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The financial impact of head and neck cancer caregiving: a qualitative study

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ABSTRACT

Background: There is a lack of research on the financial impacts that head and neck cancer has on caregivers.

Objective: To explore the overall financial impact of head and neck cancer on caregivers; to describe the factors that mitigate this impact.

Methods: Interviews with 31 caregivers (mean time caring: 5.7 years).

Results: Head and neck cancer had a considerable financial impact on caregivers. It resulted in out of pocket costs and caregivers and/or their relative/friend with cancer often became under- or un- employed. Caregivers with large debts or ongoing expenses appeared to be particularly vulnerable to cancer-related financial pressures. Finance related psychological stress was prevalent, although some caregivers hid their psychological difficulties from other people. Factors which help caregivers to mitigate financial distress included having private health insurance and being able to access to medical and/or social welfare benefits.

Conclusions: Head and neck cancer can cause caregivers substantial financial and psychological distress. Distress may be mitigated by providing caregivers and their households with access to welfare benefits.

Implications for practice: Health professionals should be aware that head and neck cancer can have short and long-term financial consequences for caregivers and their families. Health professionals should refer patients and their caregivers to medical social workers who can help them with their financial issues.

INTRODUCTION

Cancer can have negative effects on individuals' economic wellbeing, coming with a series of direct and indirect costs and disrupting individuals' abilities to acquire and maintain work [1-3].

Consequently, a large number of individuals who develop cancer report financial hardship [4].

Cancer's financial consequences are not limited to patients; they extend to caregivers. Caregivers are often confronted with out of pocket costs that they may find difficult to bear [4--7]. A significant proportion lose time at work because of their caregiving responsibilities [8--10]. Many who remain in paid employment describe challenges attempting to balance work with cancer support activities [3]. Head and neck cancer (HNC) is a particularly severe form of cancer that can have pernicious effects on patients'/ survivors' abilities to participate in the workforce [11].

These difficulties stem from the fatigue, speech problems, oral dysfunction, anxiety and changes in appearance that are associated with this type of cancer. To date, only a limited number of studies have examined the financial effects of HNC on caregivers; this reflects a lack of investigation into caregivers' wellbeing [12] and into the financial impact that cancer has on families [13]. Quantitative research indicates that 'finding out about financial support' is an important need for HNC caregivers [14]. In view of the lack of research on this topic, the purpose of the article is to explore the financial impact that HNC has on caregivers; and the factors that help to mitigate this impact. The cancer site and the potentially serious long-term consequences of HNC treatment make both patients with the cancer and the carers who look after them potentially different from other cancer populations, making it important to investigate their specific experiences.

METHODS

Setting

Geographic context

The study was conducted in the Republic of Ireland in 2014. At that time, Ireland was emerging from a major economic recession. That recession began in 2007/2008, and was triggered by a combination of global and local (the bursting of a property bubble, a banking crisis) economic factors. At its height in 2012, unemployment was circa 15%. From that peak, unemployment decreased to approximately

12% in 2013, further reducing to just under 11% in 2014.

Irish health system

In Ireland, most individuals pay to see their primary care physicians (approximately 50 euro) per visit [15]. Private health insurance is used by a substantial proportion of the population [16]. Over 30% of the population has access to a 'medical card' which is a document that provides free medical care and subsidized medicines. Medical cards are means-tested, and to qualify for one a person's weekly income must fall below a certain threshold [16]. Patients with cancer are not automatically entitled to a medical card. Individuals whose income does not fall below the cut-off threshold may apply for a card if they believe that they are suffering undue financial hardship. The medical card system therefore has a discretionary component to it. Patient without medical cards who access the public system must make copayments (€100 per night in hospital).

Sample

Ethics approval was provided by the research ethics committees of each of the participating hospitals. This study formed part of a larger project that investigated the post-treatment experiences of survivors of HNC in Ireland [11]. Five hundred and eighty-three HNC cancer survivors were identified from the database records of the Irish National Cancer and completed a survey. We asked all 583 survivors for permission to contact their caregivers about quantitative research. Two hundred and eighty five survivors granted us permission. Questionnaires were sent to all carers, 197 of whom responded (69% response rate). These 197 carers were linked to nine hospitals from across Ireland. We then asked the 197 caregivers if we could recontact them about further qualitative research. One hundred and sixty caregivers agreed; all were invited, by letter, to be interviewed. Thirty-one caregivers responded, all of whom were interviewed. Interviewees' demographic characteristics are outlined in Table 1. Interviewees' ($n=31$) demographic characteristics were representative of the wider sample from which they were drawn ($n=197$).

