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Informal caregiving in head and neck cancer: caregiving activities and psychological wellbeing.

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Abstract

The purpose of this study was to quantify the cancer support activities that informal carers of head and neck cancer survivors engage in; and the relationships between care activities and psychological wellbeing. Respondents answered a survey detailing their caring activities, the amount of time that they spent on those activities and how comfortable they felt engaging in them. Psychological wellbeing was assessed by the Depression Anxiety Stress Scales-21. 197 carers took part in the study. The majority (76%) were women, mean age 57.4. In the past month, 45% of carers did not spend any time per week helping their relative/friend with general caring activities such as cleaning the house; 31% spent 1-19 hours/week and 23% spent 20 or more hours/week doing so. Most carers were comfortable assisting their relative/friend, though more carers felt uncomfortable assisting with cancer specific support tasks (31% uncomfortable helping with medication) compared with general support tasks (7% uncomfortable helping with appointments). Feeling uncomfortable was a significant predictor of experiencing depression and anxiety. Caring for more than 20 hours a week was a borderline predictor for experiencing stress. Efforts to identify and address the reasons why carers are discomfited by caring could mitigate psychological issues in this group.

Keywords: Carer, survivor, head, neck, cancer, burden, depression, anxiety, stress, time.

Background

Introduction

Head and neck cancer is the 6th most common form of cancer worldwide, with over 500,000 new cases diagnosed each year (Mehanna *et al.* 2010). Most cases occur in individuals over 40 years of age and alcohol and tobacco use are the main etiological factors (Mehanna *et al.* 2010). Head and neck cancer is associated with high morbidity; it can cause disfigurement and directly or indirectly (as a result of medical treatment) lead to substantial difficulties with eating, swallowing and speaking (Precious *et al.* 2012). It thereby has the potential to seriously undermine an individual's quality of life (Precious *et al.* 2012). As a result, people with head and neck cancer often have complex needs (Ross *et al.* 2010).

While patients with head and neck cancer receive their cancer-directed treatment in hospitals, much of their ongoing care and support actually occurs in the community (Stenberg *et al.* 2010). There, management of the condition and its complications is often supported by family and friends (collectively referred to as informal carers or caregivers) (Given *et al.* 2001; Yabroff and Youong, 2009). To date only a limited amount of research has been conducted specifically on the helping activities that cancer carers engage in (McMullen *et al.* 2014) and the time that caregivers spend on these activities (Yabroff and Youong, 2009). The available research has found that carers provide both cancer-specific and general assistance (Given *et al.* 2001) such as preparing meals, helping with transport and household tasks, providing emotional support and assisting communication with providers (Given *et al.* 2001, Girgis and Lambert, 2009; Mosher *et al.* 2013). One recent study found that many carers appeared to be performing five or more support functions (Precious *et al.* 2012); and, in another, a substantial number of cancer carers reported feeling overwhelmed by the number of care related tasks that they have to manage (Girgis *et al.* 2013). For some carers the time commitment involved in

1 caregiving is substantial and equivalent to a fulltime job (Girgis *et al.* 2013). **As people with**
2 **cancer are living longer as a result of improved medical treatment (Maddens *et al.* 2012)**
3 **an increasing number of carers are providing support over the longer term (what is**
4 **referred to as the post-treatment phase, or survivorship phase, of caring).**

5 Given the sometimes substantial time and task demands of caregiving for someone recovering
6 from cancer, it is perhaps unsurprising that some carers report poor psychological wellbeing.
7 For example many caregivers, including carers of people with head and neck cancer, appear to
8 experience emotional distress as a result of caring (Nijboer *et al.* 1998; Given *et al.* 2001;
9 Oyeboode, 2003; Verdonck-de Leeuw, 2007; Drabe *et al.* 2008; Ross *et al.* 2010; Stenberg *et*
10 *al.* 2010; Longacre *et al.* 2012; Jayani and Hurria, 2012; Romito *et al.* 2013; Lee *et al.* 2014).
11 Some studies, in fact, have found that the rates of anxiety and depression experienced by carers
12 exceeds those among patients (Vickery *et al.* 2003; Lambert *et al.* 2013).

