


## PAPER

# Barriers to active self-management following treatment for head and neck cancer: Survivors' perspectives

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## Abstract

**Objective:** Active self-management practices may help head and neck cancer (HNC) survivors to deal with challenges to their physical, functional, social, and psychological well-being presented by HNC and its treatment. This study investigates the factors perceived by HNC survivors to act as barriers to their active self-management following primary treatment.

**Methods:** In this qualitative study, 27 HNC survivors identified through 4 designated cancer centres in Ireland participated in face-to-face semistructured interviews. Interviews were audio-recorded, transcribed, and analysed using thematic analysis.

**Results:** Four themes (and associated subthemes) describing barriers to survivors' active self-management were identified: *emotional barriers* (eg, fear of recurrence), *symptom-related barriers* (eg, loss of taste), *structural barriers* (eg, access to appropriate health services), and *self-evaluative barriers* (eg, interpersonal self-evaluative concerns).

**Conclusions:** This is the first study to describe HNC survivors' views about barriers to their active self-management after treatment. The findings have important implications for self-management research and intervention development concerning HNC survivorship.

## KEYWORDS

cancer, cancer survivorship, head and neck cancer, oncology, psycho-oncology, qualitative, self-management

## 1 | BACKGROUND

Self-management can be defined as "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition", p. 178.<sup>1</sup> Its main aim is to help individuals to maintain a sense of wellness, rather than illness, in their central perspective.<sup>2</sup> Daily self-management involves ongoing medical management, maintaining, changing, and creating meaningful behaviours or life roles, or dealing with emotional challenges.<sup>2</sup> Individuals who collaborate with health care professionals, attempt to maintain valued roles, and use adaptive coping strategies

may be classified as "active self-managers".<sup>3</sup> For individuals with cancer, self-management is necessary at all stages of the postdiagnosis trajectory.<sup>4</sup> Nonetheless, the posttreatment phase may be particularly important because of reduced involvement with, and access to, hospital-based multidisciplinary care.<sup>4</sup> Active self-management during this period may mean that a person becomes proactive and vigilant in personal care coordination,<sup>5</sup> reestablishes normal routines and social roles,<sup>4</sup> minimises the negative impact of distress,<sup>6</sup> and collaborates with health care professionals on an outpatient basis.<sup>7</sup>

Active self-management may also be particularly important following treatment for head and neck cancer (HNC). This is because

HNC and its treatment can be associated with many challenges which extend beyond the acute treatment phase, including swallowing issues,<sup>8</sup> communication difficulties,<sup>8</sup> facial disfigurement,<sup>9</sup> fear of recurrence,<sup>10</sup> and elevated levels of depression, anxiety, and distress.<sup>11,12</sup> We have previously identified the wide variety of self-management strategies that HNC survivors use following treatment.<sup>13</sup> However, while research with specific cancer groups points to a range of potential perceived barriers to active self-management following cancer treatment,<sup>14-17</sup> little is known about the factors which impede or assist HNC survivors' active use of self-management strategies. Consequently, this paper aims to identify survivors' perceptions of barriers to their active self-management after completing primary treatment for HNC. Understanding these barriers could inform the development of self-management interventions designed to develop the skills and confidence HNC survivors need to live well.

## 2 | METHODS

### 2.1 | Study design

The study used a qualitative methodology involving semistructured interviews to yield rich and detailed data regarding HNC survivors' experiences of self-management.

