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Burden and happiness in head and neck cancer carers: The role of supportive care needs

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Abstract

Purpose

Our study aimed to investigate the relationship between unmet supportive care needs and carer burden and happiness, in head and neck cancer (HNC).

Methods

285 HNC informal carers were sent a postal questionnaire between January and June, 2014, which included the Supportive Care Needs Survey for Partners and Caregivers of Cancer Survivors (SCNS-P&C) and the CarerQoI, which assesses burden and happiness. Multiple regression analysis was conducted to examine the association of: i) carer characteristics, (ii) carer situation, and (iii) unmet supportive care needs, with carer burden and happiness.

Results

197 carers completed the questionnaire (response rate=69%), 180 of whom were included in the analysis. The majority were female (76%), not in paid employment (68%) and caring for their spouse (67%). On average, carers reported relatively low levels of burden and relatively high levels of happiness. Carer factors explained 42% of variance in levels of burden and 24% of variance in levels of happiness. Healthcare service needs were associated with carer burden ($\beta = .28$, $p = .04$), while psychological needs ($\beta = -.38$, $p = .028$), health care service needs ($\beta = -.30$, $p = .049$), information needs ($\beta = .29$, $p = .028$), carer comorbidity ($\beta = -.18$, $p = .030$), and gender ($\beta = -.16$, $p = .045$) were associated with happiness.

Conclusions

Our results indicate that different aspects of carer characteristics and unmet needs are associated with carer burden and happiness. Efforts directed at reducing unmet healthcare service needs in particular are merited given their associations with both aspects of carer quality of life.

Keywords: Unmet needs; Carer burden; Quality of life, Head and neck cancer carer burden,
Happiness

Background

Head and neck cancer (HNC) is a composite term for cancers arising in the oral cavity, oropharynx and larynx [1]. Globally, HNC accounts for approximately 550,000 cases annually [2], with incidence rates rising in many countries, particularly in younger individuals, and mortality rates falling in developed countries [1]. These trends, combined with an increased role for out-patient and community care, have resulted in a rise in the importance of informal care for HNC survivors [3].

Informal carers of HNC survivors, and cancer survivors more generally, play a crucial role helping them deal with functional, clinical and psychosocial issues resulting from the disease, and its treatment [3-5]. Moreover, the burden of those caring activities can result in the emergence of significant unmet supportive care needs [5, 6]. These needs range from informational, communication, psychosocial, emotional, financial, medical, and spiritual [6-10], and are often not adequately met by health professionals [9].

Previous studies have indicated that unmet supportive care needs impose significant burdens on cancer carers, impacting on their health and quality of life [5, 6, 9, 11-13]. Specifically, unmet needs have been found to be associated with poor carer mental health [6, 14] distress [14], anxiety [9] depression [8] and fatigue [7] in cancer carer populations. In the case of HNC, Chen et al. [15] revealed that HNC patients experience relatively high supportive care needs, especially with regard to information needs, and that these were associated with higher carer burden. A further study [12] found that HNC carers' unmet care needs were associated with depression, although the findings were not statistically significant.

Despite the increasing body of evidence on cancer carers' unmet supportive care needs and their negative impact on carers' quality of life, few studies have considered both positive and negative aspects of carer quality of life, and what predicts these. The literature indicates that

carer quality of life is affected in a multidimensional manner [16-18]. The CarerQol instrument measures perceived carer burden in two positive and five negative dimensions, and measures general happiness using a single visual analogue scale (VAS), the latter increasingly recognised as a core component of quality of life [19]. This measure provides a comprehensive description of the carer experience and allows the current study to examine carer burden and quality of life in a multidimensional context.

A literature gap exists with regard to whether there is a link between HNC carers' supportive care needs and different elements of carer quality of life including burden and happiness. Our study aimed to investigate unmet supportive care needs in predicting carer burden and happiness as measured by the CarerQol, in HNC, while controlling for the influence of carer characteristics and aspects of the care situation.

Methods

Participants

This study was part of a larger project that investigated the post-treatment experiences of HNC survivors and their carers in Ireland [20, 21]. The study was survey-based, cross sectional in design and descriptive and correlational in nature.

