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Review

Assessment and measurement of head and neck lymphedema: State-of-the-science and future directions ☆

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SUMMARY

Currently, assessment and measurement of lymphedema in head and neck cancer patients is difficult. The aims of this report are to examine the current state of science regarding available measurement of head and neck lymphedema, to identify gaps in clinical evaluation of head and neck lymphedema, and to propose future research directions for advancing the assessment of head and neck lymphedema. The authors conducted a comprehensive literature review based on PubMed, CINAHL, Cochrane database, EMBASE, and PsycINFO from 1989 to 2014. Primary search terms included *head and/or neck cancer, head and/or neck and/or face, lymphedema, edema, swelling, fibrosis, measurement, assessment,* and *evaluation*. The authors also reviewed information from the Oncology Nursing Society, National Lymphedema Network, National Cancer Institute, American Cancer Society, and other related healthcare professional association web sites. Based on the nature/characteristics of measurement reported in the literature, methods for assessment of head and neck lymphedema can be categorized into: (1) patient-reported outcome (PRO) measures (e.g., symptom tool), (2) clinician-reported outcome (CRO) measures based on clinical grading criteria via a clinical exam (external lymphedema evaluation by physical examination and internal edema examination via endoscopy), and (3) technical capacity/measurement techniques (e.g., imaging techniques). Although a number of measures have been reported in the literature, clinically useful PRO and CRO measures, and reliable and sensitive measurement techniques need to be validated to address gaps in assessment of head and neck lymphedema, and to be easily used in early identification of lymphedema and assessment of treatment/interventional effects.

Introduction

It is estimated that 55,070 Americans will have developed head and neck cancer in 2014 and 12,000 patients will die of their disease [1,2]. For patients with locally advanced head and neck cancer, aggressive multi-modality therapy has been shown to improve local control and survival, but at the expense of significant acute and late treatment effects [3]. Recently, there has been an epidemic of human papillomavirus (HPV) associated oral cancers which occur in younger patients and have improved outcomes compared to cancers resulting from the traditional risk factors of smoking and alcohol abuse [4–9]. As a result of improved treatment and changing epidemiology, an increased number of head and neck cancer survivors are destined to live for protracted periods of time with the late effects from cancer and its therapy [8–11]. Aggressive identification and treatment of acute and late effects is critical to ensure optimal function and quality of life. A common, but under-recognized, detrimental effect in this population is secondary lymphedema [10].

The head and neck contains an extensive network of lymphatic channels and over 300 lymph nodes (1/3 of lymph nodes within the body) [12,13]. Cancer, surgery, and radiation may disrupt lymphatic structures, blocking lymph flow thus resulting in soft tissue edema [14–20]. In addition, muscle contraction and compression of soft tissues through movement facilitate lymph flow [12,13]. Damage to these structures due to surgery and/or radiation therapy results in decreased movement further impeding lymph flow [12]. Lymphatic dysfunction occurs when either lymphatic structures or surrounding soft tissues are damaged by head and neck cancer and its treatment limiting the lymphatic system ability to transport the lymph volume delivered to tissues. Thus, head and

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neck cancer survivors are at high risk for developing lymphedema [21,22]. When lymphedema first develops, the lymphatic system may be able to repair or compensate for lymphatic damage resulting in reduction or resolution of visible tissue swelling [12,23]. If damage is severe or no intervention is undertaken, accumulated protein-rich lymph fluid can trigger a chronic inflammatory response [12,23]. This results in a fibrosclerotic process in which fibro or fatty tissues may develop [12,23].

Head and neck cancer-related lymphedema can be categorized as involving external structures of face and neck (e.g., facial and submental tissues), internal structures of upper aero-digestive tract (e.g., tongue and epiglottis) or a combination of both [10,22]. Involvement of external sites may lead to symptoms such as skin tightness, pain and body image issues [24,25]. Involvement of internal structures results in functional deficits such as difficulty chewing, swallowing, and speaking [22,25]. A cross-sectional study found that 75% of head and neck cancer patients >3 months post-treatment had secondary lymphedema [22]. Lymphedema severity was associated with substantial symptom burden, functional impairments, and decreased quality of life [25]. Available evidence from lymphedema in other anatomical sites (e.g., upper or lower extremity) supports that early identification of lymphedema followed by timely lymphedema therapy may result in regression of swelling and prevention of late fibrosis [12,13,15,26–28]. However, without early identification and timely therapy, head and neck soft tissues affected by lymphedema can become fibrotic and contracted [12]. Patients with fibrosis and contracture may have substantial symptom burden and functional deficits [25,29]. Therefore, it is critically important to assess lymphedema as a part of routine clinical evaluation at head and neck cancer patients' follow-up visits.

