



In a bad place: Carers of patients with head and neck cancer experiences of travelling for cancer treatment



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ABSTRACT

Purpose: To explore the effect that treatment-related commuting has on carers of patients with head and neck cancer.

Method: Semi-structured interviews, thematically analysed, with 31 carers.

Results: Treatment-related commuting had a considerable impact on carers of patients with head and neck cancer, both in practical terms (economic costs, disruption) and also in psychological terms. Many carers of patients with head and neck cancer described becoming distressed by their commute. Some carers from large urban cities appeared to have hidden commuting burdens. Some carers respond to commuting stress by 'zoning out' or becoming 'like zombies'.

Conclusions: Treatment-related travel for head and neck cancer can have significant practical and psychological impacts. Health professionals should be aware of the impacts that commuting can have on head and neck caregivers. Health services may be able to take practical steps, such as providing subsidized parking, to address head and neck caregivers' difficulties.

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1. Introduction

Head and neck cancer is an illness that is associated with significant morbidity and mortality. Historically a relatively neglected condition, the past decade has seen increasing research interest on head and neck patients (Patterson et al., 2015) and carers (Badr et al., 2016; Balfe et al., 2016a, 2016b, 2016c, 2016d, 2016e; Hanly et al., 2016). Areas of the head and neck experience continue to be overlooked, however. One such area is carers' experiences of travelling to hospital for treatment. Head and neck patients and

carers tend to come from disadvantaged backgrounds, meaning that commuting might be particularly difficult for them. Moreover, carers are often elderly though increasingly more young people, particularly young women, are being diagnosed with the condition.

Research on other cancers suggest that treatment-related commuting can be a hard experience. It can lead to financial strain, for example through increased bills for petrol or diesel, extra meals/accommodation, extra parking and time away from work (Daniel et al., 2013; Hegney et al., 2005; Longo et al., 2007; Loughery and Woodgate, 2015). Commuting can disrupt people's lives (Cockle and Ogdén, 2016), and lead to generalised feelings of disturbance and uncertainty (Fitch et al., 2003; Loughery and Woodgate, 2015). This is especially the case for people who commute on an ongoing basis (Lockie et al., 2010). Commuting can also remove patients and carers from sources of support (Davis et al., 1998; Martin-McDonald et al., 2003), socially and geographically isolating them (Wagland et al., 2015). Travel can be an ordeal

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in itself, described as a 'sheer hardship' (Hegney et al., 2005; McGrath et al., 2011). Commuting may be especially difficult when carers have other commitments that they need to meet (Lockie et al., 2010). Older cancer carers might find commuting particularly challenging (Wagland et al., 2015). However, carers can extract benefits from commuting. Being away from home can encourage carers to positively reflect on their lives (Cockle and Ogden, 2016). Some carers also seek to make the 'best of things' when they are commuting, such as taking opportunities for meaningful conversations, or taking opportunities to visit sites that they would otherwise be unable to visit (Lockie et al., 2010).

2. Purpose

The aim of this paper is to examine the factors that influence carers of patients with head and neck cancer experiences of commuting with their relative/friend for treatment. While there has been some research on the topic of 'cancer commuting' in general (though even here researchers (Pesut et al., 2010; Wagland et al., 2015) have noted the limited nature of the work), this is not the case for carers of patients with head and neck cancer. This is an important absence as the findings of previous studies may not necessarily be transferable on to this population. The complex nature of head and neck cancer means that ongoing treatment is often required, necessitating 'chronic treatment commuting'.

3. Methods

Cancer services in Ireland are concentrated in specialist cancer centers in the largest urban areas. Only a few of those centers are then further specialised in head and neck cancer. Head and neck cancer can, however, be diagnosed in a variety of different hospitals, after which patients travel to the specialist centres for treatment. Only a few specialist centres provide radiotherapy services.

3.1. Sample and approach

The methods and recruitment strategy for this qualitative study have been reported elsewhere (Balfe et al., 2016d). Briefly, we conducted in-depth semi-structured interviews with 31 carers of patients with head and neck cancer (mean age 60.1; 24 carers were woman, seven were men) who were representative of a larger series of carers of patients with head and neck cancer who took part in a quantitative survey ($n = 197$) (Balfe et al., 2016e). Interviews were chosen because we wanted to explore carers' perspectives and experiences in detail (Bailey, 2002). All interviews were conducted by telephone. Interviewees were given a standard ethical briefing about the project (e.g. that they could withdraw at any point) prior to the interviews commencing. Questions were open-ended and asked interviewees to talk about their supportive care needs and their experiences of emotional distress. The questions therefore did not specifically ask about commuting-related difficulties, though this was a topic that was spontaneously raised by most interviewees (mainly in relation to the acute treatment phase). Once this issue was raised, the interviewer asked additional questions to gain further depth and understanding of the issue.

Interviews lasted between half an hour to just under one and a half hours each. They were audio-recorded, transcribed verbatim and thematically analysed. This involved firstly identifying the major themes that were present in the data that related to commuting and travel, and secondly identifying the subthemes that related to each of these themes. Illustrative quotes are given in the results section. The number in brackets after each quote refers to the interviewee's unique identifier. Where the phrase 'relative/friend' is used, this refers to the person with cancer who the carer

was looking after.

3.2. Ethics

Ethics approval was received from participating hospitals in Ireland. One ethical issue we were concerned about was protecting carers' identities. Consequently all audio recordings were deleted after interviews were transcribed. Some carers became emotional talking about their experiences. These carers were offered the names and number of psychosocial support services in Ireland. Most, however, just wanted an opportunity to talk through experiences that they had kept to themselves for a long time.

4. Results

4.1. Time during diagnosis and treatment

The head and neck cancer diagnosis was described as being like a 'bomb' by many carers, immediately transforming their lives and throwing their plans, routines and expectations into disarray.

It all just exploded then. We had no indication, he wasn't feeling unwell or anything like that (1770).

It's a life changing experience (629).

As suggested by the word 'exploded', the period around diagnosis was experienced as an 'accelerated time' by many interviewees.

Everything kind of moved real quick. (1404).

Once the diagnosis was made, treatment began. The nature of time shifted in some interviewees' accounts. Rather than being accelerated, time if anything became decelerated, slowed down and gruelling. Treatment could last for months.

He was there for months. Yes, he was up there for nearly four months. (591).

It was hard at the time. But we did it for the three months. (1696).

That was a tough time. (2260).

4.2. Commuting for treatment

All carers in this study commuted to their relative/friend's place of treatment, with the majority of the carers commuting substantial distances. Some travelled several days a week, others commuted every day. The amount of time that carers commuted in a particular week could be influenced by a number of factors including changes in their relative/friend's head and neck cancer, side-effects of treatment and the numbers of weeks that their relative/friend was in treatment.

It would be ok if you had to do it one week, you understand but we were talking about 33/34 sessions of radiotherapy. They were spread over a lot of weeks (1416).

Travel times were greatest for interviewees who lived furthest away, though they could still be significant for interviewees who lived closer by. For example one carer who did not drive noted that while it might take three hours to drive from Cork (secondary city) to Dublin (Capital city), it could also take over two hours to

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