivorship care, the collective clinical expertise of the interdisciplinary team may be applied to better address the collective cascade of functional challenges and, thus, more comprehensively monitor and address HNCa survivors' QoL.

Global Perception of Care Provision Domain

The distribution of the laryngectomees' and physicians' global perception of care provision exhibited considerable skew toward the "very pleased" anchor of the response scale (see Figure 7). The laryngectomees' responses suggested that they were generally quite pleased with the care they received from their physician posttreatment. Interestingly, the physicians' perception of their patients' judgement of their posttreatment care tended to be more tempered compared to the views of the laryngectomees. Although gaps in the scope of the provision of HNCa survivorship care were identified, overall, HNCa survivors seem to be pleased with the posttreatment care they receive.

Limitations of the Current Study

Theoretical Considerations

Theoretical limitations may exist in the pursuit to deliver care to HNCa survivors that is guided by principles that are tailored to individuals for whom death is imminent. The inclusion of the principles of palliative care in the care provided to HNCa survivors for who death is not imminent may seem unorthodox. The presentation of the *principles* in the current treatise is not intended to suggest that palliative care as a subspeciality of medicine may be seamlessly applied to the provision of care for HNCa survivors. Instead, the theoretical arguments made in the present treatise are intended to suggest that the foundational *principles* underlying the care given to those who are dying should also be offered to HNCa survivors for whom death is not imminent (MacDonald et al., 2021).

The impact of surviving HNCa may include responses such as denial, fear, anger, and myriad functional losses which are not entirely inconsistent with one's experience within the end-of-life context (Kubler-Ross, 1969, 1974). Therefore, the chronicity of HNCa survivorship may be regarded as creating a process of personal response that may mirror a grieving process (Doyle & MacDonald, 2019; Kubler-Ross, 1969; MacDonald et al., 2021). However, some elements of care that are appropriate for an individual who is acutely dying are undeniably distinct from elements of care that are suitable for a HNCa survivor (e.g., practicality of the prescription of morphine). Nevertheless, survivorship care as it is typically enacted does not provide care that exhaustively covers all facets or domains of one’s HNCa survivorship experience. Therefore, despite inherent limitations, it is suggested that the principles of palliative care may be of value to fill the gaps left by the provision of medicalized survivorship care.

Methodological Considerations

Several methodological limitations must be acknowledged. To begin, due to the exploratory nature of the present study, some psychometric properties of the questionnaire are untested (i.e., concurrent validity, criterion validity, reliability). Nevertheless, the variability in the range of mean values observed suggests that respondents were carefully considering the scaled response options specific to each question posed, rather than simply moving through the response task and selecting the same response category each time. In addition, the data collected may be threatened to some extent by bias. More specifically, this study may have been limited by potential selection bias since participants may have disproportionally represented those with higher levels of interest in survivorship and/or QoL issues or may represent those with the strongest views. Additionally, there may have been an over-representation of those individuals who are proficient internet users and/or are regular email users since recruitment for both the Survivor and Physician Groups was dependent on internet/email use. Nevertheless, the internet is cited as a worthwhile and appropriate mode for conducting survey-based research studies targeted at specific populations, especially professional groups for which mailing lists that contain email addresses are accessible for sampling (Dillman et al., 2014; Ward et al., 2009).

The risk of bias is also potentially elevated owing to the low response rate within the Physician Group. A low response rate among physician participants was anticipated based on comparable studies which estimated that a maximum achievable response rate for a survey of physicians is approximately 50% (Bradley et al., 2002; Johnson et al., 2008). Nevertheless, the physician response rate for the current study was considerably lower than this estimated maximum, which may introduce bias. Although efforts were taken to collect a representative sample by collecting data from physicians who practice at several institutions across Canada and the United States in addition to recruiting via the CSO, ultimately, the small sample size of the Physician Group increases the risk of random sampling error and, thus, raises the possibility that, by chance, the sample may not accurately represent the population.

Questionnaires were included for analysis regardless of unanswered questions, and thus the impact of missing data must be considered. However, since the number of missing responses increased as participants approached the end of the questionnaire, it was deduced that the probability of the “missingness” of a response to a question was unrelated to the value of the response to either that question or any other question (Streiner, 2002). In other words, the reason for the missing responses was likely unrelated to the outcome being measured and it was likely that the data were missing completely at random (Streiner, 2002). Thus, the “missingness” of the data in the current study was unlikely to substantially bias the results. Thus, to avoid unnecessary inflation of the Type I error rate, replacement of the missing data with the group mean was not employed. Given the exploratory nature of the current study, statistical analysis excluded missing values and calculations were based on the valid values only. However, relative to the sample of participants for whom data was complete, the proportion of “missingness” is small (i.e., >20%) and, therefore, the effect of the missing data on making a valid conclusion is likely inconsequential (Streiner, 2002). Nevertheless, although missing data were unlikely to impact internal validity, fewer data points are indicative of limitations which may influence precision.

The sample size for the Physician Group coupled with the concomitant increased risk of random sampling error may have further influenced the precision of the results. Conversely, the sample size of the Survivor Group was quite large, despite its low response rate. However, although the response rate for the Survivor Group of the current study would appear to be low, it was not dissimilar to the response rate garnered from previous research that utilized similar sampling methods (Doyle et al., 2020). For both the Survivor and Physician Groups it is important to carefully consider the width, overlap, and upper and lower boundaries of the 95% confidence intervals which ultimately effect the precision with which conclusions can be drawn. Despite the limitations of the low response rate among laryngectomee and physician participants, the considerable sample size achieved within the Survivor Group provides increased confidence in the data collected from that sample.

There is also some concern related to the sampling frame for the laryngectomee participants. More specifically, there was a population of individuals who have previously undergone total laryngectomy that were not accessed since recruitment was restricted to members of WebWhispers. The sampling frame for the physician participants may also have limited the applicability of the findings and may have influenced external validity. Furthermore, because this was a sample of convenience and, thus, nonprobability sampling methodology was utilized, assumptions cannot be made about the perceptions of laryngectomees and physicians who chose not to participate. Accordingly, it is important to note that calculating sampling error is not permitted due to the nonprobability nature of the sample (Dillman et al., 2014). However, despite the noted limitations, the present data offer insight into key stakeholders’ perceptions of aspects of palliative care that may be included in HNCa survivorship in order to better address survivors’ QoL.

Considerations Related to the Distribution of Data

As anticipated, neither the laryngectomees' nor the physicians' responses clustered around the midpoint of the response scale. Accordingly, the data were found to have a non-normal distribution and considerable skew (see Figures 1-7), thereby justifying the use of the non-parametric statistical tests. The small sample size of the Physician Group in particular further reinforced the need for non-parametric statistical testing. Moreover, the questionnaire employed an ordinal scale which collected discrete data. Thus, the assumptions of parametric tests could not be met by the data collected in the present study.

Differences between groups could not be analyzed statistically without violating the general assumptions of inferential statistical tests (e.g., there was a considerable difference in the sample sizes of the two groups and prognostic factors could not be balanced). For this reason, correlational analysis was employed to identify potential relationships between the equivalent questions on the Survivor and Physician Versions of the questionnaire. However, no statistically significant correlations were identified between the perceptions of the laryngectomees and physicians toward equivalent questions. This likely reflects that baseline differences between the two groups were such that between group comparison was futile in the present study.

Moreover, the Survivor Group was asked to consider their experience of the care they received following treatment completion. However, not only was the time since treatment completion quite varied within the Survivor Group, but the duration of time since treatment completion was a factor that was absent from the baseline characteristics of the Physician Group. That is, physician participants were asked to respond based on their current practice, while laryngectomee participants were asked to respond based on their experience with posttreatment care, irrespective of the time that has since elapsed. It is possible that there may have been developments in survivorship care, or follow-up care, across the posttreatment trajectories of the laryngectomees. It is also possible that some physicians are currently practicing in institutions with recently developed or updated survivorship programs. Thus, the potential for between group comparison was prohibited. Additionally, in light of the exploratory nature of the study, relationships between domains (i.e., between the Global Perception of Care Provision Domain and the other specific aspects of care) must also be interpreted with caution. The correlational analyses were intended to complement the findings that ultimately fulfill the study objectives (i.e., to identify and describe perceptions regarding principles of palliative care in the context of HNCa survivorship care). For these reasons, only the large and conceptually sound correlations were discussed to enrich the overall understanding of the laryngectomees' and physicians' perceptions.

Clinical Implications

To inform the provision of care, there is increasing recognition and awareness that the patients' perspective must be at the core of research programs (Geyh et al., 2007). It follows that HNCa survivors' perspectives are critical within a research program intended to serve this population (Bickenbach et al., 1999). The findings of the current study may serve to inform clinical practice by drawing attention to specific aspects of care that are identified to be of importance to laryngectomees. By highlighting areas of survivorship care in which gaps exist between what survivors deem to be germane and what they have received in actual practice, efforts may be undertaken to fill such gaps. The discrepancy between the laryngectomees' widely expressed desire for the inclusion of the principles of palliative care and their reports of the more limited implementation of the principles in actual practice suggests the need for infrastructural changes to facilitate better actualization of the principles of palliative care in

HNCa survivorship care. Such infrastructural changes are likely required to make the inclusion of the principles of palliative care a normal part of survivorship care and, in turn, bolster the focus on QoL.

