Worry in Head and Neck Cancer Caregivers

The Role of Survivor Factors, Care-Related Stressors, and Loneliness in Predicting Fear of Recurrence

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Background: Fear of recurrence (FOR) is a primary concern for both cancer survivors and their caregivers, yet little is known about what care-related factors exacerbate this worry.

Objectives: This study aimed to establish the role of care-related stressors—as distinct from survivor characteristics—in predicting FOR in head and neck cancer caregivers.

Methods: HNC survivor–caregiver dyads took part in a mailed survey. Survivors provided information on health and quality of life (using the Functional Assessment of Cancer Therapy Questionnaire). Caregivers provided sociodemographic information, impact of caring on their time and finances, as well as their level of social support (Oslo Support Scale), loneliness (3-point loneliness scale), and completed the Worry of Cancer Scale (to measure FOR).

Results: Data from 180 dyads were available for analysis. Multiple regression analysis was used to examine the role of caregiver stressors, social support, and loneliness while controlling for caregiver and survivor characteristics. The model explained 28% of the variance in Worry of Cancer scores (FOR). Caregivers who reported more loneliness, spent more time caring, and had greater financial stress from caring had higher scores on Worry of Cancer (FOR). Female caregivers, those caring for younger survivors, and those with survivors who had undergone less extensive forms of surgery also reported higher FOR.

Discussion: A combination of factors place caregivers at greater risk of cancer-related worry, paving the way for designing interventions aimed at reducing FOR in caregivers of patients with head and neck cancers.

Key Words: caregivers ● fear of recurrence ● head and neck cancer ● Ireland ● loneliness

Head and neck cancer (HNC) comprises a range of cancer sites including those of the mouth, pharynx, and larynx. Risk factors include smoking, alcohol consumption, and, more recently, infection with certain human papillomavirus strains. Consequently, global incidence rates vary substantially by country and by gender (Torre, Siegel, Ward, & Jemal, 2016). A diagnosis of HNC can have a profound effect not only on the patient themselves but also on their families and friends. HNC and its treatment can result in a number of physical and functional problems for patients, including complications with food intake such as dysphagia (difficulty swallowing), as well as visible manifestations, most notably facial mutilation (Nightingale, Lagorio, & Carnaby, 2014). Psychosocial problems often arise in light of these effects and can include social isolation, employment difficulties, and problems coping (Lebel & Devins, 2008).

In order to ease the burden for survivors as they cope with an HNC diagnosis and all that it brings, the role of informal carers (hereafter *caregivers*) is paramount in providing support and assistance (Humphris, 2016). However, although providing care can lead to many positive effects (Li & Loke, 2013), it can also have a negative impact on quality of life (QOL), with some caregivers of HNC survivors experiencing high levels of stress as a result of their roles (Longacre, Ridge, Burtness, Galloway, & Fang, 2012). A diagnosis of cancer entails an element of uncertainty, which can have an impact on survivor well-being (Hall, Mishel, & Germino, 2014). Perhaps because of this uncertainty, a frequently reported concern is general worry about cancer and specifically a fear that the cancer will recur or progress (Simard et al., 2013). Across a range of cancer sites, fear of recurrence (FOR) has been shown to considerably

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impact on the QOL of both survivors (Simard et al., 2013; Thewes et al., 2014) and their caregivers (Mellon, Kershaw, Northouse, & Freeman-Gibb, 2007; Simard et al., 2013), which can in turn lead to problems coping (Simard et al., 2013).

For survivors of HNC, FOR has repeatedly emerged as the most highly ranked concern (Rogers, Cross, Talwar, Lowe, & Humphris, 2016) and reports suggest that this fear is even more prevalent in caregivers than in HNC survivors themselves (Hodges & Humphris, 2009; Lin, Chen, Chang, Fang, & Lai, 2016; Longacre et al., 2012). Following diagnosis, FOR predicts levels of posttraumatic stress disorder in caregivers more strongly than the clinical characteristics of the survivors (Posluszny et al., 2015). FOR is also negatively correlated with HNC caregiver physical and mental health (Lin et al., 2016), highlighting the burden than this may entail. Moreover, not only can FOR have negative implications for caregivers themselves, it may also interfere with the caregiving role by distracting the caregiver from fulfilling their caring tasks (Kim, Carver, Spillers, Love-Ghaffari, & Kaw, 2012). Beyond this, given the dyadic nature of FOR, caregivers' fears can affect those of the patients, potentially decreasing their well-being further (Kim, Carver, et al., 2012; Mellon et al., 2007).