13
14 Identifying psychological distress, and the risk factors and causes of such distress in caregivers
15 is an important end not only in itself, but also because previous research suggests that carers'
16 distress can undermine patients' functioning (Dempster *et al.* 2011; Longacre *et al.* 2012; Otis-
17 Green *et al.* 2012). **A number of factors have been identified as being associated with**
18 **increased risk of psychosocial distress in head and neck cancer carers including: having**
19 **a strong fear of recurrence (Hodges and Humphris 2009), being female (Blood *et al.* 1994)**
20 **being unemployed and having lower educational attainment (Lee *et al.* 2014), greater time**
21 **spent caregiving (Ross *et al.* 2010), a disrupted life schedule and the presence of feeding**
22 **tubes (Verdonck-de Leeuw *et al.* 2010).** Despite the findings mentioned here, however,
23 overall relatively few studies have aimed to identify risk factors for poor psychological health
24 in head and neck cancer carers' (Lee *et al.* 2014); and most of those (including the studies
25 identified her) have sought to identify risk factors in the period soon after diagnosis and/or
26 treatment (Badr *et al.* 2010; Hodges and Humphris 2009; Ross *et al.* 2010; Verdonck-de Leeuw
27 *et al.* 2010). In particular, very few studies appear to have investigated whether aspects of the
28 caregiving burden (such as time spent on caring or tasks performed) are associated with head
29 and neck carers' psychological wellbeing.

30
31 We therefore conducted a study to quantify: the cancer support activities that long-term carers
32 of survivors with head and neck cancer engage in; how comfortable they feel engaging in these

tasks; the time that carers spend on these tasks; and the relationship between psychological distress and caring in this group.

Methods

Design

This investigation was part of a larger study that examined the post-treatment experiences of survivors of head and neck cancer in Ireland (Thomas *et al.* 2014; Pearce *et al.* 2014). For that larger study, 583 head and neck cancer survivors completed a survey that examined their unmet needs. Additionally, 17 survivors and 32 healthcare professionals completed pilot qualitative interviews that focused a). on survivors' unmet needs and b). the tasks that carers assisted survivors with.

We asked all 583 head and neck cancer survivors who had completed the postal questionnaire 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, if they had one). Two hundred and eighty five survivors granted us permission. We wrote to all 285 carers providing them with information about the study, and indicated that we would send them a questionnaire two weeks after they received the initial contact letter. Questionnaires were then sent to all 285 carers, 197 of whom responded (69% response rate). When carers returned 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.

Survey

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

1 survivors' diagnosis was obtained the National Cancer Registry of Ireland's patient
2 records database, and was therefore not based on carer self-report.

4 **DASS-21**

5 To assess carers' psychological wellbeing we used the validated 21 question version of the
6 Depression Anxiety and Stress Scale. The DASS measures psychological wellbeing in
7 three dimensions (anxiety, depression, distress) and is considered to be a reliable measure
8 with good construct validity (Henry and Crawford, 2005).

10 **Financial stress and strain**

11 Following the definitions of Francouer (2005) we examined financial stress (which stems
12 from events that are financial stressors on a household) and subjective financial strain
13 (which is an individual's subjective perception of financial strain). Financial stress and
14 strain questions were extracted from Sharp *et al.*'s (2013) study. Financial stress was
15 examined with a question on how the carer felt about their household's financial situation
16 since their relative/friend was diagnosed with head and neck cancer. Financial strain was
17 assessed with questions on the household's ability to make ends meet in the past month
18 and the impact that caring had on the household's ability to make ends meet. Response
19 options for all three questions were six/seven point likert scales ranging from 'much more
20 difficult'/'very concerned' to 'much less difficult'/'much less concerned' (Sharp *et al.*
21 2013).

23 **Activities of daily living time use instrument**

24 Following Hanly *et al.* (2013) respondents were given a list of 12 activities of daily living
25 that they could potentially help their relative/friend with as part of their caring role
26 (cleaning the house; washing/ironing/shopping/maintenance work and odd jobs;
27 preparing food and drink; personal care; cancer specific care; moving around the house;
28 eating and drinking; making trips and visiting family or friends; assisting with travelling
29 to see a health professional; organising help and taking care of financial matters). For
30 each activity, respondents were asked to describe how many hours that they spent per
31 week in the past month on the activity as a result of caring for their relative/friend.

33 **Head and neck specific care activities**

Twelve specific head and neck related care activities that carers assisted their relative/friends with were identified from interviews with survivors and healthcare professionals. These activities were: preparing special foods; helping with communication; helping to look after feeding tubes; helping to look after breathing tubes; helping with medical complications such as fluid going down the airway; helping with mouth care routines; helping their relative/friend to manage their emotions; helping their relative/friend to deal with changes to their appearance; looking after their relative/friend's appointments; helping with financial matters; helping with communication difficulties; and helping their relative/friend to navigate the health system. For each of these activities carers were asked if they helped their relative/friend (yes/no); and if they did help them, if they felt comfortable doing so (answering a five point likert scale ranging from very uncomfortable to very comfortable).

Data analysis

All analysis was carried out using Stata 12.

Carers' demographic characteristics and financial status were summarised using simple descriptive statistics and chi-square tests.

