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Supportive care needs and distress in patients with non-melanoma skin cancer: Nothing to worry about?

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ABSTRACT

Purpose: There is a paucity of psychosocial research on non-melanoma skin cancer (NMSC) despite the fact that these malignancies mainly develop on the head and neck, frequently recur, and are associated with an increased risk for other cancers. The current study aims to respond to this gap in the scholarship by determining the prevalence of supportive care needs and examining the relationship between patients' needs and distress.

Method: A cross-sectional research protocol included a consecutive sample of 60 patients with squamous and/or basal cell carcinomas who completed a survey comprised of the Skin Cancer Index (SCI), the Hospital Anxiety and Depression Scale (HADS), the Supportive Care Needs (SCNS) Survey, an inquiry about informational needs regarding skin cancer prevention, and a socio-demographic questionnaire.

Results: More than half of the patients indicated unmet needs, most frequently endorsing moderate and high needs for help with: the prevention of future skin cancers, the health system and informational matters. Psychological needs were strongly associated with skin cancer-specific and general distress. Higher levels of anxious and depressive symptoms were related to greater patient needs across all domains.

Conclusions: Despite NMSC not being life threatening in most cases, there is a significant proportion of patients, who have unmet supportive care needs and experience heightened distress levels. This study raises awareness for health care professionals to be vigilant about the supportive care needs and the psychological health of patients with non-melanoma skin cancer.

1. Introduction

Non-melanoma skin cancers,[1] the majority of which are cutaneous basal cell carcinoma and cutaneous squamous cell carcinoma, are the most commonly diagnosed cancers worldwide (Jemal et al., 2010; Lomas et al., 2012; Mistry et al., 2012). Between 2 and 3 million NMSCs occur globally each year and the incidence continues to raise annually (World Health Organization, 2014). The 3-year disease-specific survival rate of patients with SCC is 85%, while BCC is rarely life threatening (Clayman et al., 2005; Kim and Armstrong, 2012; Lewis and Weinstock, 2007). However, individuals diagnosed with NMSC are more likely to die from melanoma or non-cutaneous cancers than the general population (Kahn et al., 1998). Moreover, NMSC comes with high rates of recurrences and subsequent primaries (Madan et al., 2010) often occurring

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[1] NMSC – Non-melanoma Skin CancerBCC – Basal Cell CarcinomaSCC– Squamous Cell Carcinoma.

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despite improved sun protection (Chen et al., 2008; Czarnecki and Czarnecki, 2002; Karagas et al., 1992; Marcil and Stern, 2000; Song et al., 2013; Stern, 2010). Furthermore, NMSCs can have a negative impact on quality of life (QoL) as well as impose a significant and increasing financial burden on health services worldwide (Lomas et al., 2012). Thus, early detection of subsequent disease is essential to reducing morbidity and NMSC-related health care costs since the treatment of advanced lesions is more invasive and expensive (Alam et al., 2011; Barker et al., 2011). Early detection can be achieved through skin examination by physicians but also by patients themselves (Körner et al., 2013a). The need to advise patients on skin self-examination is important because a personal history of NMSC increases the risk for melanoma (Song et al., 2013; Stracci et al., 2012) and the majority of melanomas are self-detected with self-examination leading to earlier treatment (Geller et al., 2007; Körner et al., 2013b).

The majority of NMSCs develop in visible areas of the skin, such as the head and neck, often leaving conspicuous scars (Caddick et al., 2012; Mistry et al., 2012). Facial disfigurement can lead to clinically significant levels of distress and social concerns while the extent of the disfigurement is often unrelated to the magnitude of the psychosocial correlates of the disease (Blackford et al., 1996; Rhee et al., 2007; Robinson, 1997; Steinbauer et al., 2011). Despite these characteristics of NMSC, research into the psychosocial correlates of BCC or SCC is scarce (Bates et al., 2013; Waalboer-Spuij and Nijsten, 2013). Further, the scholarship on psychological distress and QoL of individuals with NMSC is scarce and research into the supportive care needs is virtually non-existent (Barker et al., 2011; Bath-Hextall et al., 2013). Nevertheless, there is some evidence indicating that even non-metastatic NMSCs come with significant concerns for the affected individuals and can impact the physical as well as the psychological and interpersonal wellbeing. For example, in a small sample of 52 patients with NMSC, 31% of the participants indicated moderate to severe QoL impairment due to physical symptoms of the disease and its treatment, feeling self-conscious/embarrassed and negative effects of these symptoms on daily living and leisure activities (Steinbauer et al., 2011). Among a larger sample of 211 patients with NMSC the most pronounced concerns were worries about future skin cancers, anxiety about the skin cancer, and worries about the scarsize with mean scores of 45, 55, and 56, respectively, (on a scale of 0–100 with lower scores indicating stronger concerns) while the means for all other emotional, social, and appearance-related concerns ranged between 61 and 87 (Rhee et al., 2006). Despite QoL improvements after surgery, patients continued to indicate stronger emotional and appearance-related concerns than social concerns (Rhee et al., 2007).