Although a systematic review of the literature found that younger age, presence, and severity of physical symptoms and lower QOL were associated with higher FOR across cancer survivors (Simard et al., 2013), less evidence is available for the caregiver population. Although some studies have attempted to investigate what leads to FOR in cancer caregivers generally (Crist & Grunfeld, 2013; Mellon et al., 2007; Simard et al., 2013), few have done so systematically in the HNC population. Examination of predictors of FOR in HNC caregivers has mainly focused on survivor or caregiver characteristics (Hodges & Humphris, 2009), including treatment-related factors (Lin et al., 2016). Less attention has been paid to how care-related stressors, such as the time or financial costs involved in caring, may impact on this. Social support is known to attenuate burden in HNC caregivers (Chen et al., 2009) and is crucial in buffering against stress (Park et al., 2012). However, perceptions of loneliness, as distinct from actual support, may be even more key in influencing FOR given the negative impact loneliness has on QOL in a range of settings (Ekwall, Sivberg, & Hallberg, 2005; Hawkley & Cacioppo, 2010; Stenberg, Ruland, & Miaskowski, 2010). Whether social support or loneliness influences FOR among HNC caregivers does not appear to have been investigated.

In recent years, a variety of conceptual frameworks have been proposed to explain FOR in cancer survivors, including relational frame theory and the self-regulatory executive function model (Fardell et al., 2016). The most dominant approach—and one that has received the most empirical support, however—is the common sense model (CSM). The CSM has been adapted as an explanatory framework for FOR in cancer survivors generally (Lee-Jones, Humphris, Dixon, &

Hatcher, 1997) and in HNC survivors specifically (Llewellyn, Weinman, McGurk, & Humphris, 2008). At its core, the CSM proposes that illness representations are formed based on information currently available to the survivor. The interpretation of this information involves both cognitive and emotional elements, which in turn impact on coping strategies. Such information can include general ideas (e.g., cultural knowledge of cancer), external social environment (e.g., information provided by healthcare professionals), and current experience (Llewellyn et al., 2008). In the context of our study, it is reasonable to expect that caregivers' FOR would also be influenced by such representations, including their perceptions of loneliness and the burdens associated with care.

Purpose

The importance of meeting the needs of cancer caregivers has been recognized as vital for reducing stress and increasing the well-being of both caregivers and survivors (Chen et al., 2009; Sklenarova et al., 2015). Because FOR consistently emerges among the most highly ranked needs, a greater understanding of its predictors is merited. Our primary research question is hence to address what leads to FOR in HNC caregivers. More specifically, this study aims to investigate the predictors of FOR in HNC caregivers, examining the role of caregiver stressors, social support, and loneliness while controlling for caregiver and survivor characteristics. A greater understanding of how these factors combine to impact cancer-related worry in caregivers may help inform interventions aimed at reducing FOR.

METHODS

Participants and Design

The study entailed a cross-sectional design with two phases. Ethical approval was granted from nine university hospital ethics committees covering all the major centres at which HNC is treated in Ireland. Following this approval, 991 HNC survivors, identified from the National Cancer Registry, Ireland (NCRI), were contacted in April 2012. Treating clinicians were asked to screen survivors and exclude those who had died, were less than 8 months postdiagnosis, were under the age of 18, had a recent recurrence (in the last few months), were terminally ill, or had dementia.

Of the 583 survivors who completed the questionnaire and provided written consent by post, 258 indicated they had a caregiver who could be contacted. These caregivers were sent a letter with information about the study between March and December 2013, along with a questionnaire to complete and a written consent form.

Instruments

Survivor Characteristics and Health Information Survivors provided sociodemographic and health information, including age and time since diagnosis. Further information

was obtained from NCRI records to determine survivors' cancer stage at diagnosis and treatment received, including chemotherapy, radiotherapy, and surgery. For those who had undergone cancer-directed surgery, additional information about the extent of surgery was obtained from the NCR database. An oral surgeon (EOS) broadly classified each type of surgery as major or minor in terms of the likely functional impact that this would have on the survivor postsurgery.

