



Top ten concerns burdening people with cancer: Perceptions of patients with cancer and the nurses caring for them

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ABSTRACT

Purpose: We examined the concerns that nurses perceive patients to have, whether these are congruent with patients' concerns and whether they vary according to cancer site. We also examined Distress Thermometer scores according to cancer site.

Method: A cross-sectional survey design: (i) secondary analysis of an existing Holistic Needs Assessment (HNA) and Distress Thermometer (DT) dataset was used, (ii) a survey of specialist nurse teams to identify their perceptions of patient concerns. Data collected between January 2015 and June 2016 from the HNA database from one NHS Trust in England (n = 1233 patients). Specialist nurse teams for breast, colorectal, gynaecology, skin and urology cancers identified the concerns that they perceived their patients would report.

Results: The HNA showed high internal consistency (Cronbach's alpha 0.86). Across the five cancer sites, nurses identified between 3 and 6 of the top ten concerns (TTC) expressed by patients, with wide variation across cancer sites. Nine of the TTC were significantly associated ($p < 0.05$) with a specific cancer site. The breast and gynaecological cancer groups both recorded significantly higher median Distress Thermometer scores than the urology, skin and colorectal cancer groups (Kruskal-Wallis χ^2 (4, n = 1228) 186.695, $p = < .01$).

Conclusions: One of the aims of the eHNA is to enable service delivery appropriate to patient needs. Our findings suggest that this will only be achieved if eHNA is examined, and services developed, by individual cancer site. The misconception of patient needs by specialist nurses underscores the importance of review of information provided by patients during consultations.

1. Introduction

The vision for *living with and beyond a cancer diagnosis* involves a cultural shift to focus on recovery, health and wellbeing, with care based on a model of empowerment (Department of Health, Macmillan Cancer Support and NHS Improvement, 2013). Empowerment is enacted through an emphasis on information about services that patients may access, rather than referrals, allowing patients to make an informed choice. However, this model also emphasises the importance of a mutually agreed care plan, jointly owned by the patient and health professionals.

A number of health needs have been identified by people living with cancer with findings from a systematic review 15 years ago revealing that physical, emotional, psychological, social, practical, and financial needs were highly prevalent domains of need (National Breast Cancer Centre and National Cancer Control Initiative, 2003). More recent

studies support this finding, although patient and physician identification of needs is not always congruent (Baile et al., 2011). The ongoing needs of an individual with cancer can be easily misconstrued, which may lead to delays in appropriate interventions and referrals (Bestall et al., 2004) with unmet health needs in newly diagnosed older people found to range from 15 to 93% (Puts et al., 2012).

A number of measures have been used to capture the needs of people with cancer, including the Patient Concerns Inventory (Wells et al., 2015a), Distress Thermometer and Problem List (DT&PL) (National Comprehensive Cancer Network, 2016), the Supportive Care Needs Survey (SCNS-SF34) (Boyes et al., 2009) and the Holistic Needs Assessment (IPSOS Mori Social Research Institute, 2013). The Distress Thermometer has revealed differences between cancer sites (Zabora et al., 2001) and studies have investigated illnesses such as depression (Kreber et al., 2014) across cancer sites. However, studies exploring met and unmet needs of people with cancer have often tended to focus

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on single sites, such as colorectal cancer or breast cancer; in a qualitative study, interviews were conducted with head and neck and breast cancer survivors but researchers did not compare findings by cancer site (Lubberding et al., 2015) in a study across cancer sites, use of the electronic version of the HNA (eHNA) resulted in more than half of participants reporting its' utility in discussing concerns with their health care team (Ipsos Mori, 2015).

In the UK, the National Cancer Survivorship Initiative aims to offer all people with cancer the opportunity to complete a holistic needs assessment (HNA), focusing on a wide range of factors that may impact on the wellbeing of the patient (Department of Health, 2012a; National Cancer Action Team, 2013). The underpinning ethos of the 48-item HNA is not to identify hierarchies of need for the individual but to ensure that all needs are captured (Snowden and Fleming, 2015). However, it is also important to understand what needs are of most importance, in order to inform service planning, hence there has been an emphasis on identifying the top ten concerns (TTC) for people with cancer (Kuczkowska et al., 2015). Whilst this has been undertaken across all cancers, there has been no detailed analysis of differences by cancer site.

The Holistic Needs assessment (HNA) has a two-fold purpose: to help those with cancer better express their needs and to enable health care professionals to plan care, with targeted, bespoke support. The concerns documented in the Holistic Needs Assessment have been grouped into five domains: physical, practical, social, emotional and spiritual (Snowden and Fleming, 2015). The aim of this study was to compare the primary concerns as expressed by people with cancer and as perceived by the nurses who care for them and to examine whether these vary according to cancer site.

