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## Using the patients concerns inventory for distress screening in post-treatment head and neck cancer survivors

Naseem Ghazali <sup>a, b, \*</sup>, Brenda Roe <sup>c</sup>, Derek Lowe <sup>b, c</sup>, Sank Tandon <sup>d</sup>, Terry Jones <sup>a, d</sup>, Richard Shaw <sup>a, b</sup>, Janet Risk <sup>a</sup>, Simon N. Rogers <sup>b, c</sup>

<sup>a</sup> Department of Molecular & Clinical Cancer Medicine, Institute of Translational Medicine, University of Liverpool, Liverpool, UK

<sup>b</sup> Regional Maxillofacial Unit, Aintree University Hospitals NHS Trust, Liverpool, UK

<sup>c</sup> Evidence-Based Practice Research Centre, Faculty of Health & Social Care, Edge Hill University, Ormskirk, UK

<sup>d</sup> ENT Unit, Aintree University Hospitals NHS Trust, Liverpool, UK

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### ABSTRACT

**Purpose:** Cancer patients can experience significant distress during their cancer trajectory, which impacts upon clinical outcomes and quality of life. Screening for distress using holistic assessments can help identify and address unmet concerns/needs. The purpose of this study was to evaluate the relationship between concerns and distress, and the impact of distress on clinic outcomes in post-treatment head and neck cancer patients.

**Methods:** 170 patients attending routine follow-up clinics were prospectively recruited. All patients completed the Patient Concerns Inventory (PCI) and the Distress thermometer (DT) at preconsultation. **Results:** The rate of significant distress (i.e. DT cut-off score  $\geq 4$ ) was 36% (62/170). Significantly distressed patients selected more items overall than patients without distress (mean, median (QR) of 5.40, 5 (2–8) vs 2.61, 2 (0–4),  $p < 0.001$ ). Significant distress was most strongly associated with Physical and Functional well-being ( $p < 0.001$ ) and Psychological and Emotional well-being domains ( $p = 0.001$ ). On balance, very little difference was noted between cut-off points of either  $\geq 4$  or  $\geq 5$  PCI items of concern selected. Both cut-off points demonstrated an acceptable level of sensitivity, specificity and predictive values for significant distress. Consultations were longer with increasing numbers of concerns.

**Conclusions:** Just over one-third of patients are significantly distressed. They were more likely to express a higher number of concerns. A cutoff score  $\geq 4$  or  $\geq 5$  PCI items selected can identify those at risk of significant distress. Concerns causing significant distress were related to emotional/psychological issues and physical function.

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## 1. Introduction

Distress is commonly experienced during the cancer trajectory and significantly impacts upon cancer care and its outcomes, justifying calls for its screening (Carlson et al., 2012). Screening for distress is regarded as the primary step in managing cancer-related distress. This process involves identifying contributing causes, ranging from common practical, physical, and psychological problems/concerns by way of holistic assessments (Carlson et al., 2012;

Richardson et al., 2007), and developing individualized supportive care plan to meet these issues. It is suggested that the number and severity of cancer patients' concerns is associated with development of distress (Maguire, 2002; Chaturvedi et al., 1996).

There is an accumulating body of work surrounding patient's concerns in the head and neck cancer (HNC) population based on the Patients Concerns Inventory (PCI). The PCI is a holistic tool that helps HNC patients disclose items of concern during routine clinical consultations, and also assists patients in indicating professionals with whom they wish to see or be referred to (Rogers et al., 2009). The PCI has been successfully rolled out as a sign-posting tool for supportive care across a regional HNC network in the United Kingdom.

\* Corresponding author. Regional Maxillofacial Unit, University Hospital Aintree, Lower Lane, Liverpool, L9 7AL, UK. Fax: +44 151 529 5288.

E-mail address: [naseemghazali@doctors.org.uk](mailto:naseemghazali@doctors.org.uk) (N. Ghazali).

There is a wide range of reported HNC patient concerns (Rogers et al., 2010). Preliminary analysis of this dataset identified the most common patient concerns were fear of recurrence (FoR, 37%), dental health/teeth (27%), chewing (24%), pain in head/neck (20%), fatigue/tiredness (19%), saliva (18%) and swallowing (18%) (Rogers et al., 2009). When the PCI is used in conjunction with other measures, it is possible to identify individuals with significant problems i.e. requiring attention/support in specific areas. For example, those with significant problems from FoR can be identified when the PCI is used in conjunction with the FoR questionnaire (Rogers et al., 2010; Ghazali et al., 2013). Also, patients with significant problems in areas of mood and anxiety (Kanatas et al., 2012), pain (Rogers et al., 2012), appearance (Flexen et al., 2012), and speech and swallowing (Ghazali et al., 2012a) can be identified when the PCI is used in conjunction with the University of Washington Quality of Life version 4 (UWQOL).