Saturation (that is the point where no new themes emerged from the interviews) was reached at interview twenty five. The sample size is within best practice guidelines for studies based on semi-structured qualitative interviews [17].

Approach

Interviews were used to enable us to explore caregivers' perspectives. Qualitative research is useful for generating an overall estimation of the financial impact that cancer has on individuals [4]. The first author conducted all inter-views via telephone. Telephone interviews were chosen primarily for reasons to do with access; carers were located across Ireland, and it would have been impossible for the researcher to interview them face-to face. Interviewing by telephone is a standard qualitative data collection technique [18,19]. However it may have some disadvantages. For example, it does not provide the inter-viewer with non-verbal information that they could use to gain a more detailed insight into interviewees' experiences. Interviews lasted 31–84 min.

Before each interview began, the interviewer provided caregivers with verbal information about the study. Care-givers were told that they could stop the interview at any point, that the interviews would be recorded and transcribed, and that the results would be reported anonymously.

Interviewees gave verbal consent.

Interviews were semi-structured and split into two general sections. The first section examined caregivers' needs. The second section investigated caregivers' experiences of emotional distress. The questions in the topic guide did not specifically ask caregivers about financial problems or distress, but were open-ended, for example asking about what aspects of HNC caring caregivers found to be upsetting. Financial problems stemming from HNC were raised by most ($n = 29$) interviewees. No interviewee was from a minority ethnic group.

Analysis

Interviews were thematically analyzed using a word- processing package (MS Word) to organize material. The first author coded the first 10 interviews and the other authors provided feedback. The first author then coded the remainder of the interviews. Analysis for each interview began by 'open coding' the interview transcript. These codes were then compared with one another both within and across interview transcripts in order to determine if some of them could be subsumed under high level 'categories'. These categories formed the main sections of the analysis (financial impact during primary treatment, financial impact in post-primary treatment and mitigating costs). An example of how analysis was conducted: First, the analysis revealed multiple factors in caregivers' accounts that related to financial impact (commuting costs, overnight accommodation, need for family to return home, need to give up work in short-term, pre-existing financial commitments, need to give up work

for longer amount of time, out of pocket expenses, pay general and cancer bills, compromised care, keep financial stress a secret). Each one of these factors was conceptualized as a code. We sought to determine an efficient way to group these codes together and determined that certain financial impacts related to the time surrounding diagnosis and certain ones to longer-term impacts. Financial impacts during primary treatment therefore became a category/major theme (and an organizing section of this article) with a series of codes beneath it (commuting costs, overnight accommodation, need for family to return home, need to give up work in short-term, pre-existing financial commitments). Financial impacts during post-primary treatment also became its own category/organizing theme with its own subsidiary codes (need to give up work for longer amount of time, out of pocket expenses, pay general and cancer bills, compromised care, keep financial stress a secret). Quotes from participants are provided in the results section to illustrate themes. The number in brackets after each quote (e.g. 1416) refers to the caregivers' unique study identifier. Where the phrase 'relative/friend' is used, this refers to the person with cancer who the caregiver was looking after.

RESULTS

Most interviewees were female ($n = 24$) (Table 1). Their mean age was 60, and the majority (23) were not in paid work. Twenty-eight interviewees were married to their relative/friend. The mean time between cancer diagnosis and the interview was 5.7 years.

Financial impact during primary treatment phase

Most caregivers indicated that HNC had a financial impact on their household during the time period surrounding primary treatment. Caregivers often needed to travel to different cities with their relatives/friends for medical appointments and treatment. This necessitated either driving by car, with fuel and parking costs, or by public transport, with costs for tickets.

The cost of commuting was enormous (1412). Our finances what we had put together were strained in a lot of ways. It was very difficult. (1464).

If their relative/friend's condition deteriorated, or if they were in therapy, caregivers could find themselves paying for overnight accommodation. Six caregivers noted that their children returned home from abroad to be with the family once the diagnosis was made. Such decisions could result in significant costs in the form of plane tickets or the young person being forced to leave their jobs.

