



Balfe, M., Keohane, K., O'Brien, K. M., Gooberman-Hill, R., Maguire, B., Hanly, P., O' Sullivan, E., & Sharp, L. (2017). In a bad place: Carers of patients with head and neck cancer experiences of travelling for cancer treatment. *European Journal of Oncology Nursing*, 30, 29-34. <https://doi.org/10.1016/j.ejon.2017.07.001>

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[10.1016/j.ejon.2017.07.001](https://doi.org/10.1016/j.ejon.2017.07.001)

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In a bad place: head and neck cancer carers' experiences of travelling for cancer treatment

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

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

Results: Treatment-related commuting had a considerable impact on head and neck carers, both in practical terms (economic costs, disruption) and also in psychological terms. Many head and neck carers 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.

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; Balfe et al., 2016b; Balfe et al., 2016c; Balfe et al., 2016d; Balfe et al., 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 et al., 2015). Commuting can disrupt people's lives (Cockle and Ogden, 2016), and lead to generalised feelings of disturbance and uncertainty (Fitch et al., 2003; Loughery et al., 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 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 head and neck carers' 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 head and neck carers. 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 head and neck carers (mean age 60.1; 24 carers were woman, seven were men) who were representative of a larger series of head and neck cancer carers 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 commute by public transport from one end of Dublin to the other.

It was six or seven weeks I suppose, of intensive travel. Every day, five days a week you're going in to the hospital (1230).

Carers felt that it was important to travel to the hospital in order to provide support for their relative/friend. However some also felt that head and neck cancer posed specific difficulties for patients that necessitated carers being at the hospital.

I was going 80 miles because the man can't talk. (1696).

4.3. Difficulties of commuting

Commuting was difficult for carers. Firstly there was the economic cost of travelling, which included often unanticipated costs such as parking.

The thing is we live down in the countryside and it was costing so much to go on the train every weekend, a return ticket (591).

If you brought the car in it was cheaper to park further away than it was to park in the hospital for the day. (994).

More generally, commuting was experienced as a significant burden, both in terms of the time that it took, but also in terms of the emotional toll that it extracted from carers.

We left at 8.30am and we'd only be back at 5. There's no quick way of doing that when you live over two hours away from a hospital. That's the way it is for us really. (2077).

I found that horrendous, going into that hospital every single day for six weeks. In, out for treatment. That's very, very hard (1770).

Some carers noted that they found commuting difficult because of the sheer distance that could be involved.

I drive, but I'm not a long-distance driver. I like to go from A to B, into town to do my shopping, pop into see my family. I don't like to go long distance, so that was hard (2171).

Some carers noted that they tried to make the 'best of things' while they were commuting; however even their ability to do so could be limited by financial pressures and general anxieties and worries.

4.4. Splitting

Treatment-related commuting tended to spatially and emotionally 'split' carers. Many carers continued to work and to meet family obligations while they were travelling to and from hospital, meaning that in they frequently felt that they had to be in two places at once. This often placed them under significant time pressure. Some interviewees noted that it felt like they were "trying to divide yourself in so many ways" (2240c) as a result of being pulled between competing places and priorities.

I was doing two jobs, and I literally went to the hospital and back. I didn't take any time off sick, off work, nothing; I just went from one job up and back. It was just constant, backwards and forwards. It was tough. (1416).

It was like being on a roundabout. (723).

A number of factors intensified experiences of being 'split'. One was being forced to take on additional activities, for example work related tasks, that their relative/friend would ordinarily have dealt with. Needing to take on additional tasks was often something that became more important rather than less so as treatment progressed and carers' relatives/friends became weaker.

I was doing all of the other things that my husband would normally do and he couldn't do, and then trying to get to the hospital. And it was just exhausting really. (629).

Carers who had further caring duties such as needing to look after children or elderly parents described particularly disaggregated spatial situations, with some travelling several hours to the hospital for appointments, then returning home to collect the children after school, then in some cases returning to hospital again. Carers also felt that the time that they spent commuting was in a sense wasted time, time that was taken away from their normal lives and experiences.

So when he was admitted to hospital, I'd just go to work in the morning up until two o'clock, I would go to the hospital again to see him. I'd come home and pick up my youngest from school, and all the rest of it, but he was very, very sick. (2240).