As the other member of the patient-physician dyad, it is also important to represent the perceptions of those physicians with direct involvement in the care of HNCa survivors. Physicians are an integral and often dominant part of the clinical pathway, so their perceptions are also essential to guiding clinical practice (Bradley et al., 2000). As survivorship care guidelines continue to be developed to improve the quality of care for HNCa survivors, physicians' perceptions play a central role in gaining an understanding of potential facilitators and barriers of implementing an approach to survivorship care that is guided by the principles of palliative care. In essence, by identifying gaps that exist between ideal and actual care, potential barriers (e.g., attitudinal, infrastructural, or those related to knowledge/training) causing these gaps may be recognized and addressed. In turn, physicians' perceptions toward the role of the principles of palliative care in HNCa survivorship care in ideal circumstances may offer insights into their willingness to actually deliver these principles to their patients (Cherny & Catane, 2003). However, feasibility issues pertaining to resources, whether financial, structural, or personnel based, must be acknowledged. Nevertheless, the present study is viewed as a positive beginning step to an approach that may facilitate the highest quality of survivorship care secondary to HNCa treatment and the potential range of consequences it may pose to the individual.

Directions for Future Research

The findings of the present study provide an initial foundation on which future research can build a robust understanding of the potential for the principles of palliative care to bolster the focus on QoL in HNCa survivorship care. Although laryngectomees and physicians are critical stakeholders to represent in a research program pertaining to HNCa survivorship care, the perceptions of other integral stakeholders (i.e., speech-language pathologists, physical therapists, psychologists, oncology social workers, occupational therapists, and/or family members and significant others) are also significant and represent a critical area of future inquiry. Although not analyzed in detail, the open-ended comments provided by laryngectomee participants in the present study align with the need for the examination of other integral stakeholders (see Appendix L). That is, many respondents commented on the importance of other stakeholders in survivorship care, specifically speech-language pathologists. Additionally, it would be valuable for future research to explore *between group* differences among stakeholders' perceptions of the inclusion of principles of palliative care in survivorship care.

The data collected in the present study may be used as the basis for hypothesis testing in future studies. It is also recommended that future research investigate the effect of employing the principles of palliative care in HNCa survivorship care on survivors' QoL using a randomized controlled trial (RCT) study design. More specifically, in an RCT, laryngectomees could be randomly assigned to a "treatment group", in which principles of palliative care are *added* to the usual standard of survivorship care, or a "control group", in which survivorship care is guided by the usual "gold standard" of care. This approach would serve to reduce any ethical concerns related to withholding a specific treatment that is likely to be beneficial. QoL outcomes could be assessed using any number of the tools available which demonstrate strong psychometric properties (e.g., EORTC QLQ-C30 and EORTC QLQ-H&N35; The Functional Assessment of Cancer Therapy Scale [FACT-G] with head and neck subscale [HNS]; University of Washington QoL Questionnaire [UW-QOL]). Such data could provide valuable information on the effect of the principles of palliative care on survivors' QoL. In turn, this information could serve to inform survivorship guidelines to expand their scope and promote survivorship care that more comprehensively addresses the full spectrum of one's lived experience with HNCa.

Conclusions

In summary, the laryngectomees and physicians who participated in this study tended to perceive that the central principles of palliative care *should* be regularly included in HNCa survivorship care. However, results also suggested that the inclusion of these principles in HNCa survivorship care is more limited and quite variable in actual practice. Within the Symptom Management domain, although the consideration of psychological and social concerns was affirmatively perceived by the laryngectomees and physicians, the predominant focus on physical symptoms was clear. The findings from the Physician Role Definition domain suggest that there is a need for clarification in order to promote increased alignment between laryngectomees' and physicians' perceptions regarding a physician's role in posttreatment HNCa survivorship care. Patient-physician communication was perceived by laryngectomees and physicians as an aspect of care that should be central in HNCa survivorship care, although patient-physician communication is variably incorporated in actual practice. That being said, aspects of patient-physician communication that pertained to physicians' aptitude in discussing difficult topics and survivorship issues were found to be correlated with patients' global perception of their posttreatment care. Considerations of autonomy, dignity, QoL, informational support, involvement of family members and/or significant others, survivors' social networks and aspirations, and the notion of interdisciplinary care all resonated with both the laryngectomees and physicians. Overall, HNCa survivors' global perception of posttreatment care provision appeared to be quite high, despite identified gaps in the scope of the provision of HNCa survivorship care.

Ultimately, the findings of the present study provide insights into laryngectomees' and physicians' perspectives of the frequency with which the principles of palliative care should be included in survivorship care in ideal circumstances and the frequency with which these principles are included in actual practice. A commonality among these foundational principles of palliative care is their role in supporting and enhancing QoL. Thus, the present findings may provide information that serves to facilitate and promote the inclusion of aspects of care that bolster the focus on QoL in HNCa survivorship care. In doing so, the disease focus that is dominant in care provision may be broadened to include a QoL focus and associated outcome measures. Although the principles of palliative care traditionally guide the care of individuals for whom *death* is imminent, it is paradoxical to wait until individuals are at the end-of-life before addressing an array of factors that may positively influence their QoL (MacDonald et al., 2021). If these principles are included in HNCa survivorship care, such care may become more adept at returning HNCa survivors to as meaningful a *life* as possible.

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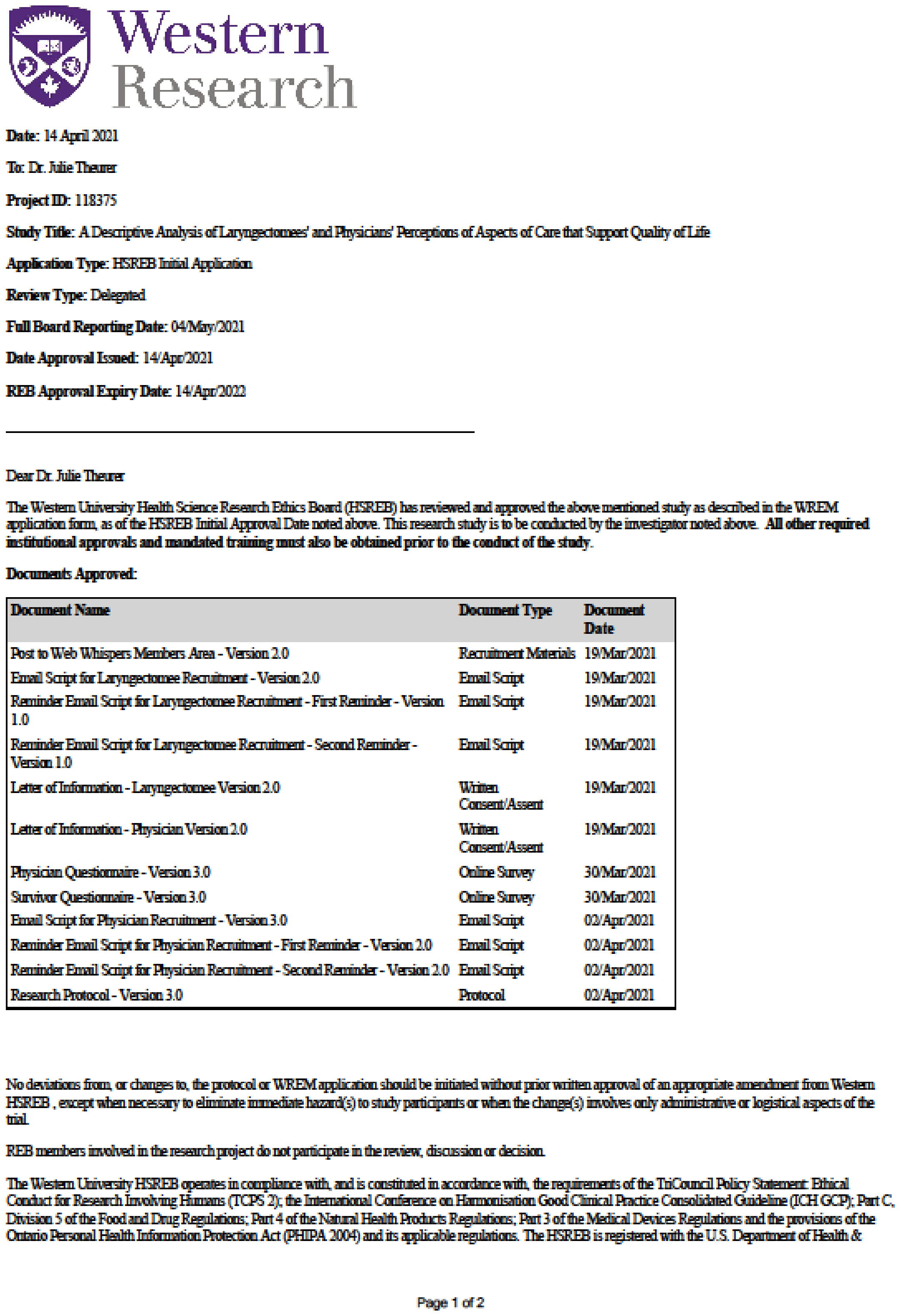
APPENDIX A



Western Research

Date: 14 April 2021

To: Dr. Julie Theurer

Project ID: 118375

Study Title: A Descriptive Analysis of Laryngectomees' and Physicians' Perceptions of Aspects of Care that Support Quality of Life

Application Type: HSREB Initial Application

Review Type: Delegated

Full Board Reporting Date: 04/May/2021

Date Approval Issued: 14/Apr/2021

REB Approval Expiry Date: 14/Apr/2022

Dear Dr. Julie Theurer

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above mentioned study as described in the WREM application form, as of the HSREB Initial Approval Date noted above. This research study is to be conducted by the investigator noted above. **All other required institutional approvals and mandated training must also be obtained prior to the conduct of the study.**

Documents Approved:

Document Name	Document Type	Document Date
Post to Web Whispers Members Area - Version 2.0	Recruitment Materials	19/Mar/2021
Email Script for Laryngectomee Recruitment - Version 2.0	Email Script	19/Mar/2021
Reminder Email Script for Laryngectomee Recruitment - First Reminder - Version 1.0	Email Script	19/Mar/2021
Reminder Email Script for Laryngectomee Recruitment - Second Reminder - Version 1.0	Email Script	19/Mar/2021
Letter of Information - Laryngectomee Version 2.0	Written Consent/Assent	19/Mar/2021
Letter of Information - Physician Version 2.0	Written Consent/Assent	19/Mar/2021
Physician Questionnaire - Version 3.0	Online Survey	30/Mar/2021
Survivor Questionnaire - Version 3.0	Online Survey	30/Mar/2021
Email Script for Physician Recruitment - Version 3.0	Email Script	02/Apr/2021
Reminder Email Script for Physician Recruitment - First Reminder - Version 2.0	Email Script	02/Apr/2021
Reminder Email Script for Physician Recruitment - Second Reminder - Version 2.0	Email Script	02/Apr/2021
Research Protocol - Version 3.0	Protocol	02/Apr/2021