### 2.2 | Participants and recruitment

After obtaining ethical approval from 4 designated cancer centres in Ireland [SJH/AMNCH\_REC\_Reference\_2014/05/Chairman's\_Action; RVEEH\_REC\_25/06/14; Merlin\_Park\_University\_Hospital\_Clinical\_REC\_C.A.1100; UCC\_Clinical\_REC\_ECM\_4\_(bbb)\_03/06/14], a nominated clinical nurse specialist from each centre identified eligible individuals attending outpatient HNC clinics using a purposeful critical case sampling approach.<sup>18</sup> Specifically, each clinical nurse specialist was asked to identify HNC survivors with a range of challenges (speech difficulties, swallowing difficulties, facial disfigurement, and social isolation). Individuals were eligible to participate if they were 8 to 60 months post-diagnosis, at least 18 years old, and spoke sufficient English for the purpose of the study. Individuals undergoing or awaiting treatment, or receiving palliative care, were excluded. Further details on recruitment are provided elsewhere.<sup>13</sup>

### 2.3 | Data collection and analysis

The first author conducted semistructured interviews with individuals consenting to participate at a time and location convenient to them. The topic guide covered (a) challenges encountered following treatment for HNC, (b) self-management strategies used to deal with these challenges, and (c) any perceived barriers in their use. The interviews (duration 35-255 minutes) were audio-recorded, transcribed verbatim, and anonymised. For the current paper, data were thematically analysed using Braun and Clarke's<sup>19</sup> 6-step model. This involved (1) data immersion and anonymisation, (2) data coding, (3) analysing the codes in isolation to purposefully identify themes, (4) relating thematic material back to coded data extracts to ensure they were coherent, (5)

clearly defining and naming themes, and (6) writing up the results. Barlow et al's<sup>1</sup> definition of self-management (provided above) was used to interpret the data. In the latter analysis stages, thematic material was discarded if it did not fit well together, or where there was a dearth of rich quotations clearly describing participants' perceived barriers to their emotional, medical, and/or role management following primary treatment. The final author validated the analysis by checking the quotes and themes to ensure that they made sense. Participants were allocated a pseudonym (of the same sex) to protect their identity.

## 3 | RESULTS

Full participant characteristics are provided elsewhere.<sup>13</sup> Of the 26 participants, 18 were male, 20 were over 55 years old, 13 had been diagnosed with HNC within the preceding 24 months, and all received more than 1 treatment modality. Participants had cancers of the larynx (n = 9), tonsils (n = 6), tongue (n = 5), oral cavity (n = 5), or pharynx (n = 2) respectively. Four key themes and associated subthemes relating to barriers to active self-management among HNC survivors are presented below.

### 3.1 | Emotional barriers

#### 3.1.1 | Worries about posttreatment consequences

Several participants experienced worries about managing their condition and its consequences following treatment, which acted as a barrier to their active self-management. For instance, Adrian described how worrying about future consequences meant that he did not communicate concerns to health care professionals, which made him feel less prepared for posttreatment self-management.

*I remember [consultant] would examine you and he'd say, 'Is there anything you want to ask me?' I'd always say no straight away.[...] And the reason I'm always saying no is because I'm really afraid of the answers.[...] But I didn't realise that, after the treatment, it would be [as bad]. Then maybe, if I'd asked [those] questions, I would have been better armed for what was in front of me. [Adrian, 56 years].*

#### 3.1.2 | Fear of recurrence (FoR)

For many participants, fear of recurrence (FoR) was an ever-present barrier to self-management. Fiachra described how FoR was a constant concern, with hypervigilance and difficulty avoiding thoughts about recurrence affecting his ability to self-manage his emotions.

*I'm always checking for lumps. Until I get to five years, I think I'm going to be like that. When [consultant] checks your neck and says, 'I don't like the look of that' you're, like, 'Here we go again. It's going to be the start of round two.' It is a constant worry, especially when you have kids. I'm only 51. I don't want to die yet. [Fiachra, 51 years].*

### 3.1.3 | Low mood

Several participants reported how low mood following primary treatment reduced their motivation to actively self-manage their condition. For instance, Jacinta described how depression demotivated her in relation to her medical management.

*I've eliminated what's going to be valuable or invaluable [in the medical management of my condition]. It's as if [I think] what's the point? So those are areas that I know where I can see that's a depression, kind of. [Jacinta, 71 years].*

Similarly, Adrian indicated that low mood led him to start smoking again as temporary relief from his inability to perform valued activities; he regretted this behaviour which acted as a barrier to actively self-managing his condition.