Survivor QOL In order to assess QOL, survivors completed the Functional Assessment of Cancer Therapy Questionnaire (Cella et al., 1993) for HNC survivors (FACT-HN). Here participants rated their well-being over the past 7 days for 39 different items, which corresponded to four general domains (physical, social/family, emotional, and functional QOL), as well as one HNC-specific domain. Items were scored on a 5-point response scale ranging from 0 = *not at all* to 4 = *very much*. Negatively phrased items were recoded and summed to compute an overall FACT-HN score ranging between 0 and 156, with higher scores indicating higher QOL. This measure has been validated previously in HNC survivor populations (Yount et al., 2007) with high reliability (Cronbach's alpha = .79–.87). In our sample, strong reliability was also evident (Cronbach's alpha = .94).

Caregiver Characteristics and Care-Related Stressors

The caregiver questionnaire requested sociodemographic information (age, gender, employment status, relationship to survivor), as well as the impact caring had on their time and financial situation (considered care-related stressors). To measure the time spent caring, participants were asked to estimate how many extra hours per week they had spent over the past month on care-related domestic tasks, activities of daily living, instrumental activities of daily living, and cancer-specific care (Hanly et al., 2013). Responses for each of these categories were summed to give a total time spent caring. For those who reported spending some time caring (i.e., 1 or more hours per week), a median split was employed to classify caregivers into those spending a low/moderate amount of time (between 1 and 13.49 hours) and a high amount of time (≥13.5 hours) caring per week.

To assess the financial stress of caring, caregivers were asked to respond to the following question: "Would you say caring for your relative/friend has made your household's ability to make ends meet…" followed by seven options ranging from 1 = *much more difficult* to 7 = *much less difficult*. Scores for this item were recoded so that a higher score indicated higher levels of caring-related financial stress (Sharp, Carsin, & Timmons, 2013).

Caregiver Social Support and Loneliness

Social support was measured using the Oslo Support Scale (OSS-3; Dalgard et al., 2006). Participants are asked to indicate the number of people they could count on if they had a serious problem (with three response options: 1–2, 3–4, or 5+ people), how much concern they think others show in what they are doing, and how easy they perceive it to get practical help from neighbors (both items rated on a 5-point Likert scale). Responses were summed to get a total support score ranging from 4 to 13, with higher scores indicating higher levels of support. This measure has been used in a variety of populations and has been shown to have good predictive validity (Bøen, Dalgard, & Bjertness, 2012; Dalgard et al., 2006). In our sample, it had a Cronbach's alpha of .78.

Caregiver loneliness was measured using the Three-Item Loneliness Scale (Hughes, Waite, Hawkley, & Cacioppo, 2004). The Three-Item Loneliness Scale is a generic loneliness scale in which participants are invited to reflect on whether they felt they lacked friendship, left out, or isolated from others in the past month. Items were scored on a 3-point scale (from 1 = *hardly ever* to 3 = *often*) and summed to compute a total loneliness score ranging from 3 to 9, with a higher score indicating greater loneliness. Scores obtained using this measure have been shown to have good psychometric properties in previous populations, with a Cronbach's alpha of .72 and good convergent and discriminant validity (Hughes et al., 2004). In our sample, Cronbach's alpha was .91.

Fear of Recurrence To assess FOR, caregivers completed the Worry of Cancer Scale (Hodges & Humphris, 2009). Originally based on a 5-point measure to assess FOR in survivors, the measure was adapted for use in an HNC caregiver population. Caregivers were asked to rate their agreement with two items: how much they had worried about their family member or friend's cancer in the past month (ranging from 0 = *not at all* to 10 = *a great deal*), and how often they had worried about the possibility their cancer might come back (on a 5-point scale ranging from 0 = *none of the time* to 4 = *all of the time*). The items were combined and transformed to give rise to a total score ranging from 0 to 20, with higher scores indicating higher levels of cancer-related worry. Scores on the scale have been shown to have good psychometric properties (Hodges & Humphris, 2009).