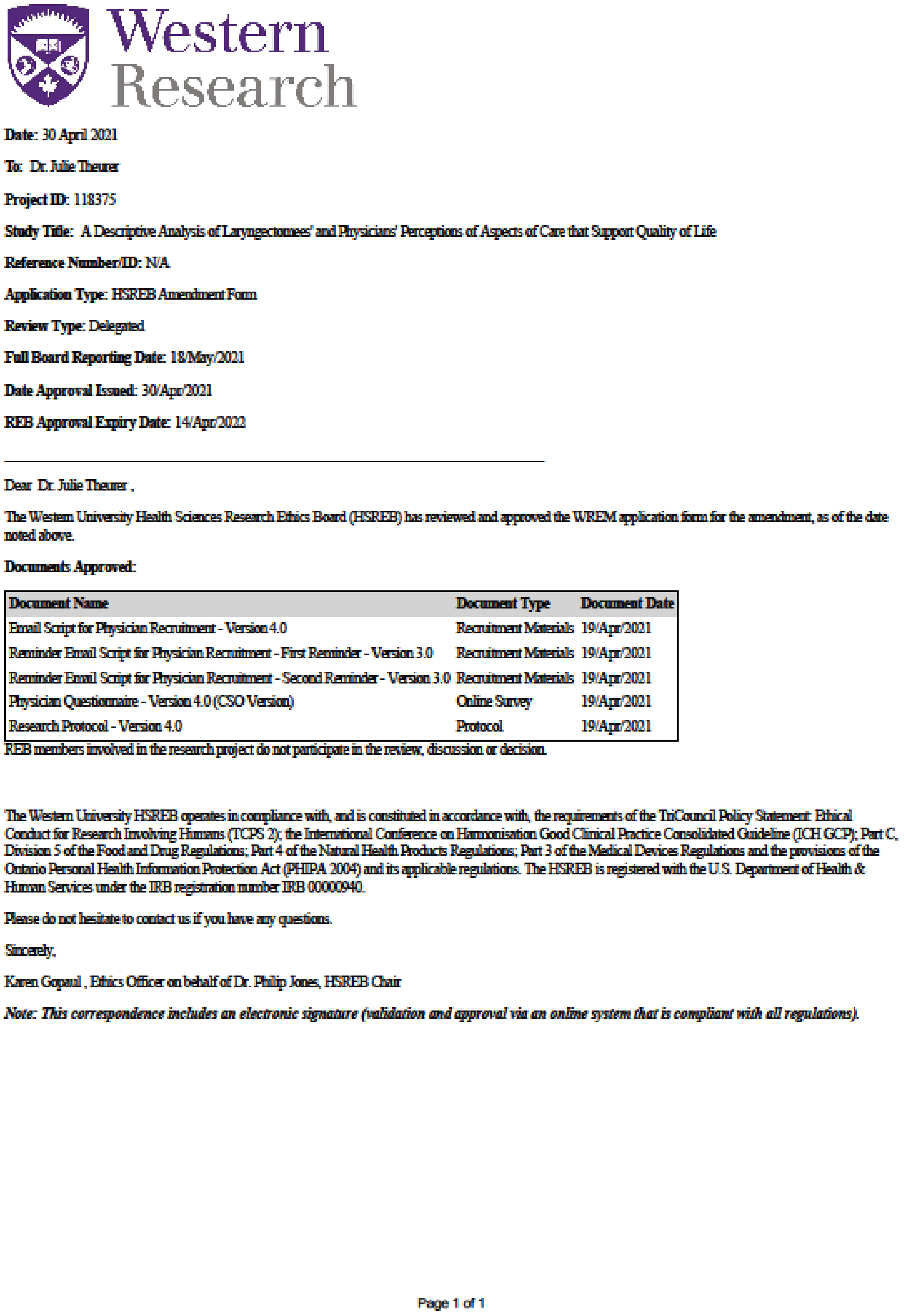
No deviations from, or changes to, the protocol or WREM application should be initiated without prior written approval of an appropriate amendment from Western HSREB , except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health &

Page 1 of 2

APPENDIX B



Western Research

Date: 30 April 2021

To: Dr. Julie Theurer

Project ID: 118375

Study Title: A Descriptive Analysis of Laryngectomees' and Physicians' Perceptions of Aspects of Care that Support Quality of Life

Reference Number/ID: N/A

Application Type: HSREB Amendment Form

Review Type: Delegated

Full Board Reporting Date: 18/May/2021

Date Approval Issued: 30/Apr/2021

REB Approval Expiry Date: 14/Apr/2022

Dear Dr. Julie Theurer ,

The Western University Health Sciences Research Ethics Board (HSREB) has reviewed and approved the WREM application form for the amendment, as of the date noted above.

Documents Approved:

Document Name	Document Type	Document Date
Email Script for Physician Recruitment - Version 4.0	Recruitment Materials	19/Apr/2021
Reminder Email Script for Physician Recruitment - First Reminder - Version 3.0	Recruitment Materials	19/Apr/2021
Reminder Email Script for Physician Recruitment - Second Reminder - Version 3.0	Recruitment Materials	19/Apr/2021
Physician Questionnaire - Version 4.0 (CSO Version)	Online Survey	19/Apr/2021
Research Protocol - Version 4.0	Protocol	19/Apr/2021

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Karen Gopaul , Ethics Officer on behalf of Dr. Philip Jones, HSREB Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Page 1 of 1

APPENDIX C

Survivor Questionnaire
For each item that follows, please select a single response option that best describes your current judgement of each statement based on your experience as a patient. Consider each item in relation to care that occurs after treatment (whether you had surgery, chemotherapy, radiation therapy, or combined treatment). There are no "right" or "wrong" answers. You may skip to the next question at any point. The information that you provide will remain confidential.

Survivor Demographic Factors	**Response Options**				
What is your age? Please provide your age in years and closest additional months.	Open text response	Prefer not to answer			
How do you identify yourself?	Male	Female	Self-identify (please specify)	Prefer not to answer	
Which race category best describes you?	White (European descent)				
	Black (African American descent/African Canadian descent/Afro-Caribbean)				
	First Nations, Mixed Ancestry, Metis, Inuit, Native American				
	East/Southeast Asian				
	South Asian				
	Middle Eastern				
	Latino				
	Self-identify (please specify)				
	Do not know				
	Prefer not to answer				
What country do you live in?	Canada	United States	Other (please specify)	Prefer not to answer	
What is the highest level of education you have achieved?	Completed high school				
	Completed college				
	Undergraduate university degree				
	Post-graduate university degree				
	Other (please specify)				
	Prefer not to answer				
How many months has it been since the completion of your cancer treatment?	Open text response	Prefer not to answer			
Which of the following cancer treatments (in addition to total laryngectomy) did you receive? Select all that apply:	Radiation therapy		Chemotherapy	Prefer not to answer	
	Before surgery	After surgery			
Which type of alaryngeal/postlaryngectomy speech do you use as your primary method?	Esophageal speech	Tracheoesophageal speech	Electro-laryngeal speech	Other (please specify)	Prefer not to answer

Continued on Next Page.

#	Question	Response Rating						
		Never	Almost never	Less than half the time	Half the time	More than half the time	Almost always	Always
1.	Under **ideal circumstances**, cancer doctors should address:							
(i)	physical concerns.							
(ii)	emotional (psychological) concerns.							
(iii)	social concerns.							
(iv)	existential/spiritual concerns.							
2.	Based on **my experience**, my cancer doctor attended to my:							
(i)	physical concerns.							
(ii)	emotional (psychological) concerns.							
(iii)	social concerns.							
(iv)	existential/spiritual concerns.							
3.	I was comfortable using my follow-up appointments with my cancer doctor to discuss:							
(i)	physical concerns.							
(ii)	emotional (psychological) concerns.							
(iii)	social concerns.							
(iv)	existential/spiritual concerns.							
4. (a)	Under **ideal circumstances**, cancer doctors should provide care that respects the patient's:							
(i)	independence and autonomy.							
(ii)	self-worth and dignity.							
(b)	Based on **my experience**, my cancer doctor provided me with care that respected my:							
(i)	independence and autonomy.							
(ii)	self-worth and dignity.							
5.	It was part of my cancer doctor's role to provide care after my treatment.							
6.	My cancer doctor's time was too limited to provide adequate care after my treatment.							
7.	I would have preferred someone other than my cancer doctor to have taken over my care after my treatment.							
8. (a)	Under **ideal circumstances**, cancer doctors should communicate with their patients about decision making and posttreatment goal setting.							
(b)	Based on **my experience**, my cancer doctor communicated with me about decision making and posttreatment goal setting.							
9. (a)	Under **ideal circumstances**, cancer doctors should have discussions with their patients concerning the goals of care that involve consideration of the patient's personal values, beliefs, and preferences.							
(b)	Based on **my experience**, my cancer doctor discussed goals of care with me that involved							

	consideration of my personal values, beliefs, and preferences.							
10.	I wanted to know what to expect after treatment and what my “new normal” was going to look like.							
11.	My cancer doctor communicated with me in a way that made me feel like he/she understood survivorship issues and the posttreatment experience.							
12.	My cancer doctor adequately communicated about difficult topics and made me feel comfortable.							
13. (a)	Under **ideal circumstances**, the care provided by cancer doctors should address “quality of life” issues.							
(b)	Based on **my experience**, my cancer doctor provided care that addressed “quality of life” issues.							
14. (a)	Under **ideal circumstances**, and at the patient’s request, cancer doctors should meet with and address the concerns of family members and/or significant others.							
(b)	Based on **my experience**, and at my request, my cancer doctor met (or would have met) with and addressed the concerns of my family members and/or significant others.							
15. (a)	Under **ideal circumstances**, cancer doctors should inform their patients about what to expect posttreatment to help them make informed decisions about their continuing care.							
(b)	Based on **my experience**, my cancer doctor informed me about what to expect posttreatment to help me make informed decisions about my continuing care.							
16. (a)	Under **ideal circumstances**, cancer doctors should provide care that helps their patients continue personal relationships since they are part of larger social networks.							
(b)	Based on **my experience**, my cancer doctor recognized that I was part of larger social networks and provided me with care that helped me to continue those relationships.							
17. (a)	Under **ideal circumstances**, cancer doctors should provide their patients with opportunities to reach their hopes and dreams of whatever is most meaningful to them.							
(b)	Based on **my experience**, my cancer doctor provided me with opportunities to reach my hopes and dreams of what was most meaningful to me.							