Caring activities were measured in three ways: 1) time spent caring per week in the past month, 2) number of head and neck specific care tasks engaged in in the past month and 3) comfort with head and neck cancer specific caring activities. Responses to the twelve questions relating to time spent caring were summed to get total time spent on caring activities per week in the stipulated time period. **As there was a high proportion (45%) of respondents who did not spend any time on these caring activities, the total time spent caring per week in the past month was transformed into a categorical variable with three levels. We were interested in comparing those who did no caring (0 hours), a moderate amount (1-19 hours) and a high amount (20+ hours) of caring in the activities of daily living time use instrument. If a respondent did not fill in any hours for any of the 12 tasks, we assumed that s/he spent no hours caring.**

The three DASS-21 psychological sub-scales were analysed separately. Respondents were included in an analysis if all seven questions of a sub-scale were completed. Scores from the seven questions on each scale were totalled using standard methods (Lovibond and Lovibond,

1995), and each response was categorised according to previously defined cut-off points. On each sub-scale, the categories were: normal, mild, moderate, severe and very severe. This classification was reduced to binary outcomes for analysis. **Following Sharp et al. (2013) Respondents were classified based on whether the response was normal or otherwise, e.g. depression of any severity (mild/moderate/severe/very severe) versus none. Similar outcome variables were created for any anxiety, and any stress.**

Multiple logistic regression was used to identify whether aspects of caregiving burden (specifically time spent caring and discomfort with one or more head and neck cancer specific tasks) were significantly associated with depression, anxiety and stress, after adjusting for other factors. Time since diagnosis was considered for inclusion in the models as it was hypothesised that those further out from diagnosis may be providing less care and thus have better psychological health. In addition financial variables were also considered for inclusion as they have been shown to be associated with psychological well-being (Sharp et al. 2013). The financial variables were: ability to make ends meet in the past month, private health insurance, effect of caring on ability to make ends meet, how respondent feels about household finances since relative/friend's diagnosis and having a medical card. Furthermore, we adjusted for socio-demographic variables (age, gender, marital status, children, employment status).

In addition to our main variables of interest - time burden and discomfort, a covariate was included in the multivariable models if it had p-value of less than 0.1 in a likelihood ratio test comparing the model containing the variable with a nested model excluding the variable. Model goodness-of-fit was checked using the Hosmer and Lemeshow test.

Missing data

Compared to those who completed the DASS-21 subscales, respondents who partially completed or did not complete these were older, and a higher proportion had a medical card, children and were not working at time of diagnosis, while a lower proportion had private health insurance.

Almost 6% (11) of subjects did not report whether they had private health insurance and we did not have a date of diagnosis (for the care recipient) for 4% (7) cases. The level of missing

data in other variables was lower and subjects with missing data for any of these covariates were excluded from relevant analyses.

Results

Respondents' characteristics and financial status

Caregivers' demographic characteristics are shown in **Table 1**. Three-quarters (76%) of respondents were women and the majority (89%) were in a relationship (married or living with a partner). Respondents' mean age was 57.4 years (standard deviation: 12.3 years). For 46% of carers the time between their relative's/friend's diagnosis and when they completed the questionnaire was less than five years; for 35% it was between 5 and 10 years; and for 15% it was over ten years. Just over half of respondents had a medical card. The majority of respondents (67%) were not in paid work.

Half of carers indicated that they found it difficult to make ends meet financially in the past month and just under half (48%) indicated that caring for their relative/friend with head and neck cancer made their financial situation more difficult. Just over half (58%) of carers indicated that they felt more concerned about their household financial situation since their relative's/friend's diagnosis.

Information on demographic and clinical characteristics of survivors is contained in table S1.

Time spent per week on general and cancer-specific caring activities

Table 2 describes the results of the activities of daily living time use instrument (Hanly *et al.* 2013). For each individual task, most carers did not spend any time per week helping their relative/friend. However for most individual tasks a small percentage of carers (between 5% and 15%) spent 6 or more hours a week helping their relative/friend. Individual tasks on which a relatively large proportion of carers were spending at least one hour a week on included: liaising with healthcare services (38%), preparing food (33%) and cleaning the house (32%). Additionally, some carers were spending substantial amounts of time per week helping their relative/friend, with 23% spending 20 or more hours a week doing so and another 31% spending between 1-19 hours.

1
2 In chi-squared tests the factors significantly associated with caring 20+ hours a week were
3 predominantly financial. Respondents with a medical card were more likely to care for 20+
4 hours than those without one (29% vs. 17%, p-value .023); those without private health
5 insurance caring were more likely to care for 20+ hours than those with insurance (32% vs.
6 17%, p-value .0005); those finding it difficult to make ends were more likely to care for more
7 than 20+ hours than those who found it easy to make ends meet (31% vs. 16%, p-value .0008);
8 and those who were more concerned about their finances since their relative/friend's diagnosis
9 were more likely to care for 20+ hours than those without such concerns (29% vs. 16%, p-
10 value .001). Relationship status and stage of cancer in the care recipient were not associated
11 with time spent caring.