Thus, skin malignancies, their treatment, as well as the inherent risk for subsequent cancers may affect the quality of life and psychological health of patients. However, research on this topic is scarce. Consequently, the objectives of the current study were 1) to assess the prevalence of skin cancer-specific distress, general distress, and supportive care needs of patients with NMSC and 2) to examine the relationship between patient needs and distress, both general and skin cancer-specific.

2. Methods

2.1. Procedure and participants

The cross-sectional study included a convenience sample of 60 consecutive patients seeking services at a major hospital in Montreal, Canada, in 2010 after a confirmed diagnosis or as part of their long-term follow-up care of localized NMSC (stage 1). Patients were eligible for study participation if they had received a diagnosis of SCC and/or BCC, were at least 18 years of age, and able to read English. Study approval was obtained from the hospital ethics board prior to patient enrolment. The hospital's policy required that the clinical care team informed eligible patients about the opportunity to participate in this study. Only those patients, who agreed to receive more information about the study protocol, were approached by the research assistants (RA). The vast majority of patients, who met with the RA, consented to completing a brief questionnaire package with the study measures while the RA retrieved disease-related information from the medical charts. However, no data was collected about patients who declined to meet the RA, patients who declined after being fully informed about the study protocol, and about reasons for non-participation. Each participant was assigned a confidential participant code.

2.2. Measures

Sociodemographic information, e.g., age, gender, marital status, household income, employment status, and education level was collected along with medical information, e.g., diagnosis, body site of the NMSC, time since diagnosis, and history of NMSC.

General distress was assessed with the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983). The HADS is a 14-item self-report measure capturing symptoms of depression and anxiety over the prior week. The total score for the HADS ranges from 0 to 21 with higher scores indicating more distress. In a large sample of cancer patients ($N = 892$), internal consistency was $\alpha = .89$ for the total scale and .83 for the subscales (López et al., 2012). In the current study sample, the internal consistency of the total and the subscales ranged between .89 and .95. The empirical literature suggests differing HADS cut-off scores when screening for clinically relevant symptoms of anxiety and depression in medical populations (Bjelland et al., 2002; Morse et al., 2005). Using the Structured Clinical Interview for DSM-IV (First et al., 1996) as criterion, a cut-off score of 13 for the HADS total balances sensitivity (.76) and specificity (.60) when screening for clinically significant distress in patients with cancer (Singer et al., 2009). Another study using the Brief Symptom Inventory (Derogatis, 1993) as the criterion measure, demonstrated a sensitivity of .94 and a specificity of .83 for this cut-off in a heterogeneous sample of 892 patients with cancer (López et al., 2012). However, Singer et al. (2009) argue for a more inclusive “clinical cut-off score” of 6, which has a sensitivity of .95 but presents a stark contrast to the cut-off score of 16, originally recommended by Zigmond and Snaith (1983) for the identification of suspicious cases in medical populations (yet not specific to cancer).

NMSC-specific distress was assessed with the Skin Cancer Index (SCI; Rhee et al., 2006), a 15-item self-report measure, which captures emotional, social, and appearance-related concerns due to NMSC. Items are scored on a five-point Likert-type scale with the response options: 1 = *Very much*; 2 = *Quite a bit*; 3 = *Moderately*; 4 = *A little bit;* and 5 = *Not at all.* The SCI scores are standardized to range between 0 and 100 with higher scores representing fewer patient concerns. Originally, this measures was developed to assess skin cancer-related QoL over the prior month (Rhee et al., 2006). Given that the SCI items solely inquire about worries, fears, and concerns, in the current project the SCI was conceptualized as skin cancer-specific distress. In our sample, the internal consistency of the $\text{SCI}_{\text{total}}$ was $\alpha = .91$ and ranged between .82 and .89 for the three subscales, which matches the reliability coefficients reported in the literature (Rhee et al., 2006).

Patient needs were assessed with the Supportive Care Needs Survey (SCNS; Bonevski et al., 2000; Boyes et al., 2009), which captures generic needs of individuals affected by cancer. The SCNS is a 34-item self-report measure comprised of five domains of