18. (a)	It is beneficial when healthcare providers from different specialties work together as a team to contribute their expertise to the care delivered after treatment.							
(b)	A collaborative care approach that allows patients to access healthcare providers from different specialties which are housed within the same clinic is beneficial in the care of survivors after treatment.							
19. (a)	Under **ideal circumstances**, either before or after surgery, cancer doctors should provide their patients with the opportunity to meet with a laryngectomized visitor to discuss posttreatment recovery and rehabilitation.							
(b)	Based on **my experience**, either before or after surgery, my cancer doctor provided me with the opportunity to meet with a laryngectomized visitor to discuss my posttreatment recovery and rehabilitation.							

20.	Overall, how pleased were you with the care you received from your cancer doctor after your cancer treatment?	Not pleased						Very pleased

21.	Is there any other information you would like to tell the researchers?	Open text response.

Qualtrics Link: https://uwo.eu.qualtrics.com/jfe/form/SV_eroIQkY3wbgYE8S

APPENDIX D

Physician Questionnaire
For each item that follows, please select a single response option that best describes your current judgment of the following statements as they relate to your care of patients treated for head and neck cancer (HNCa). Consider each item in the context of care that occurs following definitive treatment (surgery, chemotherapy, radiation therapy). There are no “right” or “wrong” answers. You may skip to the next question at any point. The information that you provide will remain confidential.

Physician Demographic Factors	Response Options			
What is your age? Please provide your age in years and closest additional months.	Open text response		Prefer not to answer	
How do you identify yourself?	Male	Female	Self-identify (please specify)	Prefer not to answer
Which race category best describes you?	White (European descent) Black (African American descent/African Canadian descent/Afro-Caribbean) First Nations, Mixed Ancestry, Metis, Inuit, Native American East/Southeast Asian South Asian Middle Eastern Latino Self-identify (please specify) Do not know Prefer not to answer			
What country do you live in?	Canada	United States	Other (please specify)	Prefer not to answer
What is your medical sub-specialty?	Otology and Neurotology Head and Neck Surgery Pediatric Otolaryngology Rhinology and Sinus Skull Base Surgery Facial Plastics and Reconstructive Surgery Laryngology Sleep Surgery Other (please specify) Prefer not to answer			
How many years of experience do you have?	Open text response		Prefer not to answer	
How would you categorize your site location/place of work?	Cancer Centre	Teaching Hospital	Other (please specify)	Prefer not to answer
What is your clinical background/training?	Open text response		Prefer not to answer	

Continued on Next Page.

#	Question	Response Rating						
		Never	Almost never	Less than half the time	Half the time	More than half the time	Almost always	Always
1.	Under **ideal circumstances** and exclusive of referrals I would make, the care that **I** provide should address survivors’:							
(i)	physical symptoms.							
(ii)	psychological symptoms.							
(iii)	social functioning.							
(iv)	existential/spiritual concerns.							
2.	In **actual practice** and exclusive of referrals I make, the care that **I** provide addresses survivors’:							
(i)	physical symptoms.							
(ii)	psychological symptoms.							
(iii)	social functioning.							
(iv)	existential/spiritual concerns.							
3.	In **actual practice**, during follow-up appointments, I feel that I am approachable regarding topics related to a patient’s:							
(i)	physical symptoms.							
(ii)	psychological symptoms.							
(iii)	social functioning.							
(iv)	existential/spiritual concerns.							
4. (a)	Under **ideal circumstances**, I should provide care that respects the patient’s:							
(i)	independence and autonomy.							
(ii)	self-worth and dignity.							
(b)	In **actual practice**, I provide care that respects the patient’s:							
(i)	independence and autonomy.							
(ii)	self-worth and dignity.							
5.	Continuing to care for survivors following the first year of regular surveillance is part of my role.							
6.	My time is too limited to provide ongoing care to survivors following the first year of regular surveillance.							
7.	I would prefer to have someone else take over the ongoing care of survivors following the first year of regular surveillance.							
8. (a)	Under **ideal circumstances**, I should communicate about decision making and goal setting with survivors.							
(b)	In **actual practice**, I communicate about decision making and goal setting with survivors.							
9. (a)	Under **ideal circumstances**, I should engage in discussions concerning the goals of care with survivors that solicit their personal values, beliefs, and preferences.							

(b)	In **actual practice**, I engage in discussions concerning the goals of care with survivors that solicit their personal values, beliefs, and preferences.							
10.	In my experience, survivors want to know what to expect and what their “new normal” will look like following definitive treatment.							
11.	My understanding of HNCa survivorship is adequate enough to discuss survivorship issues and the posttreatment experience with HNCa patients.							
12.	I am confident in my communication skills when discussing difficult topics with survivors.							
13. (a)	Under **ideal circumstances**, my care of survivors should address “quality of life” issues.							
(b)	In **actual practice**, my care of survivors addresses “quality of life” issues.							
14. (a)	Under **ideal circumstances**, and at the patient’s request, my care for survivors should include meeting with and addressing the concerns of family members and/or significant others.							
(b)	In **actual practice**, and at the patient’s request, I meet with and address the concerns of family members and/or significant others.							
15. (a)	Under **ideal circumstances**, I should inform survivors about what to expect posttreatment to help them make informed decisions regarding their care.							
(b)	In **actual practice**, I inform survivors about what to expect posttreatment to help them make informed decisions regarding their care.							
16. (a)	Under **ideal circumstances**, my care for survivors should address helping them to continue their relationships since they are part of larger social networks.							
(b)	In **actual practice**, I recognize that survivors are part of larger social networks and I provide care that helps them to continue their relationships.							
17. (a)	Under **ideal circumstances**, I should consider patients’ posttreatment aspirations (avocational, vocational, etc.) and what is most meaningful to them.							
(b)	In **actual practice**, I consider patients’ posttreatment aspirations (avocational, vocational, etc.) and what is most meaningful to them.							
18. (a)	An interdisciplinary care approach where healthcare providers from different specialties work together as a team to contribute their expertise to the care delivered following treatment completion is beneficial in the care of survivors.							

(b)	A collaborative care approach that allows patients to access healthcare providers from different specialties housed within the same clinic is beneficial in the care of survivors following treatment completion.							
19. (a)	Under **ideal circumstances**, either before or after treatment, I should provide my patients with an opportunity to meet with a HNCa survivor to discuss their recovery and rehabilitation.							
(b)	In **actual practice**, either before or after treatment, I provide my patients with an opportunity to meet with a HNCa survivor to discuss their recovery and rehabilitation.							

20.	Overall, how would you rate your patients' judgement of how pleased they are with your care following definitive treatment?	Not pleased						Very pleased

21.	Is there any other information you would like to offer the researchers?	Open text response.

Qualtrics Link: https://uwo.eu.qualtrics.com/jfe/form/SV_3vEuO71JHZg0m4m

APPENDIX E

Email Script for Laryngectomee Recruitment

Subject Line: Invitation to participate in research

Hello,

We are sending you an email because you are on the mailing list of WebWhispers. You are being invited to participate in a study that we are conducting. Briefly, the study involves a web-based survey which seeks to gather information on the perceptions of both physicians and those who undergo total laryngectomy regarding aspects of care that support quality of life. The survey is expected to take 15 minutes to complete. We cannot offer any compensation for your participation in this study. However, your time is greatly appreciated.

A reminder email will be sent in two-months' time to all WebWhispers members on the mailing list. Please note that email communication is not a secure form of communication.

If you would like to participate in this study, please click on the link below to access the letter of information and survey.

https://uwo.eu.qualtrics.com/jfe/form/SV_eroIQkY3wbgYE8S

Thank you,

Julie Theurer, Ph.D., S-LP(C), (Principal Investigator)
Communication Sciences and Disorders, Western University
[redacted]

Philip C. Doyle, Ph.D.
Professor Emeritus, Dept of OHNS, Western University
[redacted]

Student Contact: Chelsea MacDonald, M.Sc., Ph.D. (c)
Laboratory for Well-Being and Quality of Life in Oncology
Rehabilitation Sciences, Western University
[redacted]

APPENDIX F

Email Script for Physician Recruitment

Subject Line: Invitation to participate in research

Hello,

We are conducting a study which seeks to gather information regarding aspects of care that support quality of life based on perceptions of both physicians and those who undergo total laryngectomy. We would appreciate it if you can distribute this call for participation to physicians in your department who have direct involvement in the follow-up care of individuals who have been diagnosed and treated for head and neck cancer. The study involves a web-based survey. The survey is expected to take 15 minutes to complete. We cannot offer any compensation for participation in this study; however, the time taken by respondents is greatly appreciated.

One reminder email will be sent to you in three-weeks' time. We would appreciate if this email could be forwarded to the same list of email addresses that was used to distribute our initial call for participation. Please note that email communication is not a secure form of communication.

