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What factors are associated with posttraumatic growth in head and neck cancer carers?

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

[a] National Cancer Registry of Ireland, Cork Airport Business Park, Cork, Ireland
[b] Centre for Medical Psychology, University of Sydney, Sydney, Australia
[c] School of Dentistry, University College Cork, Cork, Ireland
[d] Musculskeletal Research Unit, University of Bristol, Bristol, UK
[e] Newcastle University, UK

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ABSTRACT

Purpose: Researchers have recently called for more work to be conducted on positive outcomes and head and neck cancer. The purpose of this study was to investigate the factors associated with posttraumatic growth in head and neck cancer caregivers.
Methods and sample: 197 carers were surveyed. A descriptive cross-sectional survey design was used.
Results: In multivariate analysis the following factors were statistically significantly associated with increased posttraumatic growth: social support, longer time since diagnosis, increased worry about cancer and increased financial stress and strain stemming from caring.
Conclusions: While HNC carers in the post-treatment phase of the illness trajectory can experience considerable psychological burdens, this study suggests that these burdens can lead some carers to experience growth and change and an expanded sense of themselves and their social worlds. Implications for nursing practice are discussed.

1. Introduction

Head and neck cancer (HNC) is one of the most common forms of cancer worldwide, with an estimated incidence of 6,00,000 new cases a year (Mehanna, 2010). HNC occurs mainly in older men and its principal etiological factors are tobacco and alcohol use (Mehanna, 2010). HNC can cause significant problems with eating and appearance and is considered to a particularly debilitating form of cancer (Ross et al., 2010).

A significant amount of HNC is provided in the community, where survivors of HNC are often looked after by family and friends (referred to as carers or caregivers). Caring for someone with cancer, particularly head and neck cancer, can be burdensome and have a significant negative impact on carers' psychological health (Braun et al., 2007; Longacre et al., 2012; Schaller et al., 2014). Most research on caring and cancer therefore understandably focuses on negative psychological states or outcomes. Researchers have recently begun to acknowledge, however, that caring for someone with cancer can also have positive effects (Braun et al., 2007; Tallman et al., 2014). Caregivers, for example, have noted that they often obtain intrinsic rewards from caregiving (Ross et al., 2010). Many of them appear to experience a positive, expanded sense of themselves and their social worlds as a result of helping their relative or friend, as well as an enhanced sense of purpose and a new appreciation for life (Ruf et al., 2009). These positive changes, referred to collectively as posttraumatic growth (PTG), appear to occur not despite the burdens of caring but rather because of them (Morris et al., 2012; Ruf et al., 2009; Sumalla et al., 2009; Tedeschi and Calhoun, 2004; Tallman et al., 2014). PTG means that life becomes fuller and more meaningful as a result of difficult events or situations, such as supporting loved ones with cancer (though not that life becomes less burdensome or that suffering becomes less intense as a result of doing so) (Ruf et al., 2009; Tedeschi and Calhoun, 2004). Traumatic events by themselves are insufficient

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* Corresponding author.
E-mail addresses: m.balfe@ucc.ie (M. Balfe), kobrien@ncri.ie (K. O' Brien), atimmons@ncri.ie (A. Timmons), phyllis.butow@sydney.edu.au (P. Butow), Eleanor.osullivan@ucc.ie (E. O' Sullivan), R.Gooberman-Hill@bristol.ac.uk (R. Gooberman-Hill), Linda.Sharp@newcastle.ac.uk (L. Sharp).

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to trigger PTG, however. PTG also requires that an individual reflect on the experiences that they are going through, and search those experiences for meaning. Thus, PTG is not the result of the trauma but stems from the struggle to make sense of and to cope with that trauma (Ruf et al., 2009).

To date PTG in HNC carers has been much less well-researched than PTG in survivors/patients (this is symptomatic of a wider lack of research on PTG in cancer caregivers as opposed to cancer patients/survivors (e.g. Da Silva et al., 2011; Jarrett et al., 2013; Mystakidou et al., 2015)), and the limited-albeit groundbreaking-research that has been conducted has been mainly qualitative in nature (Ruf et al., 2009; Thambyrajah et al., 2010). This reflects a general lack of research into the psychosocial concerns of HNC carers (Longacre et al., 2012; Ross et al., 2010) and into non-distress related quality of life issues in cancer caregivers more generally (Kim et al., 2012). Lack of research into psychological adjustment in HNC cancer carers in the posttreatment phase of the illness trajectory is especially lacking-most psychosocial research on HNC carers focuses on carers in the acute caregiving stage (the first year after treatment) (Ross et al., 2010). A number of previous conceptual articles and studies of patients, however, have identified factors that could potentially be associated with PTG in HNC carers, particularly in the post-acute period (1 year + after treatment). These include ruminative thinking and reflecting on traumatic events (Zoellner and Maercker, 2006), longer time since diagnosis (Linley and Joseph, 2004; Sumalla et al., 2009; Zoellner and Maercker, 2006), social support (Ho et al., 2011; Schroevers et al., 2010) and increased income levels (Ho et al., 2011).