In total, 583 HNC survivors, sampled from the National Cancer Registry Ireland, completed a postal survey. Details of this survey and the demographics of the survivor sample have been published previously [21] and included a majority of older males (67% male, mean age 63) with a substantial minority living in difficult financial circumstances prior to diagnosis (30%). Respondents were asked for permission to contact their carer if they had one (defined as a family member, friend or another person who had been helping take care of them since their diagnosis). Carer inclusion criteria for this study included being (a) designated as the

primary caregiver by the survivor and (b) caring for their relative/friend for one or more years post diagnosis. We wrote to 285 carers matching these criteria between January and June, 2014, providing them with information about the study, and sent out a questionnaire two weeks after the initial contact letter. When carers returned their questionnaire, they also provided written consent to take part in the study. Nine Irish university hospital ethics committees, covering a range of hospitals across the country, provided ethical approval for the project.

Instruments

Carer characteristics

The questionnaire collected information on the carer's sociodemographic characteristics, including their gender, age and employment status. Carers indicated whether they had any pre-existing (at the cancer diagnosis) health conditions, specifically heart problems, stroke, lung problems, diabetes, mental health problems, cancer, or other conditions. Participants who indicated one or more of these conditions were classified as having a comorbid condition.

Carer situation

Carers were asked to indicate their relationship to the survivor, as well as whether caring had any impact on their financial situation. Following Sharp et al. [22], participants were asked to indicate the extent to which caring had made it more or less difficult for their household to make ends meet on a 7-point Likert type scale, ranging from "much more difficult" (scored 1) to "much less difficult" (scored 7). Scores were reverse coded so a higher score indicated higher levels of financial stress. Time allocated to caring was assessed by asking carers to

estimate the typical amount of hours spent caring per week during the past month following Hanly et al. [23]. This included estimates of extra time spent on: domestic activities such as cleaning and food preparation; Activities of Daily Living (ADL) including assisting the survivor with personal care, eating and drinking; Instrumental Activities of Daily Living (IADL) such as moving around, health care contacts, organising help and taking care of financial matters; and cancer-specific care. The total amount of time spent caring per week was computed by summing together the estimated hours in each domain.

Carer Unmet Needs

The perceived unmet supportive care needs of carers were assessed using the Supportive Care Needs Survey for Partners and Caregivers of Cancer Survivors (SCNS-P&C) [24]. This is a 45 item measure which assesses four specific domains of unmet needs: (i) information needs, (ii) healthcare service needs, (iii) work and social needs, and (iv) psychological and emotional needs. Participants were asked to indicate whether they had no need (scored 0), a low need (1), a moderate need (2), or a high need (3) for each item. Following Chen et al. [12], we computed a standardised score ranging from 0-100 for each of the four domains, and a total standardised score. This instrument has demonstrated good reliability and validity previously [12, 24, 25] and had a Cronbach's alpha in our sample of .97.

CarerQoL

The CarerQoL was used to assess subjective carer burden and happiness. This instrument was based on the EuroQoL instrument measuring health-related quality of life and highlights connections between carer burden and quality of life which was deemed appropriate for this study. It was designed by Brouwer et al. [26] to provide, amongst other things, a

comprehensive description of the caregiving situation. While not specific to any given carer situation, this generic instrument facilitates comparisons of the effects of caring on different population groups of carers which adds to the generalisability of the derived findings in this study.

The CarerQol comprises two separate measures. The first (CarerQol-7D) is a descriptive system consisting of five negative burden ‘dimensions’ (mental health, physical health, financial problems, relational problems, problems with daily activities) and two positive ‘dimensions’ (fulfilment, support). Each dimension consists of a single item statement that has three response categories: no (1), some (2), and a lot (3), which potentially distinguish 2,187 discrete care situations. After reverse coding positive items, we summed participants’ responses to calculate a total burden score which was then standardised to 0-100. The CarerQol-7D had a Cronbach’s alpha in our sample of .623.

