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# A mixed methods examination of distress and person-centred experience of head and neck lymphoedema

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ABSTRACT

*Purpose:* This study aimed to examine the course and nature of distress and quality of life (QoL) during and after head and neck lymphoedema (HNL) treatment in people who developed HNL following treatment for head and neck cancer (HNC).

*Methods:* This study (n = 10) used a mixed method explanatory design to explore distress associated with HNL. Component 1 used a prospective repeated measures design to examine distress during a 22-week HNL program. Component 2 used a qualitative interview approach to understand the patient experience of distress after completion of HNL treatment.

*Results:* During the HNL program distress associated with HNL significantly reduced from baseline to week 6 ($p = 0.015$), and baseline to week 22 ($p = 0.007$). There were no significant differences in QoL, body image or fear of cancer progression over time. Self-reported presence of HNL significantly reduced from baseline to week 6 ($p = 0.02$), week 6 to week 22 ($p = 0.026$), and from baseline to week 22 ($p = 0.001$).

Qualitative interviews using thematic analysis following HNL treatment, revealed 6 major themes associated with the experiences of distress related to HNL – psychological impact; physical appearance and pattern/timing; experience of receiving treatment; day to day impact; supports that helped manage distress; and adjustment to a new normal.

*Conclusions:* This study found that distress associated with cancer treatment-related HNL may reduce with the delivery of a HNL program. Interview data following completion of the HNL treatment identified several themes related to HNL and its relationship with distress, function and day-to-day life.

Clinical Trial registration: HREC/12/QPAH/295.

## Introduction

The incidence of distress in the general cancer population ranges from 29 to 58% [1–3]. Distress is linked to increased rates of hospitalisation, and poorer satisfaction and compliance with treatment, poorer quality of life (QoL) and survival [4,5]. The US National Comprehensive Cancer Network (NCCN) [6] has endorsed distress as the "sixth vital sign", recommending routine distress screening during times of vulnerability along the cancer trajectory [7]. The NCCN [6] notes that patients with social issues, uncontrolled symptoms or communication barriers are at increased risk for clinically-significant distress requiring psychosocial intervention. These risk factors are common for patients with head and neck cancer (HNC).

The range and severity of side-effects experienced by patients treated for HNC are associated with high levels of distress [1]. Mucositis, impaired swallowing, xerostomia, taste alterations, and lymphoedema have been identified as persistent sequelae of HNC [8] potentially leading to higher levels of distress. These distress-inducing side-effects are associated with poorer QoL and reductions in psychosocial functioning [9]. One less-researched factor in the HNC population is the impact of head and neck lymphoedema (HNL), which affects up to 75% of survivors ($n = 81$) [10]. Following curative treatment

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with either surgery and/or (chemo)radiotherapy, HNL can develop as a result of disruption to the lymphatic system [11]. Swelling may commence during active treatment, or in the survivorship phase [12] and its development is associated with a higher symptom burden [13]. HNL has been previously found to negatively affect QoL [14] and functions of breathing and swallowing [10]. While rates of distress in the HNC population range from 20 to 49% up to 5 years post-treatment [1,15,16] there has been minimal investigation into the distress associated with HNL. In a study examining a heterogeneous cohort of people post-treatment with HNC ($n$ = 103), 47% had external lymphoedema [13], however no increase in anxiety or depression was reported in the group. A qualitative study with HNC survivors ($n$ = 10), [17] found that HNL had a negative impact on body image, but distress was not reported. Given the documented impact of HNL on QoL, and the high incidence of distress experienced by HNC survivors, the relationship between HNL, distress and QoL warrants deeper exploration.

This study aims to:

1. Examine distress and QoL in people undertaking a 22-week HNL treatment program following treatment for HNC
2. Explore the person's experience of HNL and distress and the impact on day–to-day functioning following completion of HNL treatment.

## Material and methods

### *Design*

This study used a mixed method explanatory design which employed a qualitative approach to explain the findings of quantitative data [18]. Component 1 used a prospective repeated measures design to examine distress and QoL. Component 2 used qualitative interviews to explore the patient experience of distress associated with HNL as identified in Component 1. This study was conducted at a single, quaternary hospital in Australia. Ethical clearance was received from the local Ethics Committee. All participants provided informed consent.