2. Purpose

The aim of this study was to investigate and quantify the factors associated with PTG in HNC carers who were more than one year post-treatment. Because PTG is unlikely to be explained by a single factor (Linley and Joseph, 2004), we investigated a number of factors that we hypothesized could influence PTG in these carers. Our specific hypotheses were that:

- Socio-economic factors (social support, cancer related financial stress and strain) would be associated with PTG. We hypothesized that the more social support that individuals had, and the less financial stress and strain that they experienced, the more positively they would interpret and view caring and the more benefits they would extract from the caring experience.
- Cancer related rumination (in the form of worry about cancer returning) would be associated with a higher PTG. We hypothesised that since PTG is connected with increased rumination, carers who thought and reflected more about the cancer-even in a negative context-would experience higher PTG.
- Longer time since diagnosis would be associated with increased PTG, as this would provide a long window of opportunity for carers to make sense of events.

3. Methods

The study used a cross-sectional, nonexperimental design.

3.1. Sample

This investigation formed part of a larger study that examined the post-treatment experiences of survivors of head and neck cancer. For that study, 583 head and neck cancer survivors completed a questionnaire that examined their unmet needs. We asked all 583 head and neck cancer survivors who had completed the postal survey for permission to contact their caregivers (defined as a family member, friend or another person who had been helping take care of them since their diagnosis). Two hundred and eighty five survivors granted us permission. We wrote a letter to all 285 carers providing them with information about the study, and indicated that we would send them a questionnaire a fortnight after they received the initial contact letter. The caregiver inclusion criteria consisted of being (a). designated as the primary caregiver by the survivor and (b). caring for their relative/friend for one or more years. Questionnaires were then sent to all 285 carers, 197 of whom responded (69% response rate). When carers sent back their survey they also had to return a signed consent form. Ethical approval for the carer component of the study was provided by nine Irish university hospital ethics committees. Carers were not paid to take part in the study.

3.2. Measures

3.2.1. Demographics

Carers were asked to report the following demographic characteristics: sex; relationship status (married/partner vs. not married/no partners); children (yes/no); employment status; private health insurance (yes/no); medical card (yes/no) (entitling them to free medical care in Ireland-this is generally awarded to people with low incomes). Time since survivors' diagnosis was obtained the National Cancer Registry of Ireland's patient records database, and was therefore not based on carer self-report.

3.2.2. Post-traumatic growth

The Posttraumatic Growth Inventory (PTGI) is a reliable and validated 21-question instrument that measures growth in relation to five dimensions (relating to others (7 items), new possibilities (5 items), personal strength (4 items), spiritual change (2 items) and appreciation of life (3 items)) (Tedeschi and Calhoun, 1996). For each item respondents were given a statement that described a change that they could have experienced (e.g. ‘I have developed new interests’). Respondents were then asked to indicate the degree to which they experienced this change as a result of caring for their relative/friend. The response option for each item was a 5 point likert scales (ranging from ‘0’ (‘I did not experience this change as a result of caring for my relative/friend’) to ‘5’ (I experienced this change to a very great degree as a result of taking care of my relative/friend’). Scores were summed to generate an overall score in the range 0–105. A higher score implies greater post-traumatic growth. The range of possible scores for each of the five domains depends on the number of questions related to the domain. The Cronbach alpha score for the post-traumatic growth inventory is 0.9.

3.2.3. Social support

We assessed social support using the OSLO 3 support scale (alpha coefficient 0.6) (Dalgard et al., 2006)). The OSLO 3 is a 3 item social support scale that asks the following questions: A) How many people are you close to that you can count on them if you have serious problems (response options: none, 1–2, 3–5, 6+); B) How much concern do people show in what you are doing (response options: 5 point likert scale ranging from a lot of concern to no concern); c) How easy is it for you to get practical help from your neighbours if you need it? (response options: 5 point likert scale ranging from very easy to very difficult). The OSLO 3 generates a total score ranging from 0 to 8 (classified as poor support), 9–11 (intermediate support) and 12+ (classified as high support). The OSLO 3 has been used in several studies and is considered to have good predictive validity (Boen et al., 2012).