Statistical Analysis

A multiple regression was conducted in order to determine the effect of 15 potential predictor variables on caregiver's FOR (Worry of Cancer score). Predictors were related to both survivors (age, time since diagnosis, stage of cancer, extent of surgery, whether they had been in receipt of radiotherapy and/or chemotherapy, survivor QOL) and caregivers (age, gender, relationship to survivor, employment status, caring-related financial stress, time spent caring, social support, and loneliness). Prior to analysis, bivariate correlations were conducted to ensure no violations regarding assumptions of multicollinearity. All potential predictors were fitted simultaneously in a linear regression model. Estimates were considered significant

when $p < .05$. Analysis was conducted using SPSS (Statistical Package for Social Sciences).

RESULTS

Participant Characteristics

A total of 197 caregivers completed the questionnaire (response rate = 69%). Because of missing data, 180 caregiver–survivor dyads were included in the analysis where each dyad constituted a single case. Characteristics are summarized in Table 1. FOR, as measured by the Worry of Cancer Scale, displayed wide variability ($M = 9.6$, $SD = 5.81$). This suggests that, although FOR was experienced differently among the

TABLE 1. Survivor and Caregiver Characteristics

Dyad member/characteristic/value	*n*	(%)[a]
Survivor		
Gender (male)	124	(68.9)
Cancer stage (at diagnosis)		
1–2	81	(54.4)
3–4	68	(45.6)
Chemotherapy (yes)	47	(26.1)
Radiotherapy (yes)	122	(67.4)
Cancer surgery (major; yes)	31	(17.2)
	M[a]	(*SD*)[a]
Age (years)	62.8	(10.73)
Time since diagnosis (years)	4.9	(3.79)
QOL (FACT-HN score)	111.8	(22.86)
Caregiver	*n*	(%)[a]
Gender (female)	136	(76.0)
Relationship to survivor		
Spouse	132	(73.4)
Son, daughter, or parent	34	(18.8)
Other	14	(7.8)
Employment status		
Employed/self-employed	58	(32.3)
Retired/looking after family	93	(51.7)
Other	29	(16.0)
Caregiving effort (hours/week)		
0	79	(43.6)
1–13.49	51	(28.2)
≥13.5	51	(28.2)
	M[a]	(*SD*)[a]
Age (years)	57.3	(12.48)
Financial impact of caring	4.7	(1.15)
Social support (OSS)	9.3	(2.16)
Loneliness (T-ILS)	4.5	(1.76)
Fear of recurrence (WOC)	9.6	(5.82)

Note. $N = 180$. Missing responses ranged from 0% for treatment-related variables to 17% for cancer stage. FACT-HN = Functional Assessment of Cancer Therapy-Head Neck; OSS = Oslo Support Scale; QOL = quality of life; *SD* = standard deviation; T-ILS = Three-Item Loneliness Scale; WOC = Worry of Cancer.
[a]Valid percentages for number of responses to item or based on all available data.

caregivers in our sample, some reported extremely high levels of worry with scores ranging from 0 to 20.

Multiple Regression Analysis: Predictors of FOR

Correlations among the predictors and Worry of Cancer scores (FOR) are shown in Table 2. The strongest associations with higher caregiver FOR were greater time spent caring ($r = .34$, $p < .001$), lower survivor QOL ($r = -.28$, $p < .001$), higher caregiver loneliness ($r = .27$, $p < .001$), and survivor surgery ($r = -.25$, $p < .001$). Specifically, those caring for survivors who had undergone major surgery were more likely to have lower FOR. Other significant correlations were observed between FOR and caregiver gender ($r = .21$; $p < .05$), time since diagnosis ($r = -.18$; $p < .05$), and chemotherapy ($r = .14$; $p < .05$). This means that higher FOR was more likely in female caregivers, those caring for more recently diagnosed survivors, and those caring for survivors who had undergone chemotherapy.

The distribution of the outcome (FOR as measured by Worry of Cancer scores) approximated normality. Unsurprisingly, given the sample size, the Kolmogorov–Smirnov test was significant (KS = 0.91, $df = 166$, $p = .002$); however, inspection of the distribution of scores on a histogram and the normal Q-Q plot indicated normality. A power analysis was undertaken to determine if the analysis was sufficiently powered. On the basis of the use of 15 predictor variables, an observed effect size of $R^2 = .35$, a probability level of .05, and the number of valid cases included in the analysis, the observed statistical power was 0.99.

