A2.1: Development of a Lymphedema Symptom Survey in Head and Neck Cancer Patients

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Abstract:
Introduction: Because cancer treatment disrupts lymphatic structures, damages soft tissue leading to scar tissue formation and fibrosis, and further affects lymphatic function, head and neck cancer (HNC) patients may be at risk for developing secondary lymphedema. HNC patients
may develop secondary lymphedema externally (e.g., submental area) and internally (e.g., laryngeal and pharyngeal). It not only influences patients’ most visible body areas (e.g., face and neck), but it also influences basic functions (e.g., breathing and swallowing). HNC patients with secondary lymphedema may have numerous symptom management issues. Currently, there is no instrument available to assess secondary lymphedema-related symptoms in HNC patients. The purpose of this study was to develop a symptom survey for HNC patients with secondary lymphedema.

**Method(s):** The study developed the Lymphedema Symptom Intensity & Distress Survey-Head & Neck (LSIDS-HN) through the two phases. During phase one, the expert panel and 18 HNC patients with secondary lymphedema reviewed the initial item pool developed by the researcher via literature review. The initial item pool (36-item) was revised into an initial symptom checklist (55-item) according to the expert panel’s suggestions. The initial symptom checklist (55-item) was revised into LSIDS-HN (67-item) according to 18 HNC patients’ symptomatic experiences. During phase two, 30 additional HNC patients with secondary lymphedema completed the LSIDS-HN.

**Results:** Through the two phases, the final symptom survey for HNC patients with secondary lymphedema was constructed. The study also found some symptoms that have not been reported in the HNC patients, such as limited head/neck movement.

**Discussion & Conclusions:** The study found the predominant symptoms related to secondary lymphedema in HNC patients. Preliminary results show that the LSIDS-HN addressed the symptoms of external and internal lymphedema in HNC patients. The content validity and face validity of the LSIDS-HN was supported by the expert panel during developing the LSIDS-HN. Implications for further research: 1) recruit more participants to further revise the LSIDS-HN; 2) correct item wording issues; 3) reduce number of redundant items; 4) shorten the LSIDS-HN; and 5) add psychometric testing.

**Abstract History:**
This abstract has not been presented or accepted for presentation in whole or in part at the SNRS or other scientific meeting.

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