12 13 Head and neck cancer specific caring activities

14
15 **Table 3** describes the head and neck cancer specific tasks that carers assisted their
16 relative/friend with in the past month. A substantial proportion of carers were helping with
17 more general, non-medical tasks such as navigating the health system (53%), helping their
18 relative/friend manage their emotions (51%) and looking after appointments (59%). Fewer
19 carers (though still almost 10%) were helping with more cancer specific care activities such as
20 feeding and breathing tubes. 76 carers (38%) helped with five or more tasks in the past month,
21 and another 76 (38%) with 1-4 tasks; 45 (23%) of carers did not help with any of these tasks in
22 the past month.

23
24 For most tasks, most carers felt comfortable helping their relative friend, though carers
25 appeared to be relatively more uncomfortable helping with the medical aspects of care such as
26 feeding and breathing tubes and medical complications (**Table 3**). For example, 85% of
27 respondents felt comfortable helping their relative/friend to navigate the healthcare system
28 whereas only 50% felt comfortable assisting them with medical complications. In chi-squared
29 tests, the main factors (significant at the $p=0.05$ level) associated with feeling uncomfortable
30 with head and neck specific cancer care tasks were: not having private health insurance, finding
31 it difficult to make ends meet and feeling concerned about household finances .

32 33 Psychological health

Of the respondents who completed the depression subscale of the DASS-21 (n=178), 66% scored in the normal range and 34% reported experiencing any level of depression. 179 respondents completed the anxiety subscale; 75% scored in the normal range and 25% reported experiencing any level of anxiety. 176 respondents completed the stress subscale and 80% scored in the normal range for stress, with 20% reporting experiencing any level of stress.

Depression

Table 4 shows the crude and adjusted odds ratios (ORs) for variables associated with depression of any severity. In the multivariable analysis the factors significantly associated with having any depression were: feeling uncomfortable helping with one or more head and neck cancer care tasks, being female, not having private health insurance and caring for a more recently diagnosed person. There was a borderline statistically significant association with time spent caring after adjusting for other factors (p=0.063).

Anxiety

In the multivariable analysis the factors significantly associated with having anxiety were: feeling uncomfortable helping with one or more head and neck cancer care tasks, finding it difficult to make financial ends meet since began caring for relative/friend, not being in paid work, having children and caring for someone with a more recent diagnosis. **There was a borderline statistically significant association with time spent caring after adjusting for other factors (p=0.065).**

Stress

In the multivariable analysis the factor significantly associated with having stress was finding it difficult to make financial ends meet in the past month. After adjusting for other factors, time spent caring (p=0.063) and feeling uncomfortable with one of more caregiving tasks (p=0.080) both showed a borderline statistically significant relationship with stress.

Discussion

This study investigated various aspects of the support activities that carers of survivors with head and neck cancer engage in and if these are related to psychological wellbeing. Overall, the results show that many carers in the post-treatment period appear to be relatively psychologically resilient, in the sense that the majority score in the normal range for anxiety, stress and depression. Many of them are not spending substantial amounts of time per month

on cancer care activities and most are comfortable with the tasks they perform. However the results also indicate that a minority of carers are spending considerable amounts of time caring per week, are engaged in a significant number of care tasks, are uncomfortable with the tasks they are performing, or are experiencing negative psychological states.

Strengths and limitations

The strengths of the study include the relatively large sample of carers; and the fact that the study investigated issues (discomfort, time spent on caring tasks) that have received little attention from previous head and neck cancer researchers. There are several limitations to the study. Many of the questions about support (concerning caring tasks and time spent caring) focused solely on the 'past month'. While questions were asked in this way to maximise recall, it may be that some carers would have engaged in cancer support activities in the past, but not in the past month. Since the participants were nominated by care recipients as being involved in caring for them, it is likely that the results presented underestimate the activities that head and neck cancer carers engage in and the time spent on those activities across the survivorship continuum. The study's cross-sectional design means that we were unable to monitor changes in caregivers' activities over time, or changes in their psychological wellbeing. **The head and neck specific task instrument that we devised was not a content validated instrument, though it does have face validity since its items were delineated by patients with head and neck cancer and head and neck cancer professionals.**

Caregiving tasks and psychological wellbeing

Carers in this study engaged in a variety of head and neck cancer specific medical and non-medical support activities (**Table 3**). The most common tasks that that carers engaged in were helping their relative/friend to manage their emotions, helping their relative/friend to navigate the healthcare system and looking after appointments. Head and neck cancer specific tasks that were medically focused, such as assisting with feeding and breathing tubes, were engaged in less often. This distribution of tasks mirrors that found in previous head and neck cancer studies, such as that of Precious *et al.* 2012. Most carers in the current study indicated that they felt comfortable engaging in most of the general support tasks, such as food preparation (**Table 3**). These findings contrast somewhat with other studies such as research by Patterson *et al.* (2013), which found that carers can sometimes be uncomfortable assisting with such activities. The difference between these findings might relate to the length of time that carers in this study