The regression model estimates are shown in Table 3. Seven variables, including two survivor factors and five caregiver factors, were significantly associated with FOR. The strongest caregiver predictors were time spent caring ($b^* = .37$, $p < .001$), gender ($b^* = .25$, $p < .001$), loneliness ($b^* = .25$, $p = .01$), the financial impact of caring ($b^* = .20$, $p = .03$), and age ($b^* = .22$, $p = .05$). Results indicate that caregivers who spent more time caring were female, had higher level of loneliness, were older, and were more likely to experience FOR. The two survivor factors to emerge as significant predictors were extent of surgery ($b^* = -.23$, $p = .01$) and survivor age ($b^* = -.22$, $p = .02$). Specifically, caregivers of younger survivors and those who had not undergone extensive surgery had significantly higher FOR scores. The model was statistically significant ($F[15, 119] = 4.26$, $p < .001$) and explained 27% of the variance in caregiver's worry of cancer score.

Inspection of the normal P-P plot of standardized residuals and the scatterplot for residuals showed that the assumptions of normality, linearity, outliers, homoscedasticity, and independence of residuals were all satisfied within the regression analysis.

DISCUSSION

Evidence has shown that FOR is a significant concern for HNC survivors and their caregivers (e.g., Hodges & Humphris, 2009; Lin et al., 2016). Consistent with this, our results showed that

TABLE 2. Correlation Matrix for Variables Used in Regression Model

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1. Survivor age (years)	1.00															
2. Time since diagnosis (years)	.11	1.00														
3. Stage of cancer[a]	-.11	.05	1.00													
4. Chemotherapy (yes)	-.25	-.12	.49	1.00												
5. Radiotherapy (yes)	-.18	-.01	.49	.38	1.00											
6. Extent of surgery[b]	.11	.33	.06	-.17	-.03	1.00										
7. Survivor QOL (FACT-HN)	.14	.17	-.03	-.13	-.11	.12	1.00									
8. Caregiver age (years)	.39	.19	-.13	-.20	-.15	.13	.19	1.00								
9. Caregiver gender[c]	.07	.09	-.07	.03	.09	.05	.04	.06	1.00							
10. Relationship[d]	-.14	.02	-.12	.02	-.01	-.02	.06	.47	-.02	1.00						
11. Employment status[e]	-.10	-.17	.13	.03	.07	-.05	.13	-.37	-.15	-.20	1.00					
12. Financial stress of caring[f]	.21	.17	-.11	-.22	-.14	.10	.32	-.06	-.03	-.14	.11	1.00				
13. Time caring[g]	.09	-.20	-.03	.06	.10	-.04	-.43	-.17	-.11	-.08	.05	-.30	1.00			
14. Social support (OSS)	.15	-.04	.01	-.12	-.06	-.04	.13	.06	-.02	-.06	-.03	.07	.05	1.00		
15. Loneliness (T-ILS)	-.11	-.10	.07	.14	.00	-.05	-.18	-.08	.15	.08	-.04	-.30	.15	-.48	1.00	
16. Fear of recurrence (WOC)	-.09	-.18	.07	.14	.09	-.25	-.28	-.05	.21	-.02	-.08	-.12	.34	.02	.02	1.00
M	62.9	4.9	2.4	0.3	0.7	0.2	111.8	57.3	1.8	0.7	0.4	3.3	0.9	9.3	4.5	9.6
SD	10.73	3.79	1.28	0.44	0.47	0.38	22.86	12.48	0.43	0.44	0.48	1.15	0.84	2.16	1.76	5.81

Note. N = 180. FACT-HN = Functional Assessment of Cancer Therapy-Head Neck; OSS = Oslo Support Scale; QOL = quality of life; SD = standard deviation; T-ILS = Three-Item Loneliness Scale; WOC = Worry of Cancer. [a]0 = Stages 1–2; 1 = Stages 3–4. [b]0 = none or minor; 1 = major. [c]0 = male; 1 = female. [d]0 = other; 1 = spouse/partner. [e]0 = other; 1 = employed. [f]Higher scores reflect higher stress. [g]0 = none; 1 = low; 2 = high.

