



Development of the Head and Neck Cancer Caregiving Task Inventory

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ABSTRACT

Purpose: Family caregivers provide vital support for patients with head and neck cancer (HNC), yet few studies have focused on HNC caregiving. Our objective was to develop and conduct initial validation of the HNC Caregiving Task Inventory, an instrument to characterize caregiving task burden in the HNC population.

Methods: This 5-phase instrument development project involved the conceptualization of caregiving task burden (Phase 1), initial instrument development (Phase 2), assessment of content validity through expert panel review (Phase 3), assessment of face validity through family caregiver review (Phase 4), and preliminary validation in a sample of 106 family caregivers (Phase 5).

Results: We identified 11 domains of the HNC caregiving role and caregiving tasks for each domain. In Phase 3, the experts deemed all tasks relevant to HNC family caregiving. No tasks were eliminated and 19 were added. In Phase 4, family caregiver feedback indicated that the tasks were comprehensive and relevant. Wording and formatting changes were made and one task was added. In Phase 5, we evaluated discrimination of responses to derive a final version comprised of 58 tasks in 11 domains. Kuder-Richardson values for domains with ≥ 3 items ranged from 0.65 to 0.94. Associations were generally high with the Caregiving Burden Scale, moderate with the Caregiver Reaction Assessment and Profile of Mood States-Short Form, and low or non-existent with the Preparedness Scale.

Conclusion: Convergent and divergent validity were supported. The HNC Caregiving Task Inventory can be used to evaluate caregiving task burden across the treatment trajectory and identify targets for intervention.

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1. Introduction

Head and neck cancer (HNC) therapy is associated with substantial symptom burden and profound functional deficits. Aggressive combined modality therapy has improved cure rates at the expense of dramatically increased acute and late side effects (Machtay et al., 2008; Murphy et al., 2007). Patients with HNC experience symptoms such as fatigue and pain which are common in the general oncologic population. In addition, patients experience unique problems such as swallowing dysfunction, airway impairment, difficulty speaking, and disfigurement. Both symptoms and functional deficits require complex and challenging supportive care regimens. Failure to adequately comply with these

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regimens may result in increased acute and late toxicity, increased resource utilization, and decreased survival (Cannon et al., 2014; Epstein et al., 2012; Kwong et al., 1997; Murphy et al., 2007; Murphy and Deng, 2015; Shinn et al., 2013). In the immediate postoperative setting or during and immediately after radiation with or without concurrent chemotherapy, patients may experience debility which impacts their capacity for self-care. Family caregiver support is therefore critical to ensure compliance with therapy and required supportive care regimens.

Family caregivers of patients with HNC take on a vital and challenging role, yet caregiving in this population remains understudied. In addition to caregiving tasks and activities common across cancer types, such as providing emotional support and managing symptoms, HNC caregivers may perform various technical procedures and tasks, such as tube feeding and tracheostomy care. They carry out caregiving activities in the context of functional changes unique to HNC, such as speech and swallowing difficulties that impact communication and lifestyle. In addition, some HNC caregivers must deal with relationship issues rooted in behaviours that presumably led to the cancer, such as nicotine and alcohol addiction.

Despite the challenging nature of HNC caregiving, only a few studies among the many conducted with cancer family caregivers have focused on this population. Most of these studies have investigated the psychological and emotional impact of caregiving on the caregiver. A literature review of psychological distress among HNC caregivers (Longacre et al., 2012) yielded only 11 studies, 3 of which were published more than 15 years ago. The literature review revealed elevated levels of emotional distress and anxiety among caregivers. More recently, Badr et al. (2014) also found high levels of caregiver distress, which increased over the first four weeks of radiotherapy. In a small prospective pilot study examining psychosocial functioning in HNC patient-caregiver dyads, Nightingale et al. (2014) found that quality of life (QOL) in both patients and caregivers decreased during treatment. Only a few studies have focused on caregiver burden (Chen et al., 2009; Nightingale et al., 2014, 2016).