1 had been helping their relative or friend (compared to Patterson *et al.*, carers in this study had
2 been caring for longer, and may have been more habituated to support tasks); alternatively,
3 carers in Patterson's study may have been looking after patients with specific food-related
4 difficulties (such as dysphagia) which carers in this study may not have had to deal with.
5 However while most carers in the current study felt comfortable with general care tasks, it was
6 notable that a relatively greater proportion of carers felt uncomfortable helping their
7 relative/friend to manage their emotions compared with activities such as looking after
8 appointments; as far as we are aware this is the first study to identify that head and neck cancer
9 carers themselves can feel uncomfortable providing emotional support. This is an important
10 finding given that providing emotional support is one of caregivers' key tasks, and one that is
11 often overlooked by healthcare professionals (Precious *et al.* 2012). Other studies of patients
12 have noted that emotional management is one of the most stressful support activities that carers
13 engage in (Precious *et al.* 2012), not least because carers may have to provide emotional
14 support while simultaneously dealing with their own emotions in relation to the caregiving role
15 (Penner *et al.* 2012).

16
17 It was also notable that while carers engaged in the medically specific care tasks (such as
18 helping with feeding and breathing tubes and helping with medical complications) less
19 frequently than the more general tasks (such as managing appointments), they generally felt
20 more uncomfortable doing so (**Table 3**). It has been suggested that carers who are
21 uncomfortable with a task may be unable to help the patient to the degree that is needed
22 (Stenberg *et al.* 2010), suggesting that finding effective ways to increase carers' comfort is
23 important for both the carer and the care recipient. Moreover, discomfort also predicted carer
24 depression and anxiety, a finding that we have not seen previously reported in relation to carers
25 of patients with head and neck cancer. Helping carers to resolve feelings of discomfort in
26 relation to cancer support activities may therefore significantly improve psychosocial
27 wellbeing among carers themselves and improve the support received by patients/survivors.
28 What it is about a task that leads a carer to feel discomfort is unclear; for some tasks, it may be
29 the length of time that people spend caring that leads to discomfort, while others (such as
30 helping with breathing or feeding tubes), may be inherently uncomfortable to engage in.
31 Further research could usefully seek to better explain this. Our findings also suggest a need for
32 healthcare professionals to ascertain exactly why some carers feel uncomfortable with these
33 tasks (for example, because they feel that they do not have enough knowledge, or the
34 appropriate skills, or confidence in their abilities, to adequately implement them), and if

necessary provide support, education or training to help carers overcome their feelings of discomfort.

Time since diagnosis

This study included carers of survivors at different points in the post-treatment trajectory. Some carers completed the survey more than ten years after the care recipient's diagnosis, others were less than five years. This is a common feature of research with carers for people with head and neck cancer, where samples are often heterogeneous (Longacre *et al.* 2012). We controlled for this heterogeneity by including time since diagnosis as an explanatory variable in our models. The evidence to date about the relationship between time since treatment and carers' mental wellbeing is mixed, with some finding that distress declines over time (Blood *et al.*, 1994), and others that time since diagnosis is not associated with mental health (Ross *et al.* 2010). Our results support the argument that caregivers typically have better psychological health the further their care-recipient is out from treatment. This is likely because they are less involved in active caring than carers of more recently diagnosed patients. It may also be that long-term carers have reached an accommodation with the cancer and its impacts on their life, and are less likely to experience emotional disequilibrium as a result.

Time spent on caregiving activities and psychological wellbeing

Just over a fifth of respondents spent 20 or more hours per week in the past month caring for their relative/friend (as assessed by the activities of daily living time use instrument); given that many of the participants were caring for longer-term survivors, these percentages are notable. Previous studies have found that extended caring can be a significant burden on carers and lead to reduced well-being (Ross *et al.* 2010; Olson *et al.* 2014). Extended caring can impact carers' lives in a variety of ways, for example reducing the time available to them for socializing, hobbies and travel (Nijboer *et al.* 1999; Longacre *et al.* 2012; Mosher *et al.* 2013; Girgis *et al.* 2013). Caring for 20+ hours per week is also likely to result in carers experiencing disruptions in their day-to-day schedules and lead them to end up juggling multiple- and often conflicting- tasks (Longacre *et al.* 2012; Mosher *et al.* 2013). Furthermore, carers may also experience significant stress as a result of wanting to help their relative/friend and feeling that their lives are restricted and disrupted by doing so (Mehta *et al.* 2014). They can be psychologically caught between wanting to help and feeling constrained. **However it is also important to note that the statistical association found in this study between mental health**

1 **and time spent caring was weak, and it appears another measure of care – discomfort**
2 **with tasks was more strongly associated with poor psychological outcome.**