The second measure (CarerQol-VAS) is a horizontal visual analogue scale that measures the well-being of carers in terms of general happiness. Scale endpoints range from “completely unhappy” (0) to “completely happy” (10). This type of broad outcome measure incorporates the disparate effects associated with informal care in the valuation process, including, for example, health effects and financial effects [27]. The ability of the CarerQol to measure the impact of caring is supported by a growing number of construct validation studies in adult carer populations where the instrument exhibited good clinical and convergent validity [26, 28-30]. Studies have demonstrated that it is a clear, easy to use and comprehensible instrument [26].

Statistical Analysis

Standard multiple regression analysis was conducted to determine the effect of predictor variables (categorised by (i) carer characteristics, (ii) carer situation, and (iii) carer support and information needs) on two outcomes: carer burden and carer happiness. Bivariate correlations were conducted prior to the regression using Pearson product-moment correlation coefficients to determine the relationship between the predictor variables and the two outcome variables, and to ensure no violation of the assumption of multicollinearity. Correlations were below the recommended criteria for determining violation of the assumption of multicollinearity [31]. Additional tests indicated no violations of the assumptions of normality, linearity, and homoscedasticity. Both models contained all potential predictor variables and associations were considered statistically significant at the 5% level (two-sided tests).

Results

Carer characteristics and care situation

A total of 197 carers completed the questionnaire yielding a response rate of 69%. For the purposes of this study, 180 respondents were included, with 17 respondents excluded due to legal, ethical and data protection reasons.

Table 1 displays frequency data for the available variables in the sample. The majority of carers were female (76%), not in paid employment (68%) and had no comorbid conditions (53%). Carers' age ranged from 23-85 years, with a mean of 57.3 (SD = 12.5). Two thirds were caring for their spouse (67%). On average, carers reported a negative impact of caring on their finances (mean financial stress= 4.7; SD = 1.2), and spent 9.5 hours a week caring for the HNC survivor, although this varied considerably with some carers experiencing a considerable time burden of up to 112 hours per week (SD = 18.4, range: 0-112).

Supportive care needs

While overall reported unmet needs were generally low (mean = 10.6), the highest ranking unmet need domain was psychological and emotional needs (14.44), followed by healthcare service needs (13.01), information needs (11.93), and work and social needs (9.57). Over half (51.4%) of carers reported at least one moderate/high unmet need.

Carer burden and happiness

Generally carers reported low levels of burden (mean = 23.2; SD = 16.6) and high levels of happiness (mean = 7.5; SD = 2.1) (Table 1). Figure 1 provides responses to the individual CarerQol dimensions. Almost all HNC carers experienced some or a lot of fulfilment caring (94%), while almost three-quarters (72%) also received support with their caring tasks. However, almost half of carers reported experiencing physical and/or mental health problems (44%). Almost one in three carers indicated financial problems due to caring (29%) while problems combining care tasks with daily activities (24%) and relationship problems (22%) were also evident.

Multiple Regression Analysis

When the carer characteristics, situation and unmet needs variables were fitted, the model of carer burden was statistically significant ($F(11, 121) = 9.82, p < .001$) and explained approximately 42% of variance in levels of burden (Table 2). Only unmet healthcare service needs was significantly positively associated with carer burden ($\beta = .28, p = .04$).

The model of carer happiness was statistically significant ($F(11, 128) = 4.95, p < .001$) and explained approximately 24% of variance in levels of happiness (Table 3). Five variables were significantly associated with happiness levels, with unmet psychological needs exhibiting the strongest effect ($\beta = -.38, p = .028$), followed by unmet health care service needs ($\beta = -.30, p = .049$), unmet information needs ($\beta = .29, p = .028$), comorbidity ($\beta = -.18, p = .030$), and gender ($\beta = -.16, p = .045$). Lower levels of unmet psychological and health care needs, higher levels of unmet information needs, absence of any comorbid physical illness, and being male were predictive of higher levels of happiness.