TABLE 3. Caregiver Fear of Recurrence: Multiple Regression Model

Predictor[a]	b*	p	b	(SE)	95% CI
Survivor age (years)	−0.22	.02	−0.12	(0.05)	[−0.22, 0.02]
Time since diagnosis (years)	−0.06	.44	−0.10	(0.13)	[−0.35, 0.16]
Stage of cancer [Stages 1–2 = 0; Stages 3–4 = 1]	0.12	.22	0.56	(0.46)	[−0.35, 1.46]
Chemotherapy [no = 0; yes = 1]	0.02	.83	0.26	(1.24)	[−2.19, 2.71]
Radiotherapy [no = 0; yes = 1]	−0.03	.76	−0.35	(1.13)	[−2.59, 1.89]
Extent of surgery [minor = 0; major = 1]	−0.23	.01	−3.58	(1.24)	[−6.04, −1.12]
Survivor QOL (FACT-HNC) (score)	−0.13	.16	−0.03	(0.02)	[−0.08, 0.01]
Caregiver age (years)	0.22	.05	0.10	(0.05)	[0.00, 0.21]
Caregiver gender [male = 0; female = 1]	0.25	< .001	3.34	(1.08)	[1.19, 5.49]
Relationship [other = 0; spouse/partner = 1]	−0.10	.30	−1.28	(1.23)	[−3.73, 1.15]
Employment status [other = 0; employed = 1]	−0.04	.61	−0.53	(1.03)	[−2.57, 1.51]
Financial stress of caring (score)	0.20	.03	1.03	(0.45)	[0.14, 1.93]
Time caring [none = 0; low = 1; high = 2]	0.37	< .001	2.54	(0.64)	[1.28, 3.81]
Social support (score)	0.14	.13	0.36	(0.24)	[−0.12, 0.84]
Loneliness (score)	0.25	.01	0.82	(0.31)	[0.21, 1.45]

Note. Because of some missing data, only those dyads that had a score for all the variables were included in the regression analysis. $N = 134$. $R^2 = .35$ ($p < .01$); adjusted $R^2 = .27$ ($p < .01$). [a]All variables are continuous unless indicated. For all continuous variables, higher scores denote higher levels of the variable in question. With the exception of social support, higher scores for all caregiver variables indicate higher degrees of burden.

just over half of caregivers reported some cancer-related worry. Our findings add to the literature by shedding light on the various factors that may increase this risk, illustrating, for the first time in HNC, the role that care-related stressors—as well as characteristics of both survivors and caregivers—play in this process. In particular, our findings point to the influence that caregiver appraisals, such as perceptions of loneliness and burden experienced through caring, may have in caregiver FOR.

> Our findings point to the influence that caregiver appraisals, such as perceptions of loneliness and burden experienced through caring, may have in caregiver fear of recurrence.

Survivor Factors

Interestingly, clinical characteristics such as stage of cancer, time since diagnosis, or whether survivors had been in receipt of chemotherapy or radiotherapy had no relationship with caregiver FOR, contrasting with some research in the area (Kim, Carver, et al., 2012). However, our results did reveal that FOR was lower in caregivers of survivors who underwent more extensive surgery. Although at first appearing counterintuitive, the observed association could be because caregivers perceive major surgery as a more conclusive treatment, thereby mitigating chances of recurrence. In contrast, when survivors have not undergone surgery or only minor surgery, the future may appear more uncertain. This fits with the literature on cancer survivorship whereby feelings of uncertainty are more prevalent when survivors are undergoing watchful

waiting as opposed to more active treatment (e.g., Bailey, Wallace, & Mishel, 2007). The perception of surgery as reducing risk of cancer has been observed in other populations. For example, women sometimes choose to have major surgery to further reduce their risk of breast cancer recurrence, even when its impact on actual risk is known to be small (Basu, Barr, Ross, & Evans, 2015). Our results imply that caregivers of HNC survivors who have *not* had such extensive procedures may benefit from additional information regarding the potential future course of the disease.