3 4 Financial difficulties

5 Financial difficulties were prevalent in this sample, with just under half of carers finding it
6 difficult to make ends meet in the past month and just under half indicating that their financial
7 situation became more difficult since they began caring (**Table 1**). Although other studies have
8 not specifically examined cancer-related financial stress and strain in head and neck caregivers,
9 they do point to financial consequences of caregiving; for example, one study reported that,
10 because cancer often prevents caregivers' from obtaining paid work, it sometimes results in
11 carers (who are often partners or wives) using up the family savings (Jayani and Hurria, 2012).
12 People with head and neck cancer and their carers also often come from disadvantaged
13 economic backgrounds to start with (Rogers *et al.* 2011) and our study population is likely to
14 be no different from others in this regard. Carers' financial problems could further stem from
15 the fact that the majority of respondents were either retired or working at home, and may
16 therefore have been living on a fixed and relatively marginal income. Caring, with its attendant
17 costs such as travelling to hospital appointments, buying special foods etc., could also put
18 substantial financial stress or strain on people who may not have significant resources at the
19 outset. Our findings also indicated (for the first time, as far as we are aware) that financial
20 difficulties were significant predictors of stress and anxiety in head and neck cancer caregivers.
21 Greater financial resources may play a buffering psychological role for people who are caring
22 for survivors of head and neck cancer, with those with more resources having more options to
23 escape from the caring burden, for example by securing formal care services that can provide
24 psychological relief. Those with fewer resources however may be trapped firmly in the caring
25 role with few possibilities to escape from its demands (Gaugler *et al.* 2005).

26 27 Implications for services

28 A significant predictor of carers' psychological distress in this study was discomfort with
29 cancer care tasks. For (at least some) carers this discomfort may stem from lack of knowledge,
30 confidence and skill about cancer care activities, such as how to assist with breathing and
31 feeding tubes. It has been previously noted that many cancer carers receive no formal training,
32 and that many of them feel unprepared for their caring responsibilities or have too much
33 responsibility placed on them (Bookman *et al.* 2007). Healthcare professionals
34 (psychooncology and general medical) might be able to supply some carers with the support

1 and training that they need to address their discomfort; though this requires health professionals
2 to be ready to ascertain and assess carers' levels of comfort. With this knowledge at least some
3 carers should feel more empowered and have greater feelings of mastery and control, which
4 could in turn serve to combat feelings of helplessness, anxiety and stress. Where resources are
5 available the findings also suggest that it might be useful for healthcare professionals
6 (especially community based health professionals) to assist with care tasks that caregivers find
7 especially uncomfortable. Secondly, the findings indicate that health professionals need to pay
8 particular attention to carers of people with head and neck cancer who are at risk of poor
9 mental health, such as those with financial issues, those who are older and those caring for
10 substantial amounts of time per week. **Thirdly, there is a need for researchers to develop a**
11 **fully validated instrument (rather than just face validated) to assess time and task burden**
12 **in head and neck cancer caregivers.**

15 Conclusion

16 The results of this study suggest that, in the post-treatment period, many informal carers of
17 head and neck cancer patients appear to be doing reasonably well. However the results also
18 indicate that there is a minority of carers who are spending large amounts of time caring per
19 week, who are engaged in a significant number of care tasks, who are uncomfortable with the
20 tasks they are performing, and who are experiencing negative psychological states. Efforts to
21 identify and address the reasons why carers are discomforted by caring could be a quick and
22 cost-effective way to mitigate psychological issues in this group.

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Tables

Tables

Table 1. Characteristics of carers of survivors of head and neck cancer.

	n	(%)
number of respondents	197	(100)
Socio-demographic		
sex		
Male	44	(22)
Female	150	(76)
Not reported	3	(2)
current marital status		
married/partner	171	(88)
not married	24	(12)
Not reported	2	(1)
have children		
Yes	168	(85)
No	24	(12)
not reported	5	(3)
employment status		
paid employment	64	(32)
looking after family/home	52	(26)
retired/unemployed/disability	80	(41)
Financial		
ability to make financial		
ends meet in last month		

difficult	100	(51)
easy	96	(49)
Not reported	1	(<1)
effect of caring on ability to make ends meet		
more difficult	94	(48)
no change	88	(45)
less difficult	10	(5)
Not reported	5	(2)
feelings about household finances since diagnosis		
more concerned	114	(58)
no change	68	(34)
less concerned	12	(6)
Not reported	3	(2)
medical card (entitling bearer to free medical care)		
Yes	106	(54)
No	87	(44)
Not reported	4	(2)
private medical insurance		
Yes	102	(52)
No	84	(43)
Not reported	11	(5)
Time since cancer diagnosis of care recipient		
<5 years	91	(46)
5-9.99 years	70	(35)
10+ years	29	(15)
Not reported	7	(4)

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Table 2: Time per week spent on household activities and cancer related assistance activities as a result of caring in the last month