If physicians in your department would like to participate in this study, they can click on the link below to access the letter of information and survey.

https://uwo.eu.qualtrics.com/jfe/form/SV_3vEuO71JHZg0m4m

Thank you,

Julie Theurer, Ph.D., S-LP(C) (Principal Investigator)
Communication Sciences and Disorders, Western University
[redacted]

Philip C. Doyle, Ph.D.
Professor Emeritus, Dept of OHNS, Western University
[redacted]

Student Contact: Chelsea MacDonald, M.Sc., Ph.D. (c)
Laboratory for Well-Being and Quality of Life in Oncology
Rehabilitation Sciences, Western University
[redacted]

APPENDIX G

Email Script for CSO Physician Recruitment

Subject Line: Invitation to participate in research

Hello,

We are conducting a study which seeks to gather information regarding aspects of care that support quality of life based on perceptions of both physicians and those who undergo total laryngectomy. You are eligible to participate in this study if you are a physician who is involved in the direct follow-up care of individuals who have been diagnosed and treated for head and neck cancer. The study involves a short web-based survey. The survey is expected to take 15 minutes to complete. We cannot offer any compensation for participation in this study; however, your time is greatly appreciated.

A reminder email will be sent to you in three-weeks' time. Please note that email communication is not a secure form of communication.

If you would like to participate in this study, please click on the link below to access the letter of information and begin the survey.

https://uwo.eu.qualtrics.com/jfe/form/SV_3vEuO71JHZg0m4m

Thank you,

Julie Theurer, Ph.D., S-LP(C) (Principal Investigator)
Communication Sciences and Disorders, Western University
[redacted]

Philip C. Doyle, Ph.D.
Professor Emeritus, Dept of OHNS, Western University
[redacted]

Student Contact: Chelsea MacDonald, M.Sc., Ph.D. (c)
Laboratory for Well-Being and Quality of Life in Oncology
Rehabilitation Sciences, Western University
[redacted]

APPENDIX H

A Descriptive Analysis of Laryngectomees' and Physicians' Perceptions of Aspects of Care that Support Quality of Life

Laboratory for Well-Being and Quality of Life in Oncology
Rehabilitation Sciences
Western University

Letter of Information

Principal Investigator: Julie A. Theurer, Ph.D., S-LP(C)

Co-Investigators: Chelsea A. MacDonald, M.Sc., Ph.D.(candidate) & Philip C. Doyle, Ph.D.

Introduction

This letter provides information to help you decide whether or not to participate in this study. It is important for you to understand why the study is being conducted and what it involves. Please read this letter carefully and feel free to ask questions if anything presented is not clear or if there is something that you do not understand.

You are being invited to participate in this study because you have undergone a total laryngectomy. This study seeks to gather information on the perceptions of both physicians and those who undergo total laryngectomy regarding aspects of care that support quality of life (QoL). Should you choose to participate, you will be part of the laryngectomee group.

This study represents a portion of a Ph.D. thesis project for one of the investigators (C.M.).

Activities of Participation

If you agree to participate, you will be asked to complete a short online survey. This survey takes approximately 15 minutes to complete. You may take a break at any time if needed. The survey will ask you to provide demographic information such as your age and race. The remainder of the survey will gather information on your perceptions of aspects of care that support QoL in actual practice, as well as under ideal circumstances.

Voluntary Participation

Your participation in this study is entirely voluntary. You may decide not to be in this study. If you choose not to participate it will have no impact on you. If you choose to participate, you have the right to not answer individual questions and you may exit the survey at any time. There are no known risks or discomforts associated with participating in this study. You are unlikely to directly benefit as a result of your participation in this research study. However, a better understanding and awareness of issues related to QoL in head and neck cancer (HNCa) survivorship may be gained from your participation.

If you decide to withdraw from the study and not complete the survey in full, your incomplete data will be removed. However, your data cannot be withdrawn if you complete the questionnaire in full due to the fact that your data is anonymous; hence, your responses cannot be identified after the questionnaire is completed.

Compensation

We cannot offer any compensation for your participation in this study. However, your time is greatly appreciated.

Confidentiality

All data obtained will remain confidential. Furthermore, your survey responses will contain no personally identifiable information. Therefore, your identity will remain anonymous. All study data will be stored on the Qualtrics servers until the completion of the study, at which time the data will be downloaded and stored electronically in a password protected database at Western University for a period of 7 years. Only the researchers will have access to the information collected for the study. Representatives of Western University and its Health Sciences Research Ethics Board that oversees the ethical conduct of this study may also access study data. If the results of the study are published, your name will not be used.

Should you have any questions about this research study, please contact Julie Theurer at [redacted], ext. [redacted], or email Chelsea MacDonald at [redacted].

Should you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics [redacted], or email: [redacted]. The Research Ethics Board (REB) is a group of people who oversee the ethical conduct of research studies. The REB is not part of the study team. Everything that you discuss will be kept confidential.

Consent

By proceeding to the survey, you are acknowledging that you have read and agreed to the conditions of this study. By completing the survey, you are consenting to participation in this study; and as such, your survey responses will be entered into a database and used for this study.

This letter is for you to keep. If you wish to maintain a copy of this letter for your records, please print it now.

APPENDIX I

A Descriptive Analysis of Laryngectomees' and Physicians' Perceptions of Aspects of Care that Support Quality of Life

Laboratory for Well-Being and Quality of Life in Oncology
Rehabilitation Sciences
Western University

Letter of Information

Principal Investigator: Julie A. Theurer, Ph.D., S-LP(C)

Co-Investigators: Chelsea A. MacDonald, M.Sc., Ph.D.(candidate) & Philip C. Doyle, Ph.D.

Introduction

This letter provides information to help you decide whether or not to participate in this study. It is important for you to understand why the study is being conducted and what it involves. Please read this letter carefully and feel free to ask questions if anything presented is not clear or if there is something that you do not understand.

You are being invited to participate in this study because you are a physician who has direct involvement with the care of individuals who have been diagnosed with head and neck cancer (HNCa). This study seeks to gather information on the perceptions of both physicians and those who undergo total laryngectomy regarding aspects of care that support quality of life (QoL). Should you choose to participate, you will be part of the physician group.

This study represents a portion of a Ph.D. thesis project for one of the investigators (C.M.).

Activities of Participation

If you agree to participate, you will be asked to complete a short online survey. This survey takes approximately 15 minutes to complete. You may take a break at any time if needed. The survey will ask you to provide demographic information such as your age and race. The remainder of the survey will gather information on your perceptions of aspects of care that support QoL in actual practice, as well as under ideal circumstances.

Voluntary Participation

Your participation in this study is entirely voluntary. You may decide not to be in this study. If you choose not to participate it will have no impact on you. If you choose to participate, you have the right to not answer individual questions and you may exit the survey at any time. There are no known risks or discomforts associated with participating in this study. You are unlikely to directly benefit as a result of your participation in this research study. However, a better understanding and awareness of issues related to QoL in HNCa survivorship may be gained from your participation.

If you decide to withdraw from the study and not complete the survey in full, your incomplete data will be removed. However, your data cannot be withdrawn if you complete the questionnaire in full due to the fact that your data is anonymous; hence, your responses cannot be identified after the questionnaire is completed.

Compensation

We cannot offer any compensation for your participation in this study. However, your time is greatly appreciated.

Confidentiality

All data obtained will remain confidential. Furthermore, your survey responses will contain no personally identifiable information. Therefore, your identity will remain anonymous. All study data will be stored on the Qualtrics servers until the completion of the study, at which time the data will be downloaded and stored electronically in a password protected database at Western University for a period of 7 years. Only the researchers will have access to the information collected for the study. Representatives of Western University and its Health Sciences Research Ethics Board that oversees the ethical conduct of this study may also access study data. If the results of the study are published, your name will not be used.

Should you have any questions about this research study, please contact Julie Theurer at [redacted], ext. [redacted], or email Chelsea MacDonald at [redacted].

Should you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics [redacted], or email: [redacted]. The Research Ethics Board (REB) is a group of people who oversee the ethical conduct of research studies. The REB is not part of the study team. Everything that you discuss will be kept confidential.