Recently, Lin et al. (2016) observed that FOR was higher in HNC caregivers who had cared for patients with short posttreatment durations as opposed to those with longer posttreatment durations. These findings complement our results but also suggest that the time that has elapsed since treatment should also be taken into account in considering whether caregivers are at risk of experiencing FOR. Healthcare professionals need to be aware that, although caregivers of those who undergo radical resection take a degree of confidence from surgical removal of a tumor, this may not apply when survivors have received other less-invasive forms of treatment.

The only other survivor characteristic found to predict caregiver FOR in our study was age. Younger age has consistently arisen in the a predictor of FOR in survivors themselves (Crist & Grunfeld, 2013; Rogers et al., 2016), potentially because a diagnosis earlier in life is viewed as interrupting the expected course of the lifespan, acting as a threat to future life projects (Simard et al., 2013). A similar analogy could be used for caregivers; those caring for younger family members/friends may have more concerns regarding the impact this may have on the survivor's (and perhaps their own) life and relationships.

Caregiver Characteristics and Care-Related Stressors

Two caregiver demographic characteristics emerged as significant predictors of FOR. Specifically, we found that older caregivers, as well as those who were female, reported higher cancer-related worry. Although this has not emerged as a consistent finding among cancer caregivers (Simard et al., 2013), some studies note that female caregivers are at greater risk of experiencing FOR (Matthews, 2003). This may in part be due to gender differences in coping, with female caregivers viewing themselves as instrumental in providing emotional—in addition to physical or practical—support (Ussher & Sandoval, 2008). This greater emotional connectedness may result in more concern over future recurrence and the multifaceted implications this may entail. Regarding age, older caregivers may report greater FOR due to their own fears of not being in as strong a position to support survivors as they age. For example, older caregivers of colorectal cancer survivors have lower QOL from caring, namely in the physical domain (Hanly, Maguire, Hyland, & Sharp, 2015). Separately, the fact that older caregivers experience higher FOR may simply reflect cohort differences in knowledge and beliefs about cancer (e.g., that it is a life-threatening disease), which, given more recent advances in treatment and increases in survival rates (Torre et al., 2016), may not be the perception of younger caregivers.

Beyond demographic characteristics, we also found that two care-related stressors, the financial impact, and time burden associated with HNC care, were associated with caregiver FOR. A recent review showed a substantial economic burden associated with HNC (Wissinger, Griebsch, Lungershausen, Foster, & Pashos, 2014). In Ireland, the costs of cancer are often borne, not only by the survivor, but by their caregivers (Sharp et al., 2013). Out-of-pocket costs are incurred on items such as prescription medicine, bills, nutritional supplements, and travel costs (Hanly et al., 2013; Kim, Spillers, & Hall, 2012). Caregivers may also be required to take time off work to care, which can affect psychological well-being (Hanly et al., 2015; Kim & Spillers, 2010), and indeed physical health (Kim & Spillers, 2010). It may be that caregivers who have already incurred financial losses associated with caring feel they have limited capacity to absorb a second wave of costs induced by a recurrence.

A heavier time burden related to caring tasks also arose as a key predictor of FOR. HNC caregiver tasks can be especially onerous with caregivers often taking on a diverse range of roles, including food providers, symptom monitors, and motivators (Pettersson, Berterö, Unosson, & Börjeson, 2014). The impact of caring for cancer survivors on caregivers' schedules abound (Stenberg et al., 2010) with time associated with cancer care significantly related to various aspects of caregiver burden (Maguire, Hanly, Hyland, & Sharp, 2016). Our finding that FOR is most strongly associated with the time involved in caring extends these previous findings. Caring for HNC survivors may highlight problems with self-care, eating, pain, and

fatigue, all of which may act as a reminder to the caregiver of the survivor's previous diagnosis and may, in turn, exacerbate FOR.