Discussion

HNC carer subjective burden

While most HNC carers experienced fulfilment with their caring tasks, almost a half reported, at least to some extent, both mental and physical health problems. A few previous studies have reported that HNC carers experience significant deficits in psychological health compared to the general population [13, 32], and indeed cancer carers have been reported to experience more distress, and more reductions in quality of life than cancer patients themselves [10]. Nevertheless, the heterogeneity of measures used to assess HNC carer quality of life [18, 32] has hampered cross study comparisons and limited assessment to broad level findings. Similar to the measurement of quality of life in HNC patients [32], there appears to be no gold standard questionnaire used in practice. Future work should look towards standardising the measurement of HNC carer quality of life, or at a minimum decreasing the number of instruments used, in order to increase the generalisability of the derived results. Less evidence is available on the physical health burden on cancer carers

generally, or HNC carers specifically. Our results indicate that physical health problems are common, and that there would be value in further exploring the influences on this.

A degree of consensus exists in the literature across disease types with regard to the positive aspects associated with care (fulfilment and support) as measured by the CarerQol-7D [29, 33]. The extent, however, to which carers experience negative aspects of care appears to vary by disease. HNC carers in our study reported a higher financial burden (29% reported at least some financial burden) than in previous studies of adult informal carers [28]: 12% with financial difficulties and carers of people with other non-cancer conditions (depression [34]: 20%; Duchenne muscular dystrophy [33]: 17%), but less than carers of children with autism [35]: 52%. This may reflect an association between HNC and low socio-economic status [36]. Also, HNC carers in our study reported fewer relationship problems with their care recipients than carers of people with other non-cancer conditions [28, 29, 34] possibly indicating a relatively strong bond between patient-carer dyads in HNC, however comparison with other HNC carer populations is limited due to the dearth in application of the CarerQol in this area. The observed association is consistent with research in other cancer populations in Ireland [37] and could reflect cultural norms in Ireland.

Subjective HNC carer burden associations

Unmet healthcare service needs were significantly associated with carer burden. The importance of healthcare services to carers in our sample was reflected in the rankings of single item questions which relate to healthcare service needs including: looking after the carers own health (ranked 2nd of 45 potential unmet needs), addressing fears about the patient's mental and physical deterioration (5th), accessing treatment information (7th) and discussing concerns with doctors (9th).

Carer unmet healthcare needs have been consistently reported throughout the general cancer literature [6, 10, 24, 25], and in the HNC specific literature [12, 15]. In a recent study, 39% of cancer carers of patients with various diagnoses and disease stages indicated dissatisfaction with the amount of time health care professionals spent on informing them and 30% were dissatisfied with their level of involvement in the patient's treatment or care [38]. In line with our findings, unmet needs in this domain have been associated with carer distress [10] and well-being [25] indicating the impact this can have on various aspects of quality of life.

Our findings on the importance of the information aspects of unmet healthcare needs may reflect the fact that decisions regarding cancer treatment and care are seldom made by the patients alone. Patients rely on their social networks and interpersonal relationships to inform decision-making [39]. This may especially be the case with HNC where the functional and social impairments among survivors [3, 11], and their resulting care needs, are complex. This creates a complex environment for carers who invariably experience heightened healthcare needs which may be unmet, as evidenced here.

HNC carer happiness associations

On average, HNC carers reported reasonably high levels of happiness – comparable with population norms from the European Quality of Life Survey [40] - suggesting that caring for HNC survivors did not significantly impact on their well-being. This may be because, rather than decreasing happiness, caring may in fact increase happiness, especially if the time involved is less than 6 hours a week [41]. Although our results did not indicate those spending less time caring were happier overall, a number of other associations emerged which yielded insight into the factors involved in this process.

Consistent with other research (e.g. [41]), we found that female carers of HNC survivors had lower levels of happiness than their male counterparts, a difference which cannot be accounted for by longer hours spent caring. While female carers did not report feeling more burdened by care, their lower level of happiness may reflect an underlying need for more psychological support, [4, 16]; we found that female carers in our sample reported higher psychological and emotional unmet needs than male carers. Similarly, while comorbidity did not influence carer burden, it did demonstrate a significant association with happiness, suggesting that those carers suffering from health complications are more likely to suffer deficits in quality of life, a finding echoed elsewhere [29, 37, 41]. This may be explained by the fact that those with comorbid conditions have a greater difficulty combining care with their daily activities [29], however it cannot be ruled out that lower happiness could be due to the comorbid condition itself, rather than the act of caring.