Different factors have been related to the expression of specific concerns. For example, predictors of those experiencing significant FoR concerns over time (35%) were related to patient-related characteristics (i.e. female gender, those experiencing anxiety and mood disorders) rather than clinicopathological characteristics (Ghazali et al., 2013). On the other hand, clinicopathological factors were important predictors for those citing pain concerns with significant problems (i.e. received radiotherapy (RT), age < 65 years) (Rogers et al., 2012) and in those citing appearance concerns with significant appearance issues (i.e. oropharyngeal tumours, large primary tumours, and age <65 years) (Flexen et al., 2012). However, the relationship between patient concerns and distress in HNC has not been explored.

The Distress thermometer (DT) is a rapid, validated screening instrument for cancer-related distress for patients with various cancer types in America (National Comprehensive Cancer Network, 2005) and the United Kingdom (Gessler et al., 2008). However, there was paucity in the literature regarding patient concerns related to distress and the use of DT in distress screening in HNC population. A DT score of  $\geq 5$  was originally recommended as denoting significant distress necessitating psychosocial referral (National Comprehensive Cancer Network, 2005) but a DT score of  $\geq 4$  has been shown to correlate with optimal sensitivity and specificity to the Hospital Anxiety Depression Scale (HADS) in various cross cultural studies in identifying significant distress (Jacobsen et al., 2005; Ozalp et al., 2007; Shim et al., 2006; Grassi et al., 2013). Recently, we found that a DT cut-off score of  $\geq 4$  was effective in screening for significant anxiety and mood problems against the UWQOL in disease-free, post-treatment HNC survivors attending out-patient clinics (Ghazali et al., 2017), where just over one-third of HNC patients (36%, 94/261) reported significant distress.

The primary objective of this study was to determine the relationship between distress and patient concerns in a cohort of disease-free, post-treatment HNC patients attending routine follow-up. A specific objective was to evaluate the relationship between the numbers of concerns with significant distress, so as to identify suitable cut-off point based on the number of items selected on the PCI that could be used as a simple indicator for clinicians in risk assessing significant distress in clinic. The secondary aims were to determine the significance of distress on outcomes of clinic consultations in relation to patient's concerns.

## 2. Methods

This study obtained research ethics approval from the North West Research ethics committee (study reference: 11/H1002/7). The study was conducted in two HNC outpatient clinics within the Merseyside region.

### 2.1. Subjects

Study participants comprised surgeons and patients. Four consultant surgeons comprising two Oral & Maxillofacial surgeons and two Otolaryngology, Head and Neck surgeons, without prior experience of using the PCI were invited to participate in this study and formed a convenience sample. The inclusion criteria for patient recruitment were disease-free HNC survivors who had completed primary treatment of at least 6 weeks and had not used the PCI before. The exclusion criteria included HNC patients who were at pre-treatment or palliative stage of survivorship. In addition, patients who were unable to speak or read English were excluded.

### 2.2. Measures

#### 2.2.1. Distress thermometer (DT)

The DT is a single item self-report measure of distress. This instrument is scaled from 0 (no distress) to 10 (severe distress) in a thermometer layout to rate the level of distress experienced. A DT cut-off score of  $\geq 4$  correlates with optimal sensitivity and specificity to the HADS in various cross cultural studies (Jacobsen et al., 2005; Ozalp et al., 2007; Shim et al., 2006; Grassi et al., 2013), and is effective in identifying significant anxiety and mood problems with good sensitivity and specificity to the UWQOL in HNC (Ghazali et al., 2017).

#### 2.2.2. Patient Concerns Inventory (PCI)

The PCI is a checklist comprising 57 items of patient concern and 18 professionals tiled alphabetically (Ghazali et al., 2015). These items have been grouped into 5 domains: (A) Physical and Functional well-being (29 items); (B) Psychological and Emotional well-being/Spiritual (14 items); (C) Social care/Social well-being (9 items); (D) Treatment-related (4 items) and (E) Other (1 items). The PCI asks respondents to indicate items from the checklist they were concerned about and wanted to discuss with the doctor during their consultation. Patients were also asked to indicate professionals from the checklist they would like to speak or be referred to.

### 2.3. Study design

This work is part of a wider prospective project evaluating the PCI intervention set up into three study blocks organized sequentially. In Block 1, patients did not complete the PCI before their consultation, representing usual practice and the control group. In Block 2, patients completed the PCI at the pre-consultation stage but the PCI was withheld from clinicians during consultation, representing the 'control in attention' group. In Block 3, patients completed the PCI at the pre-consultation stage; the completed PCI was passed on to the clinicians and was available for use during the consultation, representing the intervention group. For the purpose of this study only patients from Blocks 2 and 3 were selected, and the PCI data acquired was derived from the clinic they had first experienced using the PCI.

All recruited patients also completed the DT at pre-consultation. Questionnaires were administered in a paper format. The length of consultation was determined from the start to the end of consultation, which was audio-recorded and subsequently transcribed. Thematic content analyses of the audio-recorded transcriptions were carried out by two assessors (NG, BR) based on a thematic framework approach (Ghazali et al., 2012b). Clinic outcomes were classified as medical (e.g. placement on surgical waiting list to aid rehabilitation, institution of symptomatic or supportive medical treatment, request for investigations, and onward referrals) or non-medical actions (e.g. provide information, advice on lifestyle, strategies for coping, and reassurance).

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