Exacerbating factors in primary treatment phase

Caregivers' relatives/friends often had to give up paid work as their treatment intensified.

Once he was diagnosed he didn't go back to work. (2048).

Several caregivers said that they gave up paid work in order to look after their relative/friend; however most continued to work (albeit often with reduced hours) in order to maintain a steady income flow into the household. Pre-existing routine non-cancer related expenses (such as mortgages) could become more onerous as household income reduced. Because of these financial stresses most caregivers experienced considerable concern about their financial situation (financial strain) during this phase of the cancer trajectory.

It was stressful. Wondering where the next day's pound was going to come from. (1167) You have to give up the car, give up the health insurance. You get thrifty, very thrifty. (2260).

Financial impact in post-primary treatment phase

A minority of caregivers said that HNC had little impact on them financially during the post-primary treatment period, the months and years following HNC treatment. In some cases, relatives/friends fully recovered from HNC and returned to fulltime work. Some survivors worked in managerial positions, enabling them to work even when physically weakened.

He's a plumber, but he only supervises now. That's how he was able to go back to work. (2040).

A number of caregivers noted that they did not have any pre-existing financial commitments such as mortgages to repay, and therefore their costs were manageable even on a reduced income.

I owned my house, we've no mortgage. We've been lucky (404).

Most however, indicated that HNC had long-term financial consequences. Survivors were often forced to permanently give up work, reducing the household's income on an ongoing basis.

He was working until he went in to hospital. He hasn't worked since (723).

Several caregivers also decided to permanently give up work in order to become their relative/friend's fulltime caregiver.

When the tracheostomy went in I had to be here, I couldn't hold a job. (723)

A number of caregivers noted that given their age (early to mid 60s) they had to retire during this phase of the survivorship trajectory irrespective of their relative/friend's treatment outcome, for example because their own strength was weakening, preventing them from engaging in manual work. This could be financially very problematic if their relative/friend was also no longer capable of work.

Furthermore, non-cancer related out of pocket costs could remain high.

One caregiver described having to try to pay bills, college expenses for her children, a mortgage and healthcare assistance for elderly parents while being on a reduced income, describing the whole

situation as ‘ridiculous’. Cancer-related costs, such as doctors’ visits and gel feeding packs, could also continue to be considerable.

We spent a fortune buying flavoured foods, different flavoured ones. (1230).

Two caregivers noted that their households compromised care in order to reduce costs; others noted that they only infrequently attended doctors.

You have to buy a speech valve, you should buy one every two months but we do it every four. (929).

Many caregivers described the long-term financial impacts of HNC as highly distressing. Caregivers often attempted to keep information about their household’s financial situation from their relative/friend in order to emotionally protect them, leaving the caregiver to deal with the strain on their own.

We needed money, it was tough, trying to keep everything in control. I didn’t want him to worry (2171).

Exacerbating factors in the post-primary treatment phase

Caregivers noted that macroeconomic external circumstances could intensify difficult micro-financial situations. One caregiver noted that she and her husband bought property in 2006, but that property subsequently collapsed in value during the Irish property crash of 2008. They lost all of their savings, money that they could have used to buffer the financial impact of HNC. Another caregiver (mid-30s), whose husband had to quit his job after his diagnosis, noted the difficulty of finding work in Ireland between 2008 and 2010 when the recession was at its height.

The illness and the recession hit at the same time. We lost anything that he had to retire, wiped out (1770).

Mitigating the financial impacts of head and neck cancer

A number of factors helped to mitigate the financial impact of HNC. Flexible work arrangements allowed caregivers to support their relative/friend while continuing in employment.

They were good at work. I could work in the evening. (2077).

Practical support from caregivers' communities, for example in the form of fundraising, helped to offset out of pocket costs. Private health insurance was also seen as useful.

The insurance picked up everything. So we weren't too affected. (1770).

The other factor that mitigated the financial impact of cancer was being able to obtain either a medical card or access social welfare payments.

The medical card, we've been blessed, even these drinks – which are very expensive – they're all provided. (2270).

However, caregivers' also revealed problematic issues in relation to state benefits and medical care. A few caregivers said that they and their relatives/friends with cancer were unaware that they could access social welfare payments, and only acquired this knowledge accidentally.