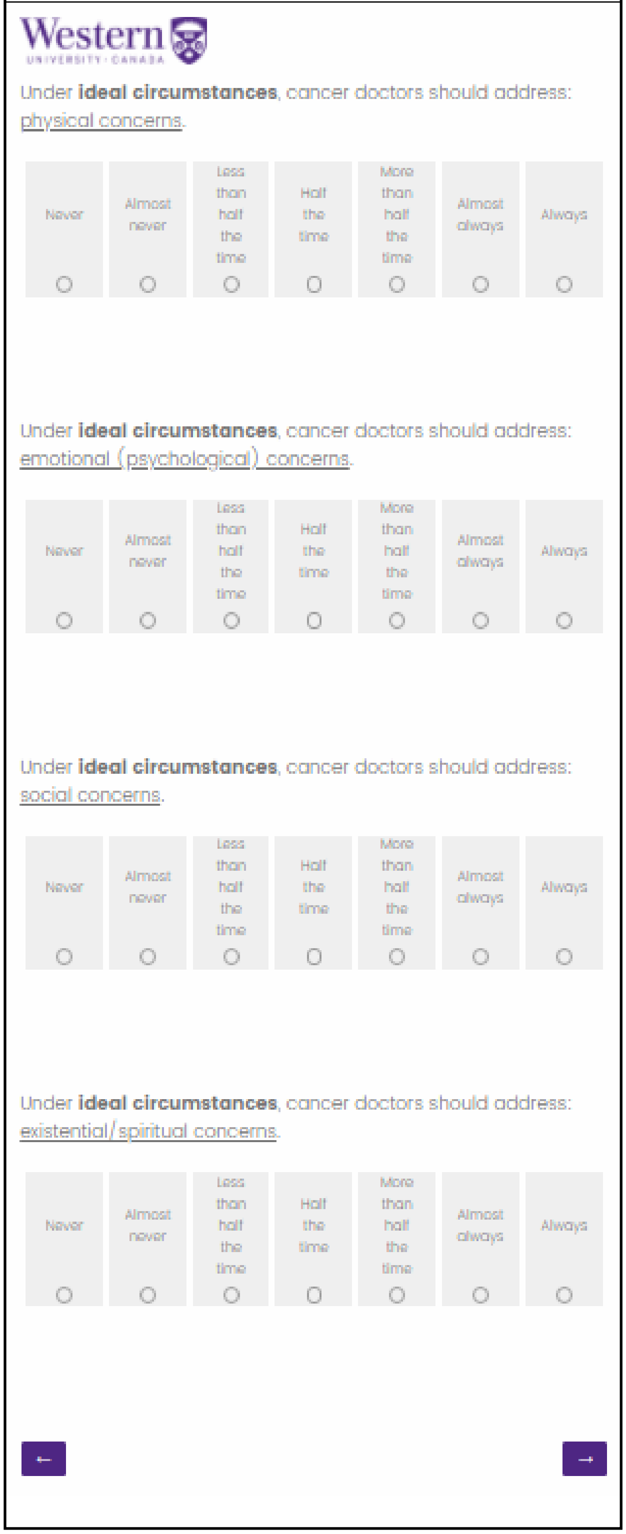
Consent

By proceeding to the survey, you are acknowledging that you have read and agreed to the conditions of this study. By completing the survey, you are consenting to participation in this study; and as such, your survey responses will be entered into a database and used for this study.

This letter is for you to keep. If you wish to maintain a copy of this letter for your records, please print it now.

APPENDIX J

Sample of Participant View of Question 1: Survivor Version



Under **ideal circumstances**, cancer doctors should address: physical concerns.

Never ○	Almost never ○	Less than half the time ○	Half the time ○	More than half the time ○	Almost always ○	Always ○

Under **ideal circumstances**, cancer doctors should address: emotional (psychological) concerns.

Never ○	Almost never ○	Less than half the time ○	Half the time ○	More than half the time ○	Almost always ○	Always ○

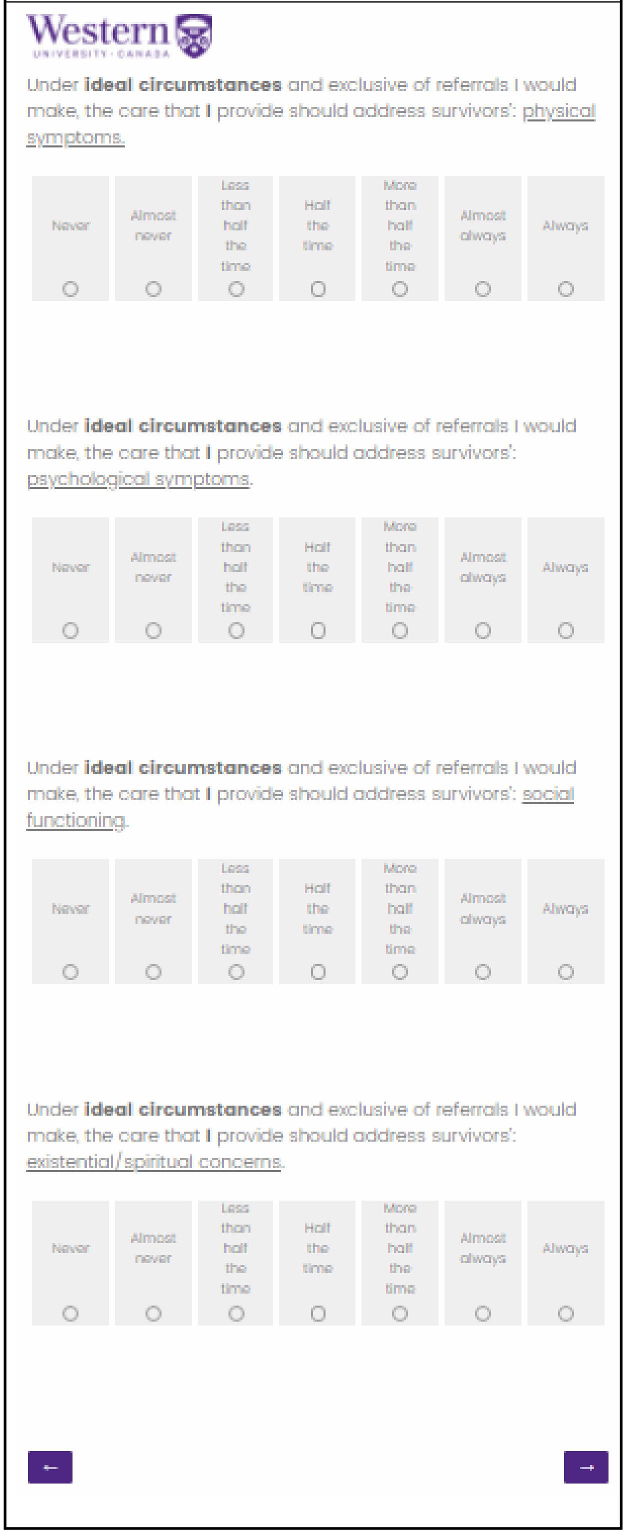
Under **ideal circumstances**, cancer doctors should address: social concerns.

Never ○	Almost never ○	Less than half the time ○	Half the time ○	More than half the time ○	Almost always ○	Always ○

Under **ideal circumstances**, cancer doctors should address: existential/spiritual concerns.

Never ○	Almost never ○	Less than half the time ○	Half the time ○	More than half the time ○	Almost always ○	Always ○

Sample of Participant View of Question 1: Physician Version



Under **ideal circumstances** and exclusive of referrals I would make, the care that **I** provide should address survivors': physical symptoms.

Never ○	Almost never ○	Less than half the time ○	Half the time ○	More than half the time ○	Almost always ○	Always ○

Under **ideal circumstances** and exclusive of referrals I would make, the care that **I** provide should address survivors': psychological symptoms.

Never ○	Almost never ○	Less than half the time ○	Half the time ○	More than half the time ○	Almost always ○	Always ○

Under **ideal circumstances** and exclusive of referrals I would make, the care that **I** provide should address survivors': social functioning.

Never ○	Almost never ○	Less than half the time ○	Half the time ○	More than half the time ○	Almost always ○	Always ○

Under **ideal circumstances** and exclusive of referrals I would make, the care that **I** provide should address survivors': existential/spiritual concerns.

Never ○	Almost never ○	Less than half the time ○	Half the time ○	More than half the time ○	Almost always ○	Always ○

APPENDIX K

Frequency Table for Survivor Group (SG) and Physician Group (PG) Responses to Individual Questions on the Questionnaire

Question	Never		Almost Never		Less than Half the Time		Half the Time		More than Half the Time		Almost Always		Always	
	SG	PG	SG	PG	SG	PG	SG	PG	SG	PG	SG	PG	SG	PG
1(i)	1		1		2		8		9	2	52	7	153	23
	(0.4)		(0.4)		(0.9)		(3.5)		(3.9)	(6.3)	(22.5)	(21.9)	(66.2)	(71.9)
1(ii)	2		3		10	2	12	2	11	6	53	8	134	14
	(0.9)		(1.3)		(4.3)	(6.3)	(5.2)	(6.3)	(4.8)	(18.8)	(22.9)	(25.0)	(58.0)	(43.8)
1(iii)	6		10	2	15	3	25	2	17	8	52	5	100	12
	(2.6)		(4.3)	(6.3)	(6.5)	(9.4)	(10.8)	(6.3)	(7.4)	(25.0)	(22.5)	(15.6)	(43.3)	(37.5)
1(iv)	34	1	43	6	12	7	23	3	18	2	48	5	46	7
	(14.7)	(3.1)	(18.6)	(18.8)	(5.2)	(21.9)	(10.0)	(9.4)	(7.8)	(6.3)	(20.8)	(15.6)	(19.9)	(21.9)
2(i)	4		11		6		19		22	3	49	7	113	21
	(1.7)		(4.8)		(2.6)		(8.2)		(9.5)	(9.4)	(21.2)	(21.9)	(48.9)	(65.6)
2(ii)	27		33		25	5	28	5	28	9	33	9	50	3
	(11.7)		(14.3)		(10.8)	(15.6)	(12.1)	(15.6)	(12.1)	(28.1)	(14.3)	(28.1)	(21.6)	(9.4)
2(iii)	50		48	3	22	9	23	4	17	5	30	7	34	3
	(21.6)		(20.8)	(9.4)	(9.5)	(28.1)	(10.0)	(12.5)	(7.4)	(15.6)	(13.0)	(21.9)	(14.7)	(9.4)
2(iv)	109	2	45	15	18	5	11	3	8	3	17	3	15	
	(47.2)	(6.3)	(19.5)	(46.9)	(7.8)	(15.6)	(4.8)	(9.4)	(3.5)	(9.4)	(7.4)	(9.4)	(6.5)	
3(i)	7		13		3		12		18		44	5	124	24
	(3.0)		(5.6)		(1.3)		(5.2)		(7.8)		(19.0)	(15.6)	(53.7)	(75.0)
3(ii)	34		47		12		23	3	12	2	33	13	62	12
	(14.7)		(20.3)		(5.2)		(10.0)	(9.4)	(5.2)	(6.3)	(14.3)	(40.6)	(26.8)	(37.5)
3(iii)	52	1	39		19		17	4	15	7	28	9	51	9
	(22.5)	(3.1)	(16.9)		(8.2)		(7.4)	(12.5)	(6.5)	(21.9)	(12.1)	(28.1)	(22.1)	(28.1)
3(iv)	108	1	45	3	10	6	13	4	8	4	11	6	24	6
	(46.8)	(3.1)	(19.5)	(9.4)	(4.3)	(18.8)	(5.6)	(12.5)	(3.5)	(12.5)	(4.8)	(18.8)	(10.4)	(18.8)
4(a)(i)	2		1		1		5		13	2	43	3	151	24
	(0.9)		(0.4)		(0.4)		(2.2)		(5.6)	(6.3)	(18.6)	(9.4)	(65.4)	(75.0)

