Associations between neighbourhood support and financial burden with unmet needs of head and neck cancer survivors

Katie M. O'Brien [a],[*], Aileen Timmons [a], Phyllis Butow [b], Rachael Gooberman-Hill [c], Eleanor O'Sullivan [d], Myles Balfe [a], Linda Sharp [e]

[a] The National Cancer Registry, Building 6800, Cork Airport Business Park, Kinsale Road, Cork, Ireland
[b] Centre of Medical Psychology, University of Sydney, Sydney, Australia
[c] Musculoskeletal Research Unit, University of Bristol, Southmead Hospital, Westbury-on-Trym, Bristol, UK
[d] School of Dentistry, University College Cork, Ireland
[e] Institute of Health & Society, Newcastle University, Newcastle upon Tyne, UK

ABSTRACT

Purpose: To assess the unmet needs of head and neck cancer survivors and investigate associated factors. In particular, to explore whether social support (family/friends and neighbours) and financial burden are associated with unmet needs of head and neck cancer (HNC) survivors.
Methods: This was a cross-sectional study of HNC survivors, with 583 respondents included in the analysis. Information was collected on unmet supportive care needs as measured by the Supportive Care Needs Survey (SCNS-SF34). Poisson regression with robust standard errors was used to examine factors associated with having one or more needs in each of the five domains (physical; psychological; sexuality; patient care and support; and health system and information).
Results: The mean age of respondents was 62.9 years (standard deviation 11.3 years) and one third of respondents were female. The top ten unmet needs was composed exclusively of items from the physical and psychological domains. Financial strain due to cancer and finding it difficult to obtain practical help from a neighbour were both associated with unmet needs in each of the five domains, in the adjusted analyses.
Conclusion: Whilst in each domain, a minority of respondents have unmet needs, approximately half of respondents reported at least one unmet need, with the commonest unmet needs in the psychological domain. Providing services to people with these needs should be a priority for healthcare providers. We suggest that studies, which identify risk factors for unmet needs, could be used to develop screening tools or aid in the targeting of support.

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Introduction

In 2012, there were an estimated 686,000 new head and neck cancers diagnosed worldwide and 376,000 deaths from head and neck cancer [1], making it the seventh most common cancer worldwide both in terms of newly diagnosed cases and numbers of deaths [1]. Because of the close proximity of head and neck cancers to areas of anatomy involved in vital functions of daily living such as breathing, eating, drinking, and speaking, many survivors of head and neck cancer experience long-term side-effects of treatment which may be severe ([2]). The chronic nature of some of the side-effects experienced by survivors means that they may face

a wide range of challenges post-treatment, requiring assistance to adapt, cope with, or manage [3].

There is a paucity of information on supportive care needs for people diagnosed with head and neck cancer, particularly for those who are finished active treatment. A qualitative study carried out by Moore et al. [4] explored supportive care needs of eight head and neck cancer survivors. They found that adjustment was adversely influenced by loss of access to the supportive hospital environment after treatment, which resulted in feelings of isolation post-treatment. The supportive care needs of 165 oral cancer patients from a hospital in northern Taiwan, were investigated by Chen et al. [5]. The highest prevalence of unmet needs was in the area of health system and information. So et al. [6] found that supportive care needs have a mediating effect on the relationship between characteristics of head and neck cancer survivors and

their quality of life. Further work with a large representative sample is required to elucidate unmet needs focussing on survivors of head and neck cancer in the post-treatment phase using validated instruments.

Previous studies have explored unmet needs in heterogeneous or other specific cancer types [7–9]. In their paper on supportive care needs of cancer patients in the immediate post treatment phase, Armes suggests that factors such as specific coping style and perceived social support may be influential in determining supportive care need [10]. McDowell et al. [11] also found that a lower level of social support predicted unmet supportive care needs in the sexuality domain for patients/survivors with a variety of cancers and treatments. We postulated that a deficit in social support is associated with increased unmet needs in head and neck cancer survivors. Social support can come in the form of family, friends or neighbourhood support. Each of these offers different levels of support, and may be overlapping. In general, it is expected that deeper bonds are formed with family/friends than neighbours. Conversely neighbours may be more available to provide immediate practical support for everyday tasks ([12,13]).