### *Participants*

For Component 1, participants were identified via treating HNC consultant referred to the hospital Lymphoedema Service. Participants were assessed by the Lymphoedema consultant as having established HNL, and eligible to participate if : (1) ≥18 years of age; (2) diagnosis of HNC, and 2 months post active cancer treatment; (3) minimum, soft visible reversible oedema of the neck or submental region; (4) life expectancy > 12 months; and (5) not pregnant. Consecutive participants meeting the criteria were offered participation in the study over a 12-month recruitment period from June 2014 to June 2015. Following completion of Component 1, participants were offered to participate in Component 2 of the study.

Participants recruited to this study were involved in a concurrent study examining physical outcomes of a 22-week HNL treatment program [19]. This study provided therapist-directed treatment in addition to self-management of HNL. Treatment details and results of this study have been reported elsewhere [19].

### *Materials*

The following measures were completed at baseline, week 6, and week 22 of a 22-week HNL treatment program:

(i) Distress: The Distress Thermometer (DT) [6,26] is a widely-used tool which was modified to incorporate a specific question about distress related to lymphoedema: "On a scale of 0–10 with 0 being no distress at all and 10 being the worst distress you can imagine, describe your lymphoedema over the last week". A score greater than 4 is a flag for intervention for distress [6,26].

(ii) QoL: was assessed using the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire: Head and Neck 43 (EORTC QLQ-H&N43) [20] – a 73-item questionnaire, developed from the validated EORTC-QLQ H&N35 [21], which explores symptoms associated with HNC and QoL. At the time of study design this was the only validated HNC-specific QoL assessment that included a question relating to lymphoedema [20]. Higher scores (0–100), reflect higher degree of symptom burden associated with HNC, while a higher QoL score (0–100) reflects a higher QoL. Scoring was completed as per recommendations of Feyers [22]. Linear transformation was applied to obtain a score out of 0–100, from the raw score (range 0–4) for the symptom scale, and raw score (0–7) for the QoL scale. Based on previous reports of impact of HNL [13,14], single-items relating to QoL, body image, fear of progression and lymphoedema were included for analysis.

A single semi-structured interview was conducted 10–22 months after completion of the 22-week HNL treatment, once the data from Component 1 was analysed. An eight-question interview guide was designed based on current literature and expert clinical knowledge (Appendix A). The qualitative interview was designed to explore the participant's experience of distress in relation to their HNL [23]. The proposed questions were reviewed by three lymphoedema therapists and consensus reached regarding the appropriateness in meeting aims of the study. Interviews were conducted by the principal investigator (JN), an advanced occupational therapist/lymphoedema therapist with extensive clinical experience working with patients with HNC/HNL. The interviewer was known to the participants from the consent and assessment processes but had not conducted any treatment to optimise frank disclosure [24].

Participants were offered the option to complete the interview face-to-face or via phone and provided with an interview guide one week prior to aid reflection of their experience prior to their interview. Participants who completed a face-to-face interview were shown a photo of themselves from their baseline assessment, and those who completed phone reviews were asked to reflect on their appearance when first referred to the lymphoedema clinic. Interviews were audio-recorded and transcribed verbatim for analysis. Participant checking was conducted for all interviews. Participants were sent a follow-up survey of proposed themes and asked to rate agreement/neutral/disagreement to the themes.

### *Data analysis*

Participant characteristics were summarised using descriptive statistics. For Component 1, analysis of the DT and EORTC QLQ- H&N43 data over time was undertaken using the Freidman test, with pairwise comparisons and Bonferroni correction for multiple comparisons. Post hoc tests were completed using Wilcoxon Signed Rank test. All analyses were conducted using SPSS version 22.

For Component 2, thematic analysis was conducted by the principal investigator (JN) and three other HNC specialists who were not involved in the interview process. Analysis of the interviews was conducted using the model proposed by Braun and Clarke [25] which has been used previously in the HNC cohort [9]. This model uses a 6-phase inductive approach which looks at patterns and develops themes [25]. The phases include: 1. familiarity with data; 2. generating initial codes; 3. searching the themes; 4. reviewing the themes; 5. defining and naming themes and; 6. producing the report [25].

## Results

### *Participants*

Eleven eligible participants presented to the clinic during the study time frame. One potential participant declined, ten participants were