I never thought that there was such a thing as a caregiver's allowance. I only found out two weeks ago. (2429)

Two caregivers also said that they felt ashamed asking for social welfare assistance from the State, and felt that doing so signified that they had somehow 'failed'; as such they delayed seeking access to payments to which they were entitled.

I had never gone begging for anything, it was very difficult. (591).

A number of caregivers described significant battles with State agencies to access medical cards. Caregivers sometimes framed these struggles in the context of Ireland's economic recession from 2008 to 2014, and cutbacks to the health service in light of this recession, and/or sometimes in the context of lack of empathy on the part of an overly bureaucratic social welfare system.

This guy came [from social welfare]. He UPSET ME SO MUCH [very loudly] with his tone, and his tone was like, 'Who are you to expect your husband to get money?' (1416).

Caregivers described how medical cards could be removed from their relative/friend once the social welfare system determined that their HNC was no longer an issue, even when caregivers believed that their relative/friend continued to be strongly impacted by cancer.

So he got the medical card for a year. Next thing it was taken off him. (2240).

The psychological impact of losing a medical card was considerable, with one caregiver's husband telling her that he would be 'better off dead' when he lost his medical card; this understandably distressed the caregiver. There was a belief amongst many caregivers that the social welfare system could not be trusted to put caregivers' or survivors' interests first; caregivers believed that the system's main interest during the recession was cost-cutting.

Because of this even caregivers whose relative/friend had a medical card were anxious about that their medical card could be taken off them.

You don't know what will happen because you see a lot of children with special needs and they're not being granted medical cards. You hear about all these cuts. You just don't know from month to month how things are going to pan out with the country in general and the government. That's a worry. (2077).

A number of caregivers sought to ensure access to medical cards by approaching 'champions' to argue on their behalf with the social welfare system. In several cases these champions were local politicians. Caregivers felt that these individuals would have the best chance of ensuring that their relatives/friends would gain access to and keep their social welfare and medical benefits.

I wrote to my politician and got a call afterwards from the medical card people asking me to resubmit all my paper- work and we've had it [medical card] since. (629)

DISCUSSION

This qualitative study investigated the financial repercussions of HNC for caregivers. It supports the findings of previous research which has found that HNC can have a significant impact on caregivers' wellbeing [20]. It also helps to address the lack of research on the financial aspects of cancer caregiving, particularly HNC caregiving [13].

HNC in this study reported substantial hardship. However not all were equally affected. Caregivers with younger families, those who had substantial pre-existing financial commitments, those whose relative/friend experienced major medical interventions such as tracheostomies, or whose relative/friend worked in physically demanding employment appeared to be particularly financially vulnerable. Furthermore, financial stress was dynamic [13]; caregivers who were not financially stressed at one phase in the survivorship trajectory could become so at a later phase. This could happen for several reasons. For example, HNC could create a vulnerability (loss of income) that might be manageable at one point in time, but could become unmanageable when it interacted with another risk factor (sometimes non-cancer related, such as caregivers physically weakening when they entered their 60s) in a later phase of the cancer trajectory. Caregivers also noted that unexpected 'black swan' events, such as investments that performed badly, could suddenly render financial strain unbearable by undermining their capacity to absorb financial shocks. In summary, caregivers' vulnerability to HNC related financial stress appeared to be partly related to long-term pre-existing financial commitments (e.g. having children, paying off a mortgage), partly to the characteristics of the survivors' HNC, and partly to unexpected events that could suddenly emerge in caregivers' lives.

Several findings are concerning. One was that caregivers often kept their financial-related emotional distress a secret from other people to prevent their relative/friend with cancer from becoming upset. By keeping their distress a secret caregivers may also have been denying themselves access to emotional support. A second cause of concern was the information deficiencies described by some caregivers; this is similar to Chen *et al.*'s [14] study which found that finding out information about finances was a key need for HNC caregivers. Third, it was concerning to see the difficulties that some caregivers experienced interacting with the social welfare system. Cancer related struggles with the benefit system are not something that is unique to Ireland [21,22], or even to HNC within Ireland [23]. That HNC caregivers' financial wellbeing may depend on idiosyncratic interventions such as relying on politicians to champion their cause is worrying; in such a system, caregivers without such powerful advocates may be at a greater risk of losing their entitlements. It is even more problematic

because HNC is more prevalent amongst lower socio-economic groups, and individuals from these groups may be less able to work their ways through complex bureaucratic systems and gain the support of advocates. Finally, it was concerning that the large majority of caregivers did not describe receiving help or assistance from a medical social worker, even though these are the ‘system insiders’ who may be best situated to help caregivers and their families.