At the time like I had all that added pressure as well, you know, young, a six year old and a two year old. So yeah, quite difficult. (629)

My daughter was getting married that year and I mean, I actually look back and say, "I don't even know where she bought her dress." I did nothing to help her. I don't know where she got her cake. I wasn't free to be going around. (1230).

Carers noted the emotionally corrosive effect that being split had on them. Some used words such as ‘desperate’ and ‘terrible’ to describe their situations (201). One interviewee hospitalized herself for stress; others noted that they felt constantly physically and mentally exhausted, and could become resentful of the patient and the impact that commuting and feeling split was having on their lives.

I suppose that it just takes away from your own life really. You don’t have time for yourself. Sometimes it can be a lot to do. I suppose if you really let that get to you you could really be dragged down. (2077).

You know, just with everything, going up and down to the hospitals and at that point you’re going to the hospital every few weeks, the stress levels as well. It’s constant, it’s 24/7. Just very, very stressful. (629).

You get to resent that [travelling] because you feel that you can’t escape it, but you have to remember that he’s miles away and lonely (591).

4.5. Dealing with difficulties caused by commuting

The head and neck carers in this study dealt with the emotional stress of commuting in a number of ways. Some focused all of their energies on getting from ‘a to b’. Others said that they ‘went somewhere else in the minds’ when the stress of commuting became too great. Some said they felt like they were on ‘autopilot’ during this period. What these experiences have in common is emotional and intellectual disengagement from the experience and stress of commuting.

I don't know how I did it, every single day, back and forth, back and forth to the hospital. I think you don't realise you're doing it. You just do it. I don’t know if I went through red lights. I was like a zombie as regards like, I kind of shut it away. Driving my car, there would be times where I would think ‘God, how did I get here?’ (2260).

I can’t remember what I was doing. (1851).

It is a bit of a blur to me. I don’t even remember driving in. The whole thing was just difficult. (1770)

One carer noted that while her 'zombie' experience was partly driven by stress, it was also more practically driven partly by the lack of sleep caused by continual travel. The word rocking in the following extract is interesting because in common usage it is a word that is linked with the motion of a train; it suggests a hollowed-out, repetitive, rolling mentality that stays with the interviewee even after she has returned home for the day. In this sense, commuting began to colonize all aspects of her life.

I was getting very little sleep. Very, very little. You know when you'd come home your head would be rocking. If I was on the train I wouldn't be home till 10.30-11pm and then I'd be up again at 6am to get the 7am train if I was going the following morning. You can't relax. You go around like a zombie. (1167).

4.6. Additional supports

Carers identified a number of factors which helped them to deal with the strains of commuting. One was being able to draw on emotional and practical support from their family and friends, who could for example take care of children while the carer was travelling. Hospitals could also offer practical support, for example by allowing the children of younger carers to access onsite crèches or play areas, or allowing carers to sleep overnight if a bed was available. Some hospitals or charities also provided carers and their relative/friends with access to community transport.

They let me stay once, one night they had a free bed. Which was great. (1412).

We got a double room [in a bed and breakfast that the hospital arranged] and that really was a safety valve. (1416).

We were very lucky. We were part of the system as I say, we had the collection bus which collected us and took us out to the hospital. (1835).

However these types of support could be imperfect. Social supports sometimes dropped off if carers' demands on their social network (for example for child minding) became too great. Some carers also did not want to tell their family about the stresses they were under in order to protect them.

We have two daughters in their twenties. I didn't drag them into it at all. I just said he's grand. (2260).

Hospitals also sometimes lacked facilities for carers to stay in.

I went up and down every day. There was no place up there that I could stay. They said “you'd be as well off to go home and we'll ring you if anything happens.” This sort of shit. You're living on your nerves. (1167).

Some carers, and their relative/friends, who had the potential to stay in hospital facilities chose not to do so and to continue to commute for treatment; despite the difficulties outlined until this point, they felt that this was the best way to maintain a normal life.