4(b)(i)	5 (2.2)		11 (4.8)		7 (3.0)		13 (5.6)		15 (6.5)	1 (3.1)	59 (25.5)	12 (37.5)	107 (46.3)	16 (50.0)
4(a)(ii)	2 (0.9)		3 (1.3)		2 (0.9)		6 (2.6)		10 (4.3)	1 (3.1)	37 (16.0)	2 (6.3)	155 (67.1)	26 (81.3)
4(b)(ii)	6 (2.6)		19 (8.2)		9 (3.9)		10 (4.3)		16 (6.9)	2 (6.3)	42 (18.2)	8 (25.0)	114 (49.4)	19 (59.4)
5	9 (3.9)		11 (4.8)		13 (5.6)	1 (3.1)	11 (4.8)		21 (9.1)	1 (3.1)	53 (22.9)	3 (9.4)	98 (42.4)	24 (75.0)
6	80 (34.6)	24 (75.0)	49 (21.2)	3 (9.4)	20 (8.7)	1 (3.1)	18 (7.8)		15 (6.5)		22 (9.5)		11 (4.8)	1 (3.1)
7	124 (53.7)	16 (50.0)	31 (13.4)	11 (34.4)	7 (3.0)	1 3.1)	15 (6.5)		8 (3.5)	1 (3.1)	19 (8.2)		9 (3.9)	
8(a)		1 (3.1)	1 (0.4)		1 (0.4)		7 (3.0)		10 (4.3)	3 (9.4)	44 (19.0)	8 (25.0)	151 (65.4)	17 (53.1)
8(b)	12 (5.2)	1 (3.1)	18 (7.8)	2 (6.3)	16 (6.9)	1 (3.1)	18 (7.8)	1 (3.1)	18 (7.8)	6 (18.8)	47 (20.3)	8 (25.0)	86 (37.2)	10 (31.3)
9(a)	5 (2.2)	1 (3.1)	9 (3.9)	1 (3.1)	7 (3.0)		12 (5.2)		12 (5.2)	2 (6.3)	51 (22.1)	6 (18.8)	116 (50.2)	19 (59.4)
9(b)	19 (8.2)	1 (3.1)	34 (14.7)	2 (6.3)	21 (9.1)	2 (6.3)	20 (8.7)	2 (6.3)	19 (8.2)	6 (18.8)	36 (15.6)	9 (28.1)	62 (26.8)	7 (21.9)
10	2 (0.9)		2 (0.9)		4 (1.7)	1 (3.1)	8 (3.5)	1 (3.1)	12 (5.2)	2 (6.3)	34 (14.7)	12 (37.5)	151 (65.4)	13 (40.6)
11	7 (3.0)		21 (9.1)		11 (4.8)	2 (6.3)	21 (9.1)	1 (3.1)	18 (7.7)	6 (18.8)	51 (22.1)	11 (34.4)	82 (35.5)	8 (25.0)
12	9 (3.9)		18 (7.8)		13 (5.6)		21 (9.1)	1 (3.1)	15 (6.5)	4 (12.5)	51 (22.1)	14 (43.8)	85 (36.8)	10 (31.3)
13(a)			2 (0.9)		3 (1.3)		8 (3.5)		6 (2.6)	2 (6.3)	48 (20.8)	6 (18.8)	142 (61.5)	21 (65.6)
13(b)	9 (3.9)		20 (8.7)		18 (7.8)	2 (6.3)	19 (8.2)	1 (3.1)	15 (6.5)	4 (12.5)	51 (22.1)	14 (43.8)	78 (33.8)	8 (25.0)
14(a)	4 (1.7)		2 (0.9)		4 (1.7)		11 (4.8)	2 (6.3)	15 (6.5)	3 (9.4)	39 (16.9)	8 (25.0)	135 (58.4)	16 (50.0)

14(b)	13 (5.6)		17 (7.4)	1 (3.1)	6 (2.6)	2 (6.3)	11 (4.8)	2 (6.3)	17 (7.4)	5 (15.6)	43 (18.6)	12 (37.5)	102 (44.2)	7 (21.9)
15(a)	1 (0.4)		1 (0.4)	1 (3.1)	4 (1.7)		3 (1.3)		4 (1.7)		27 (11.7)	6 (18.8)	168 (72.1)	22 (68.8)
15(b)	9 (3.9)		16 (6.9)	1 (3.1)	14 (6.1)		18 (7.8)		20 (8.7)		48 (20.8)	15 (46.9)	84 (36.4)	13 (40.6)
16(a)	12 (5.2)	1 (3.1)	18 (7.8)	1 (3.1)	6 (2.6)	3 (9.4)	18 (7.8)		18 (7.8)	4 (12.5)	47 (20.3)	5 (15.6)	86 (37.2)	15 (46.9)
16(b)	30 (13.0)	1 (3.1)	37 (16.0)	4 (12.5)	13 (5.6)	3 (9.4)	23 (10.0)	5 (15.6)	18 (7.8)	6 (18.8)	33 (14.3)	6 (18.8)	51 (22.1)	4 (12.5)
17(a)	16 (6.9)	1 (3.1)	20 (8.7)	1 (3.1)	7 (3.0)		12 (5.2)		20 (8.7)	5 (15.6)	47 (20.3)	4 (12.5)	81 (35.1)	18 (56.3)
17(b)	35 (15.2)	1 (3.1)	34 (14.7)	1 (3.1)	9 (3.9)	2 (6.3)	24 (10.4)	3 (9.4)	20 (8.7)	5 (15.6)	35 (15.2)	9 (28.1)	44 (19.0)	8 (25.0)
18(a)							3 (1.3)		2 (0.9)		26 (11.3)	9 (28.1)	176 (76.2)	20 (62.5)
18(b)	2 (0.9)		4 (1.7)	2 (6.3)	1 (0.4)		6 (2.6)	1 (3.1)	3 (1.3)	3 (9.4)	40 (17.3)	10 (31.3)	151 (65.4)	12 (37.5)
19(a)			3 (1.3)	1 (3.1)		3 (9.4)	1 (0.4)	2 (6.3)	5 (2.2)	3 (9.4)	55 (23.8)	8 (25.0)	141 (61.0)	11 (34.4)
19(b)	78 (33.8)	2 (6.3)	7 (3.0)	9 (28.1)	6 (2.6)	8 (25.0)	8 (3.5)	4 (12.5)	6 (2.6)		23 (10.0)	4 (12.5)	79 (34.2)	1 (3.1)
20	6 (2.6)	1 (3.1)	4 (1.7)		3 (1.3)		13 (5.6)		17 (7.4)	8 (25.0)	36 (15.6)	13 (40.6)	128 (55.4)	7 (21.9)

Note: Parenthetical values represent percentages. Empty cells indicate a frequency of zero.

APPENDIX L

Wilcoxon Signed-Rank Test Results – Survivor Group

Questions		N	Mean Rank	Z	p-value
Q1(i) – Q2(i)	Negative Ranks	28[a]	36.70	-5.94	3.1621E-10
	Positive Ranks	79[b]	60.13		
	Ties	117[c]			
	Total	224			
Q1(ii) – Q2(ii)	Negative Ranks	9[d]	41.17	-10.36	1.9713E-35
	Positive Ranks	150[e]	82.33		
	Ties	64[f]			
	Total	223			
Q1(iii) – 2(iii)	Negative Ranks	17[g]	49.00	-10.33	8.1887E-33
	Positive Ranks	159[h]	92.72		
	Ties	47[i]			
	Total	223			
Q1(iv) – Q2(iv)	Negative Ranks	14[j]	41.96	-9.74	7.0081E-30
	Positive Ranks	139[k]	80.53		
	Ties	68[l]			
	Total	221			
Q4(a)(i) – Q4(b)(i)	Negative Ranks	18[m]	32.22	-6.17	2.6295E-11
	Positive Ranks	73[n]	49.40		
	Ties	125[o]			
	Total	216			
Q4(a)(ii) – Q4(b)(ii)	Negative Ranks	12[p]	34.21	-5.94	1.3113E-10
	Positive Ranks	69[q]	42.18		
	Ties	134[r]			
	Total	215			
Q8(a) – Q8(b)	Negative Ranks	7[s]	25.00	-8.44	9.5662E-24
	Positive Ranks	99[t]	55.52		
	Ties	107[u]			
	Total	213			
Q9(a) – Q9(b)	Negative Ranks	7[v]	35.07	-8.89	4.0086E-26
	Positive Ranks	112[w]	61.56		
	Ties	92[x]			
	Total	211			
Q13(a) – Q13(b)	Negative Ranks	11[y]	26.91	-8.39	1.6389E-22
	Positive Ranks	101[z]	59.72		
	Ties	97[aa]			
	Total	209			
Q14(a) – Q14(b)	Negative Ranks	20[ab]	28.05	-5.70	1.1535E-9
	Positive Ranks	66[ac]	48.18		
	Ties	123[ad]			
	Total	209			
	Negative Ranks	5[ae]	39.80	-8.64	3.5534E-25

Q15(a) – Q15(b)	Positive Ranks	106[af]	56.76		
	Ties	97[ag]			
	Total	208			
Q16(a) – Q16(b)	Negative Ranks	17[ah]	37.50	-7.06	1.1136E-14
	Positive Ranks	90[ai]	57.12		
	Ties	95[aj]			
	Total	202			
Q17(a) – Q17(b)	Negative Ranks	16[ak]	48.25	-6.86	1.0886E-13
	Positive Ranks	94[al]	56.73		
	Ties	91[am]			
	Total	201			
Q19(a) – Q19(b)	Negative Ranks	8[an]	11.63	-9.32	5.4778E-30
	Positive Ranks	111[ao]	63.49		
	Ties	86[ap]			
	Total	205			