The setting of the study was important. At the time that the study was undertaken (2014), Ireland was beginning to emerge from a major recession, which had begun in 2008. Caregivers in this study had been caring for an average of six years. As such they would have begun caring at the beginning of the recession, and continued caring throughout the period of national financial crisis. We believe that this context helps to explain a number of the study’s findings. It likely contributed to the pervasive sense of insecurity that many caregivers felt with regards to their households’ access to medical cards. Likewise several caregivers and their households noted foregoing primary care visits and rationing medication in order to reduce costs. Timmons *et al.* [16] conducted a study of financial stress and strain in Irish patients with cancer in 2006 during the economic boom in Ireland. Those authors noted that none of the patients in their study reported making treatment decisions based on cost/affordability reasons. In contrast, some caregivers in this study did describe their households making these kinds of decisions. These findings highlight the importance of considering the broader economic situation in which caregivers are embedded when examining their experiences of financial distress. This is a point that is not often made in research on cancer related financial distress, which often takes an individual-level rather than system/society-based approach to explaining financial risk and vulnerability.

It may not be usual practice for health professionals to inquire about patients’ financial needs, let alone the financial needs of those patients’ caregivers [22]. The findings of this study indicate that there is a need for health professionals to do this, however. Health professionals could help caregivers and patients/survivors by enquiring about general household financial stress and then directing caregivers and their relative/friends to medical social workers or to social welfare professionals who can assist them to navigate the social benefits system. This could include cancer charities and welfare advice services. Moffatt *et al.* [24] identify three ways that receiving information about entitlements can immediately benefit people with cancer: by lessening the impact of lost earning, by offsetting the additional costs associated with cancer and by providing a comprehensive range of on-going advice, information and onward referral to a wide variety of other agencies. It would be useful for future research to explore how financial advice could best be

provided to these care-givers, and to explore in more detail their experiences of interacting with social welfare system.

Limitations

Caregivers talked about financial difficulties that they experienced several years ago, and might therefore have glossed over or forgotten some of their experiences.

Conclusion

HNC and its long-term impacts can cause caregivers substantial financial and emotional problems. Financial and psychological distress may be mitigated by connecting caregivers and their relative/friends with HNC with social welfare systems. Medical social workers may be of particular use here. These professionals are part of the medical team so referral by clinical practitioners is possible. They would also have the knowledge to advocate for patients and liaise with social welfare officers and systems. However these is an obligation on clinical practitioners to educate head and neck caregivers and their families, who are often from disadvantaged backgrounds, about medical social workers and similar system supports. Caregivers and their families may not seek the help of these professionals if they do not know about them or understand how these professionals can help them.

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Table 1. Interviewee characteristics

| Interview sample (<i>n</i> = 31) | | |
|---|--------------|-----------|
| Gender | <i>Freq.</i> | <i>%</i> |
| Male | 7 | 23 |
| Female | 24 | 77 |
| Age | <i>Mean</i> | <i>sd</i> |
| | 60.1 | 9.4 |
| Current employment status | <i>Freq.</i> | <i>%</i> |
| Unemployed | 16 | 51.61 |
| Paid employment | 8 | 25.81 |
| Looking after family | 7 | 22.58 |
| Private health insurance | <i>Freq.</i> | <i>%</i> |
| No | 14 | 45.16 |
| Yes | 16 | 51.61 |
| Unanswered | 1 | 3.23 |
| Medical card ¹ | <i>Freq.</i> | <i>%</i> |
| No | 14 | 45.16 |
| Yes | 17 | 54.84 |
| Relationship of caregiver to person with cancer | <i>Freq.</i> | <i>%</i> |
| Spouse/partner | 28 | 90 |
| Other | 3 | 9 |
| Time since diagnosis | | |
| 5.7 years (mean), sd 2.89 years | | |