My husband was sick and tired of being in hospital, he fought that, and said, “No, I won't go into a ward, I'll travel in every day.” We'd go back and forth several days a week. As you can imagine, it was very draining (1851)

However this same carer (1851) noted that the side-effects of her husband's head and neck cancer eventually became so severe that they were eventually forced to sell their home in order to move closer to their hospital. Regular long-distance treatment commuting was simply unsustainable if it went on for too long.

4.7. Longterm- freedom of movement or return to enforced commuting

At a certain point, carers' commuting ended and their relative/friend returned home. In the longer-term, carers in this study appeared to have three general spatial trajectories. The first trajectory, which was positive, was characterised by the successful treatment of head and neck cancer. When carers were asked to talk about what it was like for their lives to be free from head and neck cancer, many described the experience in terms of freedom of movement.

We've got our lives. We are always planning little trips. He's delighted with life and he's delighted to be alive. (1464)

The doctor said, “everything seems to be clear,” And I said “can we go on holiday now?” And the doctor just looked at me and he said, “I think you need a holiday badly.” So that day we booked a very nice holiday. (1230).

Carers who followed this trajectory continued to commute annually with their relative/friends for checkups. These travel experiences were generally viewed positively, and had increasing positive ritual significance as time went on.

The second trajectory was characterised by the absence of or restriction of movement. Carers lives in this trajectory appeared to become diminished, either because their relative/friend’s condition limited them or because of increased financial hardships suffered as a result of head and neck cancer. This trajectory appeared to be characterised by spatial stasis.

The third trajectory was characterised by deterioration. Here the treatment failed and head and neck cancer returned.

When we were told the cancer was gone we nearly had a party. But anyway, by the following May we were told it was still there. (994).

The redevelopment of head and neck cancer often returned carers to commuting to the hospital on an ongoing basis. At this point carers were often older women, some many years older than they were at the point of the initial head and neck diagnosis, and some of them had developed their own health problems. Regular commuting the second time around was even more exhausting than the first time.

5. Discussion

This article is one of the few to examine head and neck carers’ experiences of commuting to hospital for treatment. It found that treatment-related travel caused carers’ practical and social problems and also often resulted in them experiencing significant psychological distress. These feelings appeared to be accentuated if travel went on for a considerable amount of time, and if carers had multiple priorities in their lives that they needed to manage while also needing to be at the hospital.

Carers in this study did **not describe positive experiences vis-a-vis** their treatment related travel, except in the post-treatment ‘check-up’ phase (though here the benefits likely came from the positive ‘all-clear’ message rather than the travel). One reason for this may have been that carers in our study did not travel ‘far enough’. Ireland is a small country and carers may therefore have been unable to fully separate their hospital experiences from their normal everyday lives. As such, commuting became an extra task that they needed to add to an already full set of everyday commitments. It was notable, for example, how many carers returned home after visiting their relative/friend in the hospital, only to return back to the hospital the next day. **Gender may also have been important here; most carers in this study were women, and their head and neck caregiving tasks may have come on top of an already heavy caregiving load that could not be put aside easily. As was noted in the interview extracts, carers fulfilled a variety of practical (household chores) and emotional supportive roles in their ordinary lives. With their relative/friends (who were mostly their husbands) in hospital, these duties if anything likely intensified as there was no one else to ‘pick up the slack’. Furthermore, female carers who worked may in effect have been forced to take on a ‘triple shift’: in work, at home (cleaning, cooking, looking after the family) and then travelling to the hospital.**

This study lends support for previous research on non-head and neck cancer-related commuting, namely that this type of travel can be extremely difficult both for people with cancer and their carers (Martin-McDonald et al., 2003; Longo et al., 2006). **Head and neck treatment related commuting clearly negatively impacts many carers, undermining their quality of life, emotional health and their wider family life.** The negative impacts that commuting has on carers are not only worrying in and of themselves, but also because prior research suggests that carer and patient quality of life are inextricably linked (Patterson et al., 2015). Although commuting burdens may generally be most difficult for rural patients (Zucca et al., 2011), the findings of this study also suggest that they may also be significant for carers who live within large urban areas that lack integrated public transport systems. Dublin for example, which is by far the largest city in Ireland and contains a significant proportion of the Irish population, has often been noted for its high volume of traffic and relatively poor public transport system (McDonald, 2012). Carers who do not drive and who live in cities where public transport is relatively poorly integrated and characterised by urban sprawl, may have ‘hidden’ commuting burdens that are similar to those of their rural counterparts. **In turn, rural**

commuters may have their own hidden burdens stemming from poor rural infrastructure, a lack of public transport and so on.