Associations between financial status and unmet needs have been reported ([14,15]) and Brooks et al. [16] have demonstrated that financial hardship is common post-cancer diagnosis. Historically, this is likely to be particularly pertinent for head and neck cancer survivors, since the socio-economic distribution of this patient group suggests that many may be at risk of financial hardship. We note however, that some new head and neck cancers are caused by HPV infection and as a result, there may be some shifting of the demographic in this patient group. Post cancer financial hardship has been associated with a range of adverse outcomes including treatment non-adherence, poorer psychological wellbeing and lower health related quality of life ([17–20]).

Our aim, therefore, was to determine the prevalence of unmet needs amongst a large sample of medium- and long-term head and neck cancer survivors and the factors associated with survivors experiencing unmet needs. Thus we considered survivors who were at least eight months from diagnosis. In particular, we were interested in investigating whether lower levels of social support and higher financial burden were associated with unmet needs after controlling for various clinical and demographic variables.

Methods

Setting

The study was conducted in Ireland, which has a mixed public-private health care system. Individuals are entitled to use the public health system; this includes hospital out-patient treatment and inpatient treatment in public hospitals. Public hospitals also offer private health care, and individuals may opt to be treated at private hospitals. Typically, those utilising private health care will have private health insurance. Possession of a medical card in Ireland entitles the holder to medical care free of charge within the public health system, including free primary general practitioner care. Medical cards are primarily awarded after means testing, though other factors like health status and age (over 70 years) are taken into account.

Design and participant recruitment

The study design was a cross-sectional, post-treatment survey of survivors of primary head and neck cancer receiving follow-up care at a range of hospitals throughout Ireland, this includes outpatient and inpatient treatment in public hospitals (14 hospitals which included all the major centres at which head and neck can-

cer is diagnosed and treated). A population based sample of head and neck cancer was identified from the Irish National Cancer Registry in April 2012. Within the definition of head and neck cancer, the following ICD 10 codes were included: cancers of the lip (COO), mouth (C01-C06), salivary glands (C07-C08), pharynx (C09-C14) and larynx (C32). Eligible individuals were invited to participate following the agreement of their main treating clinician. Exclusion criteria were as follows: the individual had died, was terminally ill, and was unaware they had cancer or the treating clinician indicated that it would be inappropriate to contact them (e.g. they had dementia). Surveys with explanatory letters of invitation, and consent forms were sent to the 991 eligible individuals. Ethical approval was provided by the research ethics committee for each of the participating hospitals.

Measures

The Supportive Care Needs Survey, Short Form (SCNS-SF34) [15] was used to measure care needs of the respondents in "the last month". This instrument measures survivors' perceived need for support in five domains: physical and daily living; psychological; sexuality; patient care and support; and health system and information. This tool is designed for a broad cancer population and is not a head and neck cancer specific tool. With respect to a particular item in the questionnaire, a person could have no need (not applicable or satisfied) or some need (at any level, low, moderate, high). In each domain we counted the number of people with one or more unmet needs for that domain.

The Oslo-3 social support scale was used to measure different aspects of social support [21]. The Oslo-3 scale contains three questions: How many people are you so close to that you can count on them if you have serious problems? (Response options: 1–2, 3–5, more than 5); How much friendly interest do people show in what you are doing? (Response options: a lot, some, uncertain, little, none); and How easy is it to get practical help from neighbours if you should need it? (Response options: very easy, easy, possible, difficult, very difficult). A total score can be constructed or questions analysed separately. Cronbach's alpha for this data set was 0.62, perhaps reflecting the multi-dimensional structure of the index. We therefore used the scores from the three questions separately in our analysis in order to explore which aspects of social support might be associated with unmet needs.

Financial burden was measured by including questions on the household financial situation derived from previous work [17,22]. Participants were asked about their household's ability to make ends meet immediately prior to their cancer diagnosis; henceforth *financial stress at diagnosis* (response options: 6-point Likert scale ranging from "very difficult" to "very easy"). They were also asked if their cancer diagnosis had made their household's ability to make ends meet more difficult; henceforth *financial stress due to cancer* (response options: 7-point Likert scale ranging from "much more difficult" to "much less difficult"). Finally, respondents were asked how concerned they were about their household's financial situation since the cancer diagnosis; henceforth known as *financial strain due to cancer*, (response options: 7-point Likert scale ranging from "much more concerned" to "much less concerned").

In addition, respondents were asked whether, at the time of diagnosis, they had private health insurance and whether they held a medical card. Information on a range of socio-demographic factors was available from the survey. Respondents were also asked if the head and neck cancer had returned or spread. Additional clinical information was obtained from the survivor's record with the National Cancer Registry. Stage was classified by TNM staging [23]. We combined stage I and II to form an early stage category and stages III and IV to form a late stage category.