Currently, assessment and measurement of lymphedema in head and neck cancer patients is difficult [10,30]. This literature review aims to examine the current state of science regarding available measurement of head and neck lymphedema to identify gaps and needs of clinical evaluation of head and neck lymphedema, and to propose future research directions for advancing the assessment of head and neck lymphedema.

Methods

The authors conducted a comprehensive and systematic literature review based on PubMed, CINAHL, Cochrane database, EMBASE, and PsycINFO from 1989–2014. Primary search terms included *head and/or neck cancer, head and/or neck and/or face, lymphedema, edema, swelling, fibrosis, measurement, assessment, instrument,* and *evaluation*. The literature search generated 46 citations that were pertinent to the topic and provided the foundation for this review. The authors also reviewed information from the Oncology Nursing Society, National Lymphedema Network, National Cancer Institute, American Cancer Society, and other related healthcare professional association web sites. Based on the nature/characteristics of measurement reported in the literature, methods for assessment of head and neck lymphedema can be categorized into: (1) patient-reported outcome (PRO) measures (e.g., self-report symptom), (2) clinician-reported outcome (CRO) measures based on clinical grading criteria via a clinical exam (external lymphedema evaluation by physical examination and internal edema examination via endoscopy) [10,22], and (3) technical capacity/measurement techniques (e.g., imaging techniques, tape measurement, and digital photographs).

Results

Patient-reported outcome (PRO) measures

Incorporating the patients' perspective into clinical practice is essential to fully capture observable and unobservable symptoms (e.g., sensations) and functional impacts of lymphedema. However, patient-reported outcome measures for lymphedema assessment in head and neck cancer patients has been vastly ignored [10,31]. Although a number of PRO measures capture symptom burden in head and neck cancer patients they focus primarily on general symptoms and functions and fail to address important and unique symptoms associated with lymphedema [19,25,32–35]. For instance, a review of the literature noted that several symptom tools (e.g., M.D. Anderson symptom inventory – head and neck module; Vanderbilt Head and Neck Symptom Survey; Head and Neck Distress Scale, Head and Neck Symptom Checklist; National Comprehensive Cancer Network – Functional Assessment of Cancer Therapy – Head and Neck Cancer Symptom Index-22, NFHNSI-22) have been developed to evaluate symptoms related to head and neck cancer and its treatment. However, none of them have incorporated a symptom domain related to head and neck lymphedema. Studies indicate that lymphedema is associated with a broad range of physical and psychological symptoms and functional deficits, some of which are unique to this physiological phenomenon [31]. For example, patients may describe soft tissue tightness within areas of swelling [31]. Because of the high visibility, external head and neck lymphedema may result in psychological symptoms (e.g., body image issues, social isolation) [19,25,31]. Also, patients may complain of functional impairments such as decreased range of motion in the neck and shoulders [10].

A recent study reported preliminary development of the tool, Lymphedema Symptom Intensity & Distress Survey-Head & Neck (LSIDS-H&N), which is the only known existing PRO measure directed specifically toward head and neck lymphedema [31]. This 65-item symptom tool was developed via a rigorous instrument development process. The article reported that (1) the LSIDS-H&N was feasible to administer, readable, and easy to use; (2) content validity was supported by expert panel review; and (3) an initial test indicated that the tool captured critical and unique symptoms related to lymphedema [31]. The authors concluded that further psychometric testing of the tool in larger sample size studies was needed [31].

Clinician-reported outcome (CRO) measures

CRO measures for external head and neck lymphedema

Several CRO measures (clinical grading criteria/tools) have been developed to evaluate external skin/soft tissue lymphedema. These grading criteria can be categorized as either general (applying to all body parts) or specific (pertaining to only the head and neck region). The most commonly used general scale for grading lymphedema is the Stages of Lymphedema (Földi's Scale) [12]; the most common head and neck specific scales for grading head/neck lymphedema are the Common Terminology Criteria for Adverse Events (CTCAE) [36] and the American Cancer Society (ACS) Scale [37]. A recent study comparing these scales found the following: (1) none of these measures have been validated; (2) each failed to capture important features of external lymphedema; and (3) none capture edema and fibrosis that coexist in some patients [30]. The M.D. Anderson Cancer Center (MDACC) Head and Neck Lymphedema Rating Scale was developed to address these gaps; however, validity and reliability data are not available [24]. Thus, the current evidence supports that available tools failed to capture the important characteristics of external lymphedema in head and neck cancer patients and are not sufficiently validated to recommend continued clinical use [30]. A valid, reliable, clinically useful tool that captures all the important features of external lymphedema in head and neck cancer is needed.

A recent publication reported the development and preliminary testing of a CRO for assessment of head and neck