It is important to be aware that objective distance may not be the sole, or even the major, driving force behind the burdens detected in this study. It is possible that some carers who travel a long distance may not experience any burden at all. Conversely, some carers who travel short distances may become very distressed by their commute. It is therefore also important to consider carers' perceived commuting burdens, which may be related to objective distance, but may also interact with other factors such as their family situation, their personal coping style, their tolerance for stress, their perception of head and neck cancer and so forth. Additional variables such as the cost of transportation, the patient's physical state, loss of income, additional care demands from other family members etc. may also influence the meaning that commuting related treatment has for carers. In this sense, the carer's perceived burden likely emerges from complex interactions between geography, sociology and psychology.

5.1. Study limitations

While this is the first study to focus in detail on treatment-related travel issues in head and neck carers – and one of only a few on this topic in cancer more generally- its limitations should be acknowledged. Carers were asked to describe retrospectively their commuting experiences, which might mean that their reflections about their travel were influenced by the passage of time as well as other issues related to the cancer, including success of treatment or whether the cancer returned or spread. Further qualitative research could consider the use of ethnographic observational methods to explore contemporaneously the experiences of carers who are in the acute commuting phase of treatment. This could provide deeper insight into the experiences and burden of treatment-related commuting. Complementary quantitative research to measure different aspects of the treatment burden (e.g. frequency of travel, out-of-pocket costs, time costs, emotional consequences) would also be of value. It might be particularly useful for researchers to develop specific validated instruments [30] to assess head and neck carers' objective and perceived travel burdens.

5.2. Additional articles

For readers who are interested, we have published three additional articles from this

study. The first (Balfe et al., 2016a) focuses on the financial impact of head and neck caregiving. The second (Balfe et al., 2016b) examines the experience of psychosocial loss that carers experience following the diagnosis of head and neck cancer and the third (Balfe et al., 2016d) looks at the reasons why caregivers sometimes cannot obtain social support from their social networks. We have also conducted a series of separate quantitative studies (Balfe et al., 2016 c, e and Hanly et al. 2016) that will provide readers with additional information about the challenges that head and neck caregivers can face.

6. Implications for practice

Researchers and health services have begun to consider how best to address the travel burdens of cancer carers (Ambroggi et al., 2015). Some health systems, for example systematically provide cancer patients with residency while they are undergoing treatment, which could help to reduce the burden on carers (Lilliehorn and Salander, 2016). Although this presents cost implications for health services, there may be benefits. Other solutions may be to provide carers with direct travel subsidies, free parking or with income tax deductions that they could use to offset some of their travel expenses (Matthew et al., 2009). One solution that has been explored in Ireland is to connect patients to people who have a car and free time; this would then allow non-family drivers to drive the patient to the hospital, reducing the travel burden on carers (Irish Cancer Society, 2016). Carers in this study also suggested additional options, such as the possibility of carers staying overnight in hospitals or in approved hospital hotels at reduced rates, or hospitals having plays areas or crèches for children. Any of these solutions would be useful.

It is worth reflecting on the point that if a society expects advanced/high-tech care for head and neck cancer, this care is going to be located in fewer centres that offer specialised treatment. That will mean that the commuting difficulties outlined in this and other studies are not going away; they will probably, if anything, intensify going forward. It is also worth reflecting on the fact that our ability to make high quality care available is often not matched by our ability to improve access or ancillary support and to spread the commuting burden amongst social networks.

7. Conclusion

This article suggests that treatment related commuting during the acute phase of head and neck cancer may have significant, negative impacts on caregivers. Practical solutions such as free

parking may be necessary to relieve this burden. At the moment, cancer related travel appears to be leaving many head and neck carers in a bad place.

Acknowledgements

Funding for this study was provided by the Irish Health Research Board. We would like to thank the carers, patients and hospitals who took part in the study. We would also like to thank the two anonymous reviewers for their very helpful comments. We would also like to thank the staff in the National Cancer Registry of Ireland for their help and support during the writing of this article.

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