2. Objectives

1. To compare the concerns expressed by patients and perceived by nurses
2. To examine concerns and distress, as measured by the distress thermometer, by cancer site
3. To compare concerns against the national survey findings

3. Design and methods

A survey design was used comprising:

1. Cross-sectional patient survey: using the eHNA and the Distress Thermometer,
2. Staff survey: specialist nurse teams identified the top ten concerns that they perceived their patients to have

3.1. Instruments

The HNA consist of 48 needs statements (e.g. 'sleep problems', 'unable to express feelings') with a scale rated from 0 (no problem) to 10 and is completed shortly after diagnosis. The electronic version (eHNA), developed by MacMillan Cancer Support UK (Ipsos Mori Social Research Institute, 2013), is completed via a tablet with the completed assessment uploaded to a secure website for viewing by the individual's care team. The eHNA has been validated with a sample of 5421 using Rasch analysis and factor analysis, and has demonstrated internal consistency and construct validity, in terms of the construct of holistic needs (Snowden and Fleming, 2015).

The Distress Thermometer (DT), developed by the National Comprehensive Cancer Network in the United States, is regarded as the forerunner to the HNA and has been used extensively to assess the psychological needs of people affected by cancer (Holland and Bultz, 2007). Although the HNA also contains psychological need statements, it is common for DT and HNA to be used together for patient assessment as it provides a global self-assessment of distress.

Five specialist nurse teams, responsible for breast, colorectal, gynaecological, skin and urological cancers, were asked to list the top ten concerns that they perceived their patients would report, without reference to the eHNA. The teams for each cancer site (e.g. the specialist breast cancer nurses) developed the list by a process of consensus within their specialist team.

We conducted a secondary analysis of data collected between Jan 2015 and June 2016 from the eHNA/DT online database for one NHS Trust. The eHNA and DT were completed by patients shortly after diagnosis, in line with its' use in other studies (Ipsos Mori Social Research Institute, 2013).

3.2. Data analysis

Descriptive statistics, including cross tabulations, were used to identify frequencies and associations in the data. Cronbach's alpha was used to determine reliability. Chi square was used to examine associations between top ten concerns statements and cancer site; Kruskal Wallis was used to examine differences between DT scores by cancer site.

4. Results

A total of 1233 patients completed the eHNA between January 2015 and June 2016 and five specialist nurse teams identified patient concerns. Patients with breast ($n = 282$) and gynaecological ($n = 79$) cancers were all female and urological cancer patients ($n = 447$) were all male. Colorectal and skin cancer patients were 49.6% and 48% female.

The internal consistency for the eHNA was high (Cronbach alpha .861); this is similar to the agreement achieved in the eHNA validation study (0.87) (Snowden and Fleming, 2015). Some items identified by our participants were ranked in the top ten concerns identified in the national study (Kuczkowska et al., 2015) but eight additional concerns were identified by our participants (see Table 1).

The top ten concerns identified in the Macmillan study (Kuczkowska et al., 2015) were identified as a concern for between 2.7 and 29.8% of the patients included in our study (see Table 2). Nine of the ten individual statements were also significantly associated ($p < 0.05$) with a specific cancer site (see Table 2). The three top concerns (*worry/fear/anxiety, tiredness/exhaustion/fatigue and sleep problems/nightmares*) were common across all five cancer sites.

The median DT score was zero for colorectal and skin cancer (IQR 4 and 2 respectively) (see Table 2). Kruskal-Wallis test revealed a statistically significant difference in Distress Thermometer score across the five cancer sites, $\chi^2(4, n = 1228) 186.69, p = < .01$ (see Table 2). The breast cancer and gynaecological cancer groups both recorded significantly higher median scores than the urology, skin and colorectal cancer groups. These differences remained significant following Bonferroni adjustment.

Across the five cancer sites, nurses identified between 3 and 6 of the TTC reported by patients; of note the breast cancer and gynaecological

Table 1
Concerns identified in our data but not listed in the top ten concerns national survey by Kuczkowska et al. (2015).

| Concern | Prevalence |
|-------------------------------|------------|
| Bowel changes or constipation | 17.1% |
| Partner | 15.1% |
| Nervousness | 14.0% |
| Unable to make plans | 12.2% |
| Getting to places | 10.7% |
| Panicky | 10.4% |
| Children | 9.8% |
| People close to you | 9.6% |

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