Activity	0 hours		1-5 hours		6+ hours		Any time	
	n	(%)	n	(%)	n	(%)	n	%
Cleaning house	134	(68)	34	(17)	29	(15)	63	(32)
Washing ironing	151	(77)	33	(17)	13	(7)	46	(24)
Shopping	128	(65)	51	(26)	18	(9)	69	(35)
Odd jobs	140	(71)	39	(20)	18	(9)	57	(29)
Preparing food	132	(67)	38	(19)	27	(14)	65	(33)
Assisting relative/friend with personal care	176	(89)	12	(6)	9	(5)	21	(11)
Cancer specific care Assisting relative/friend move around house	167	(85)	17	(9)	13	(7)	30	(16)
Helping relative/friend with eating and drinking	188	(95)	8	(4)	1	(1)	9	(5)
Making trips	184	(93)	9	(5)	4	(2)	13	(7)
Visiting doctor	149	(76)	31	(16)	17	(9)	48	(25)
Assisting with financial matters	122	(62)	56	(28)	19	(10)	75	(38)
	152	(77)	34	(17)	11	(6)	45	(23)

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6 **Table 3 : Head and neck cancer specific** activities that carers assisted survivors with in the
7 past month, and carers’ level of comfort with helping with these activities

Help with...	Yes		If yes, then how comfortable with task?							
			uncomfortable		neither comfortable nor uncomfortable		comfortable		Not reported *	
	n	%	n	%	n	%	n	%	n	%
food preparation	62	(31)	6	(10)	6	(10)	49	(79)	1	(2)
medication	62	(31)	7	(11)	6	(10)	48	(77)	1	(2)
feeding tubes	19	(10)	4	(21)	2	(11)	13	(68)		
breathing tubes	18	(9)	4	(22)	1	(6)	12	(67)	1	(6)
medical complications	16	(8)	6	(38)	2	(13)	8	(50)		
mouth routine	29	(15)	4	(14)	4	(14)	21	(72)		
managing emotions	101	(51)	21	(21)	10	(10)	70	(69)		
dealing with change in appearance	65	(33)	11	(17)	10	(15)	44	(68)		
communication difficulties	82	(42)	9	(8)	9	(8)	95	(83)	1	(1)
looking after appointments	114	(59)	7	(9)	8	(10)	62	(77)	4	(5)

financial

management

navigate healthcare

system

81	(41)	21	(26)	6	(7)	55	(67)
104	(53)	9	(9)	7	(7)	88	(85)

1 *Missing values refer to respondents who indicated that they helped with an activity, but did
2 not indicate whether or not they felt comfortable doing so.

3 **Table 4. Variables associated with depression, anxiety and stress; multiple logistic**
4 **regression (OR) with 95% confidence intervals and p-values.**

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	depression		anxiety			stress	
	<u>univariable</u>	<u>multivariable</u>	<u>univariable</u>	<u>multivariable</u>		<u>univariable</u>	<u>multivariable</u>
	crude OR	adjusted OR ²	crude OR	adjusted OR ³		crude OR	adjusted OR ⁴
	95% CI, p-value ¹	95% CI, p-value ¹	95% CI, p-value ¹	95% CI, p-value ¹	p-	95% CI, p-value ¹	95% CI, p-value ¹
time burden							
0 hours	ref	ref	ref	ref		ref	ref
1-19 hours	0.85 [0.40,0.84]	0.64 [0.25, 1.67]	1.52 [0.63, 3.7]	0.63 [0.21, 1.91]		1.17 [0.43,3.18]	0.91 [0.32,2.61]
20+ hours	2.85 [1.32,6.16]	2.20 [0.81, 5.78]	4.65 [1.98,10.9]	2.35 [0.83, 6.68]		3.7 [1.50,9.11]	2.61 [1.01,6.80]
	p = 0.008	p = 0.063	p = 0.001	p = 0.065		p = 0.009	p = 0.063
discomfort with head and neck cancer care tasks							
no	ref	ref	ref	ref		ref	ref
one or more	5.11 [2.31,11.3]	6.54 [2.2, 19.5]	3.71 [1.69,8.18]	3.83 [1.38,10.6]		3.14 [1.35,7.30]	2.25 [0.92,5.5]
	p < 0.001	p < 0.001	p = 0.001	p = 0.01		p = 0.01	p = 0.080
gender							
male	ref	ref	ref			ref	
female	2.35 [1.01,5.50]	2.64 [0.97, 7.24]	2.2 [0.86, 5.67]			1.85 [0.66,5.17]	
	p = 0.04	p = 0.047	p = 0.08			p = 0.22	
Private health insurance							
no	ref	ref	ref			ref	
yes	0.34 [0.18,0.67]	0.44 [0.20, 0.98]	2.1 [1.01,4.18]			0.42 [0.19,0.92]	
	p = 0.001	p = 0.043	p = 0.008			p = 0.029	
time between cancer diagnosis of care recipient and survey							
< 5 years	ref	ref	ref	ref		ref	
5-9 years	1.08 [0.55,2.13]	1.53 [0.68, 3.44]	0.82 [0.40,1.70]	0.90 [0.36, 2.24]		0.93 [0.41,2.11]	
10+ years	0.36 [0.11,1.15]	0.15 [0.03, 0.69]	0.19 [0.04,0.84]	0.08 [0.01, 0.45]		0.74 [0.22,2.46]	