Note: Z-scores based on negative ranks.

a. Q1i < Q2i
b. Q1i > Q2i
c. Q1i = Q2i
d. Q1ii < Q2ii
e. Q1ii > Q2ii
f. Q1ii = Q2ii
g. Q1iii < Q2iii
h. Q1iii > Q2iii
i. Q1iii = Q2iii
j. Q1iv < Q2iv
k. Q1iv > Q2iv
l. Q1iv = Q2iv
m. Q4ai < Q4bi
n. Q4ai > Q4bi
o. Q4ai = Q4bi
p. Q4aii < Q4bii
q. Q4aii > Q4bii
r. Q4aii = Q4bii
s. Q8a < Q8b
t. Q8a > Q8b
u. Q8a = Q8b
v. Q9a < Q9b
w. Q9a > Q9b
x. Q9a = Q9b
y. Q13a < Q13b
z. Q13a > Q13b
aa. Q13a = Q13b
ab. Q14a < Q14b
ac. Q14a > Q14b
ad. Q14a = Q14b
ae. Q15a < Q15b
af. Q15a > Q15b
ag. Q15a = Q15b
ah. Q16a < Q16b
ai. Q16a > Q16b
aj. Q16a = Q16b
ak. Q17a < Q17b
al. Q17a > Q17b
am. Q17a = Q17b
an. Q19a < Q19b
ao. Q19a > Q19b
ap. Q19a = Q19b

APPENDIX M

Wilcoxon Signed-Rank Test Results – Physician Group

Questions		N	Mean Rank	Z	p-value
Q1(i) – Q2(i)	Negative Ranks	3[a]	4.83	-0.51	0.79
	Positive Ranks	5[b]	4.30		
	Ties	23[c]			
	Total	31			
Q1(ii) – Q2(ii)	Negative Ranks	0[d]	.00	-3.98	0.000004
	Positive Ranks	19[e]	10.00		
	Ties	12[f]			
	Total	31			
Q1(iii) – 2(iii)	Negative Ranks	0[g]	.00	-3.81	0.000008
	Positive Ranks	18[h]	9.50		
	Ties	13[i]			
	Total	31			
Q1(iv) – Q2(iv)	Negative Ranks	2[j]	3.50	-3.45	0.000168
	Positive Ranks	16[k]	10.25		
	Ties	12[l]			
	Total	30			
Q4(a)(i) – Q4(b)(i)	Negative Ranks	1[m]	5.00	-2.33	0.039
	Positive Ranks	8[n]	5.00		
	Ties	20[o]			
	Total	29			
Q4(a)(ii) – Q4(b)(ii)	Negative Ranks	0[p]	.00	-2.53	0.016
	Positive Ranks	7[q]	4.00		
	Ties	22[r]			
	Total	29			
Q8(a) – Q8(b)	Negative Ranks	1[s]	6.50	-3.46	0.000198
	Positive Ranks	16[t]	9.16		
	Ties	12[u]			
	Total	29			
Q9(a) – Q9(b)	Negative Ranks	0[v]	.00	-3.86	0.000008
	Positive Ranks	18[w]	9.50		
	Ties	11[x]			
	Total	29			
Q13(a) – Q13(b)	Negative Ranks	0[y]	.00	-3.88	0.000015
	Positive Ranks	17[z]	9.00		
	Ties	12[aa]			
	Total	29			
Q14(a) – Q14(b)	Negative Ranks	1[ab]	10.00	-2.51	0.007
	Positive Ranks	12[ac]	6.75		
	Ties	16[ad]			
	Total	29			
	Negative Ranks	0[ae]	.00	-3.00	0.004

Q15(a) – Q15(b)	Positive Ranks	9[af]	5.00		
	Ties	20[ag]			
	Total	29			
Q16(a) – Q16(b)	Negative Ranks	1[ah]	4.50	-3.57	0.000069
	Positive Ranks	17[ai]	9.79		
	Ties	11[aj]			
	Total	29			
Q17(a) – Q17(b)	Negative Ranks	0[ak]	.00	-3.40	0.000122
	Positive Ranks	14[al]	7.50		
	Ties	15[am]			
	Total	29			
Q19(a) – Q19(b)	Negative Ranks	1[an]	17.00	-3.95	0.000011
	Positive Ranks	24[ao]	12.83		
	Ties	3[ap]			
	Total	28			

Note: Z-scores based on negative ranks.

a. Q1i < Q2i
b. Q1i > Q2i
c. Q1i = Q2i
d. Q1ii < Q2ii
e. Q1ii > Q2ii
f. Q1ii = Q2ii
g. Q1iii < Q2iii
h. Q1iii > Q2iii
i. Q1iii = Q2iii
j. Q1iv < Q2iv
k. Q1iv > Q2iv
l. Q1iv = Q2iv
m. Q4ai < Q4bi
n. Q4ai > Q4bi
o. Q4ai = Q4bi
p. Q4aii < Q4bii
q. Q4aii > Q4bii
r. Q4aii = Q4bii
s. Q8a < Q8b
t. Q8a > Q8b
u. Q8a = Q8b
v. Q9a < Q9b
w. Q9a > Q9b
x. Q9a = Q9b
y. Q13a < Q13b
z. Q13a > Q13b
aa. Q13a = Q13b
ab. Q14a < Q14b
ac. Q14a > Q14b
ad. Q14a = Q14b
ae. Q15a < Q15b
af. Q15a > Q15b
ag. Q15a = Q15b
ah. Q16a < Q16b
ai. Q16a > Q16b
aj. Q16a = Q16b
ak. Q17a < Q17b
al. Q17a > Q17b
am. Q17a = Q17b
an. Q19a < Q19b
ao. Q19a > Q19b
ap. Q19a = Q19b

CURRICULUM VITAE

CHELSEA MACDONALD, PH.D. (candidate)

EDUCATION

2017-2021(antic.)	**Doctor of Philosophy** (candidate), Health and Rehabilitation Sciences, Rehabilitation Science *Western University, London, Ontario*
2015-2017	**Master of Science,** Health and Rehabilitation Sciences, Rehabilitation Science *Western University, London, Ontario*
2011-2015	**Bachelor of Health Science,** Honors Specialization in Health Sciences *Western University, London, Ontario*

RESEARCH EXPERIENCE

2015-Present	**Research Associate,** *Laboratory for Well-Being and Quality of Life in Oncology, Western University*
2016	**Research Coordinator,** *Parkwood Institute*
2015	**Independent Study,** *Western University*

EMPLOYMENT

2021	**Covid-19 Vaccine Clinic Administrative Assistant,** *East Wellington Family Health Team, Rockwood, Ontario*
2011-2021	**Medical Office Administrative Assistant,** *East Wellington Family Health Team, Rockwood, Ontario*
	Teaching Assistant, *Western University, London, Ontario*
2015	· Health Issues in Childhood and Adolescence (HS 2700a)
2016	· Health Issues in Childhood and Adolescence (HS 2700a)
2018	· Exercise and Activity Modification (PT 9547L)
2018	· Health-Related Quality of Life (HS 3050a)
2019	· Palliative and End of Life Care (HS 4710b)
2019	· Health-Related Quality of Life (HS 3050a)
2020	· Movement in Context (OT 9532b)
2020	· Advanced Quantitative Research Methods (HS 9788a)

VOLUNTEER EXPERIENCE & COMMUNITY INVOLVEMENT

2017	**Volunteer for World Dwarf Games,** *University of Guelph, Guelph, ON*
2014	**Volunteer with Older Adults,** *Homewood Health Centre, Guelph, ON*
2014-2015	**Member of Alzheimer's Western Club,** *Western University, London, ON*

PUBLICATIONS

Doyle, P. C., & **MacDonald, C.** (2019). Well-being and quality of life in head and neck cancer. In P. C. Doyle (Ed.) *Clinical care and rehabilitation in head and neck cancer* (pp. 445-461). Springer Nature.

MacDonald, C., Theurer, J. A., Fung, K., Yoo, J., & Doyle, P. C. (2020). Resilience: An essential element in head and neck cancer survivorship and quality of life. *Supportive Care in Cancer*, 1-9. doi: 10.1007/s00520-020-05873-4

MacDonald, C., Theurer, J. A., & Doyle, P. C. (2021). "Cured" but not "healed": The application of principles of palliative care to cancer survivorship. *Social Science & Medicine*, *275*, 1-9. https://doi.org/10.1016/j.socscimed.2021.113802

MacDonald, C., & Ziebart, C. (2021). Person-centred Research: Bringing the bedside to the bench in rehabilitation science. *Rehab Ink*, *10*. https://rehabinkmag.com

SCHOLARLY ACTIVITIES

MacDonald, C. (2018, January). *Minimizing the Impact of Disease while Maximizing Quality of Life: An Exploration of Resilience in Head and Neck Cancer Survivors*, HRS Graduate Research Conference, Western University, London, ON.

MacDonald, C. (2018, May). *An Exploration of Resilience in Head and Neck Cancer Survivors.* Graduate and Medical Student Research Day, Department of Otolaryngology – Head and Neck Surgery Clinic, LHSC, London, ON.

Davis, E., Doyle, P. C., Lynch, M. J. P., **MacDonald, C.**, & Jovanovic, N. (2017, November). *Relationship of Postlaryngectomy Voice Disability with Age and Time Posttreatment,* ASHA Convention, Los Angeles, CA.

ACADEMIC HONORS, AWARDS & SCHOLARSHIPS

2015 - 2021	Western Graduate Research Scholarship
2013 - 2015	Dean's Honor List
2011	The Western Scholarship of Excellence