After adjusting for gender and comorbidity, the perceived unmet needs of carers also had a significant impact on happiness levels. The observed association between lower unmet psychological support needs and greater happiness is consistent with the finding that a range of unmet needs put cancer carers at risk of poor mental health [24]. Meeting psychological needs in particular is important for well-being, with psychological support desired in a significant number of both HNC survivors and carers [42]. In our sample, concern about cancer recurrence was the highest ranked individual unmet need; a concern which has been previously documented to negatively impact on quality of life among HNC carers [43] and general cancer carers [44]. Of the interventions that have currently been developed to address fear of cancer recurrence [45], almost none have addressed the concerns of carers on this issue. This highlights an important gap that requires future work.

Perhaps counter-intuitively, higher levels of unmet information needs were positively associated with happiness in our sample. One possible explanation for this is that happier

carers are more predisposed to, or have a greater desire for, information. This may also be understood with reference to Norwood's [46] information needs pyramid, which describes the kinds of information that individuals seek at different levels. Perhaps less happy carers are at a lower level of information need and therefore tend to concentrate on information that satisfies an immediate need (e.g. coping information), while happier carers seek the higher level of 'helping information' requiring continuous refreshing and confirmation.

Implications

Since unmet healthcare service needs was associated with both carer burden and happiness, it is important for carer wellbeing that ways are found to better meet these needs. Longacre [47] noted that HNC carers suffering from higher objective burden (as measured by the Type of Care Index and the Hours of Care Index) prefer to receive information from health professionals as compared to carers with a lower objective burden. It follows that clearer routes by which carers can engage directly with health professionals would be beneficial. However, Longacre [47] also found that those with low objective burden are more likely to prefer seeking information from other sources, such as the internet, highlighting the need to provide alternate channels to access healthcare information.

To aid the transition from hospital to home care, access to transparent information on the various supports that the health care profession provide including speech and language therapy, dieticians and oral rehabilitation [12, 39] should be provided to carers, as well as patients. This may not only reduce unmet healthcare service needs, but also unmet information needs, potentially increasing many aspects of carer well-being (also [12]).

Strengths and limitations

A core contribution of this study is our elucidation of the association between unmet supportive care needs and HNC carer subjective burden and happiness, after adjusting for carer characteristics. This represents an extension to the current HNC literature which tends to concentrate on patient factors and carer characteristics.

Our study also has a number of limitations. The cross sectional nature of the design means that the results are specific to one time point and claims of causality cannot be made. While the response rate was relatively high, we cannot exclude the possibility of potential non-response bias and that carer quality of life may be different across groups of non-respondents compared to respondents. It is also possible that associations between individual domains of burden may differ from those examined based on an aggregate burden score, but, the nature of the CarerQol instrument limited the investigation of these individual domains. The single item CarerQol-VAS used to measure carer happiness is not specific to cancer carers and may include aspects beyond those related directly to the caregiving experience. Also, as a single item measure assessing a multidimensional construct, it is unclear which specific aspects are impaired by caring, an issue partially overcome by the use of the CarerQol-7D. Disease and treatment-related patient information has not been included in the analysis as the focus of the study was on carer-related factors. Finally, the internal reliability of the CarerQol-7D was somewhat low, likely due to incorporating less than 10 items and the sample size. This may have led to some underestimation of correlations in the analysis.

Conclusions

Our results indicated that different aspects of carer characteristics and unmet needs were associated with carer burden and happiness. While carer burden in HNC may be reduced by addressing the unmet healthcare service needs of carers, happiness was associated with a

wider range of characteristic, situational and unmet needs factors. Therefore, meeting a range of needs is important for maximising overall well-being among carers as well as recognising that particular groups may be more vulnerable to poorer quality of life – in particular female carers, and those with a pre-existing health condition.

Compliance with Ethical Standards

Conflict of interest: None

Ethical approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent: Informed consent was obtained from all individual participants included in the study.

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Figure 1: Distribution of response to CarerQol-7D dimensions for HNC carers