	p = 0.101	p = 0.037	p = 0.03	p = 0.002	0.88	
Carer age at time of survey						
	1.01 [0.99,1.03]	1.03 [1.00, 1.08]	0.99 [0.96,1.01]		1.00 [0.97,1.03]	
	p = 0.39	p = 0.024	p = 0.38		p = 0.90	
Ability to make financial ends meet in the past month						
easy	ref		ref	ref	ref	ref
difficult	2.40 [1.26,4.58]		3.93 [1.83, 8.43]	4.5 [1.7,11.8]	3.34 [1.46,7.67]	2.6 [1.09, 6.24]
	p = 0.007		p = 0.0002	p = 0.001	p = 0.003	p = 0.026
Effect of caring on ability to make ends meet						
same/less difficult	ref		ref		ref	
more difficult	2.47 [1.30,4.69]		3.06 [1.48,6.30]		2.88 [1.30,6.38]	
	p = 0.005		p = 0.002		p = 0.007	
Feel about household finances since relative/friend's diagnosis						
same/less concerned	ref		ref		ref	
more concerned	2.05 [1.06,3.94]		3.77 [1.68, 8.46]		2.44 [1.06,5.60]	
	p = 0.03		p = 0.0005		p = 0.03	
Employment status						
not employed	ref		ref	ref	ref	
paid employ	0.48 [0.23,1.02]		0.35 [0.14, 0.88]	0.20 [0.07, 0.61]	0.51 [0.20,1.32]	
looking after family/home	0.92 [0.43,1.96]		1.11 [0.50, 2.44]	0.55 [0.19, 1.57]	0.94 [0.39,2.27]	
	p = 0.12		p = 0.03	p = 0.01	p = 0.32	
medical card						
no	ref		ref		ref	
yes	1.69 [0.89,3.20]		2.10 [1.01,4.18]		2.33 [1.03,5.26]	
	p = 0.11		p = 0.04		p = 0.035	
have children						
no	ref		ref	ref	ref	
yes	2.8 [0.91,8.66]		8.78 [1.15, 67.1]	10.8 [1.23,95]	1.71 [0.48,6.11]	
	p = 0.05		p = 0.004	p=0.006	p = 0.39	

¹p-value from likelihood ratio test.

² multivariable logistic regression model adjusted for time burden, uncomfortable doing one or more tasks, gender, health insurance, time since diagnosis and age.

³ multivariable logistic regression model adjusted for time burden, uncomfortable doing one or more tasks, time since diagnosis, ability to make ends meet, employment status and have children.

⁴ multivariable logistic regression model adjusted for time burden, uncomfortable doing one or more tasks and ability to make ends meet.

Table S1: demographic and clinical variables of care-recipient population

Cancer survivor characteristics	No.	%
age		
< 50 years	43	21.8
60 – 64 years	102	51.8
65+ years	51	25.9
unknown	1	0.5
sex		
female	62	31.6
male	134	68.4
unknown	1	0.5
marital status		
married/living with partner	158	80.2
not living with partner	38	19.3
unknown	1	0.5
head and neck cancer return/spread		
no	178	90.4
yes	10	5.1
unknown	9	4.6
medical card		
no	101	51.3
yes	92	46.7
unknown	4	2
private health insurance		
no	102	51.8
yes	87	44.2
unknown	8	4.1
have children		
no	33	16.8
yes	158	80.2
unknown	6	3
live alone		
no	169	85.8
yes	24	12.2
unknown	4	2
education		
primary school	61	31

secondary school	86	43.7
3rd/4th level	43	21.8
unknown	7	3.6
residence		
Dublin	49	24.9
other city/town/village	89	45.2
countryside	58	29.4
unknown	1	0.5
employment		
paid employment	86	43.7
not paid employment	110	55.8
unknown	1	0.5
stage		
1	60	30.5
2	28	14.2
3	21	10.7
4	54	27.4
unknown	34	17.3
chemotherapy *		
yes	147	74.6
no	49	24.9
unknown	1	0.5
radiotherapy*		
yes	63	32
no	133	67.5
unknown	1	0.5
other treatment*		
yes	162	82.2
no	34	17.3
unknown	1	0.5
surgery*		
yes	59	29.9
no	137	69.5
unknown	1	0.5

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2 ***treatment** receipt within 8 months of diagnosis

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