A noteworthy feature of the existing HNC caregiving literature is the dearth of studies that focus on the tasks caregivers perform. The prevalence of individual caregiving tasks, the overall accumulation of multiple tasks, and caregivers' subjective experience of caregiving tasks during and after HNC treatment have received little attention. Most studies that have focused on caregiving tasks in the cancer population (Bakas et al., 2001; Carey et al., 1991; Chan and Chang, 1999; Chen et al., 2007; Lund et al., 2014; van Ryn et al., 2011) are not specific to HNC. One recent study did examine caregiving tasks in the HNC population, but the researchers noted the need for a validated measure of HNC-specific task burden (Balfe et al., 2016). Other studies that included tasks specifically relevant to HNC caregivers often centre only on technical procedures, such as managing feeding tubes or tracheostomy tubes, rather than the full scope of caregiving tasks. For example, Silver et al. (2004) investigated enteral nutrition among 30 older adults, 23 of whom had HNC, and their family caregivers. They identified 34 home enteral nutrition caregiving tasks and evaluated whether the caregivers performed the tasks, were trained for the tasks, or needed training. They found that caregivers provided, on average, 62 h of caregiving per week and performed an average of 20 caregiving tasks daily. An integrated literature review on the impact of tracheostomy or laryngectomy on spousal and caregiver relationships (Krouse et al., 2004) demonstrated a dearth of studies on the subject. Most of the subsequent research in this area is with parents of children with tracheostomies (Vanker et al., 2012; Kun et al., 2010) or adults with chronic respiratory failure (Barbano et al., 2009). These studies provide insights into the complex and

intensive nature of caregiving tasks and activities in various clinical populations with tracheostomies and feeding tubes, but do not provide a comprehensive picture of the caregiving role as a whole in the HNC population. Clearly, further research is needed to better understand the full range of HNC caregiving tasks across the treatment trajectory and the impact of caregiving task burden on patient and caregiver outcomes.

A significant barrier to research progress in this area is the lack of validated instruments that comprehensively characterize caregiving tasks in the HNC population and the burden such tasks may entail. A few instruments have been used to measure caregiving burden in the general cancer population, such as the Caregiver Reaction Assessment (CRA) (Given et al., 1992), the Caregiver Strain Index (Robinson, 1983), and the Burden Interview (Zarit et al., 1980), but they do not address specific tasks associated with the caregiving role in the HNC population. The Caregiving Burden Scale (CBS) (Carey et al., 1991; Oberst et al., 1989) does assess tasks associated with caregiving, but not with the specificity needed for assessment in the HNC population. To our knowledge, no instrument exists that allows researchers to comprehensively characterize the complexity of HNC caregiving tasks or task burden.

In conclusion, research on caregiving tasks in the HNC population requires more attention. A better understanding of the HNC caregiving role and required tasks will enable researchers and clinicians to develop and implement educational and supportive interventions to minimize caregiving task burden, thereby limiting adverse effects on caregiver health, emotional status, and quality of life. The purpose of this research was to develop, refine and provide preliminary validation of a new instrument titled the Head and Neck Cancer Caregiving Task Inventory, hereafter referred to as the "CTI." Our overarching goal was to develop a highly pragmatic and easy to use tool that can be used to comprehensively characterize HNC caregiving tasks and the burden they may entail across the treatment trajectory and capture caregiving needs that are amenable to intervention.

2. Development of the CTI

This instrument development project was undertaken by physicians and nurses who are HNC clinicians and supportive care researchers. The initial conceptualization and instrument development were based on existing literature (summarized above), review of common caregiving instruments, clinical experience, and reflections on the group members' previous research. The project was conducted in 5 phases: 1) conceptualization of the phenomenon of caregiving task burden, 2) initial instrument development, including identification of domains of the HNC caregiving role, the tasks performed in each domain, and a response format that would capture both objective and subjective dimensions of task burden; 3) assessment of content validity through expert panel review; 4) assessment of face validity through family caregiver review, and 5) preliminary validation in a sample of HNC family caregiver-patient dyads using a cross-sectional survey design. Institutional Review Board approval was obtained from the institutions where the project was conducted. All participants in each Phase provided written informed consent.

2.1. Phase 1: conceptualization of caregiving task burden

Family caregiving was conceptualized as a complex role that involves multiple broad domains of activity, each consisting of specific tasks. These tasks in and of themselves may or may not be burdensome. The development of the CTI was based on the assumption that identification of caregiving task burden, when it exists, is important in order to direct supportive caregiver

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