Loneliness and Social Support

Loneliness levels were generally low among caregivers in our sample, a result at odds with other studies involving cancer caregivers where feelings of isolation are common (Chin, Rokach, Findler, Lev, & Kollender, 2013; Sahin & Tan, 2012; Stenberg et al., 2010). This, along with the high levels of social support reported in our sample, may be due to cultural factors; Irish caregivers often report good social networks and family support (Hanly et al., 2015). In addition, most survivors in our sample were a number of years postdiagnosis, which may have allowed their caregivers to reestablish networks and support after an initial intensive time spent caring. However, our results show that those who did feel isolated had a higher level of cancer-related worry, and others have shown that this, in turn, may impact on QOL (Segrin, Badger, & Pasvogel, 2015). Although it could be that the stressors of caring (in particular, the time spent on care-related activities) may exacerbate feelings of loneliness, the fact that this emerged as one of the strongest predictors of FOR—even after examining the influence of survivor health, caregiver, and care-related stressors—highlights the detrimental loneliness can have in its own right. This finding fits with the literature pointing to the role loneliness plays in well-being in a range of populations (Ekwall et al., 2005; Hawkley & Cacioppo, 2010). Our results show that this applies for HNC caregivers as well. Because feelings of loneliness may in turn negatively impact on cognition and behavior (Hawkley & Cacioppo, 2010), it is likely that this may also affect the caregiver's ability to successfully provide care, which may also exacerbate cancer related worry.

In contrast to loneliness, levels of social support did not predict FOR. Although inconsistent with some findings (Chen et al., 2009), this result may be due to the fundamental difference between perceptions of social connections (i.e., loneliness), as opposed to actual objective connections (i.e., social support). As noted by Hawkley and Cacioppo (2010), loneliness is more than simply "being alone." Our results are compatible with Stenberg and colleagues (2010) observation that the perceived availability of support, rather than the actual amount of assistance provided, is the crucial factor in determining caregiver burden. These findings therefore indicate that rather than simply making support available, targeting caregivers' perception of loneliness may be one of the most effective ways of reducing FOR.

Appraisals in FOR

The findings above highlight the important role that cognitive appraisals and perceptions have in caregiver FOR. Perceived loneliness, rather than actual social support, and perceived financial stress, rather than actual employment status, are two

such examples of appraisals found to influence caregiver's worry over cancer. This fits with a growing body of literature, which shows that individual interpretations or representations are often more influential than clinical characteristics in determining FOR (e.g., Llewellyn et al., 2008). Although our findings did show that certain demographic factors and clinical characteristics can play a role in caregiver FOR, the dominating importance of perceptions (e.g., patient's perception of QOL and caregiver's perceptions of loneliness) broadly fit with the CSM framework (Llewellyn et al., 2008). In conjunction with this theory, our findings could in turn be used to inform interventions targeted at reducing caregiver FOR—in a similar vein to interventions examining FOR in HNC patients.

Strengths and Limitations

This study is unique in examining caregiver stressors as predictors of FOR within HNC. In adjusting for both survivor well-being and caregiver characteristics, we have shown how aspects of the care situation and caregivers' perceptions of their situations can increase cancer-related worry. However, there are also a number of limitations. The caregiver and survivor questionnaires took place a year apart, so it is possible that survivor health and well-being may have changed in this time; this might explain why we found no association between survivor QOL and caregiver FOR. Our sample excluded caregivers who were not nominated by survivors and/or those who chose not to respond to the questionnaire. Furthermore, those caring for survivors in Stages 3–4 of cancer were less represented in our sample, and it is possible they would have experienced greater degrees of FOR. In summary, cancer-related worry is likely to be governed by a number of complex factors beyond those which we could investigate here. Future consideration of other aspects of both survivor and caregiver health and well-being may further enhance understanding of this process.

CONCLUSION

It is now acknowledged that the treatment of HNC should take into consideration the needs of both survivors and their caregivers. However, although many interventions have focused on trying to reduce FOR in survivors, less attention has been placed on how to best minimize this in caregivers. The findings of this research pave the way for more targeted interventions to be developed to buffer against this risk in HNC caregivers. Although we have shown that certain subgroups, such as female caregivers (who are in the majority) and those caring for younger survivors, may be at risk of FOR, regardless of survivor health status or activities of care, our findings suggest that modifying aspects of the care situation could reduce FOR. In particular, minimizing the time burden of care and reducing feelings of loneliness may be effective ways of reducing cancer-related worry, with resultant benefits for both caregivers and their survivors.

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