*All the pleasures in my life had gone. I've been playing guitar for almost 40 [years] ... I just love playing it and I couldn't play. I was feeling a bit sorry for myself and smoking seemed to be the only pleasure that I had. The taste might not have been [there], but that didn't really matter because you felt the smoke hitting the back of your throat and you could blow it out. I got a wee bit depressed because it seemed to take a long time for things to improve. And you feel sorry for yourself [and] you would have a cigarette. It was a vicious circle. [Adrian, 56 years].*

## 3.2 | Symptom-related barriers

### 3.2.1 | Physical side effects and symptoms arising from treatment and its consequences

Participants described how a range of physical side effects and symptoms arising from HNC treatment and its consequences acted as barriers to their active self-management, including common issues such as pain and fatigue, and more HNC-specific issues. Rory told how the removal of his teeth in preparation for radiation therapy was a barrier to socializing with friends because of embarrassment over his physical appearance.

*I'm not a vain man; I like to be half-respectable—I cannot meet my friends with a hole in my mouth. I would like to have a few teeth. [...] That's all I want- to stand up and have a conversation with friends. Would you not be embarrassed going around like that? [Rory, 61 years].*

Another participant described how tinnitus, a side effect of cisplatin-based chemotherapy, acted as a barrier to his participation in valued activities like listening to the radio and going to restaurants and public houses.

*[Tinnitus] drives me mad at times. Say now, you're going for a drink or you go to a restaurant and there's a lot of noise, it can be [overwhelming]. [...] It does stop me going to a lot of things. [...] I don't go out at night or anything like that because I can't stand music in a pub.*

*And even with a radio, at times, I can't stand it. [Lorcan, 61 years].*

Dorota described the difficulties she experienced because of lack of taste in the months following radiotherapy, which was a barrier to following dietary advice and eating normally.

*The radiotherapy completely destroyed the taste for 2-3 months. [...] If you take something and everything didn't have any taste, it tastes like paper. This mean you don't want to eat this if you have the imagine how was taste before [sic]. [Dorota, 30 years].*

### 3.2.2 | Cognitive symptoms arising from treatment

Participants identified cognitive symptoms arising from HNC treatment, such as difficulties concentrating and remembering, as barriers to their active self-management. Jacinta described how such symptoms affected her medical management, preventing her from learning how to use a suction machine to remove phlegm following a total laryngectomy.

*[The nurse] showed me how to use [the suction machine], but I forgot. I used to be okay with [technical] stuff, but since [treatment], it's all gone. I don't have the concentration. So I think, not meaning to, but I think I'm not willing to invest time. [...] I can't get my mind to it. [Jacinta, 71 years].*

Miriam explained how memory loss since completing her treatment acted as a barrier to managing everyday activities like shopping.

*I do lose my memory a bit, since the anesthetics or since the radium or the chemo. Just the other day now, and twice we were in shops, and I normally stock up ahead—I forgot that I had completely run out of hand soap. Now, twice I did—that annoys me. [Miriam, 68 years].*

## 3.3 | Structural barriers

### 3.3.1 | Financial resources

Participants identified the financial burden of cancer as a key issue impeding their ability to manage their emotions satisfactorily. Colm explained how costs like travelling for hospital appointments put both a financial burden and added stress on his family.

*It has put extreme financial pressure on us. Every time we get in the car to go to the hospital, it's money we don't have. The financial pressures over the last two years have meant that we can't cope with the mortgage. [...] That's been an enormous burden. On a daily basis you are just wondering, "how are we going to survive this?" [Colm, 53 years].*

Another participant described how additional medical and dietary costs adversely affected his emotional well-being by increasing his

self-consciousness and compounding self-identity issues relating to a new body image.

*When I lost the weight and everything, your clothes are too big—and you can't afford to buy clothes to fit you anymore. [...] You come back and everything is hanging off you, you know it's not [good]. And if you want to meet someone and you have a jacket that's hanging down here and you have your trouser with the waist wrapped around you twice, you know? No matter what kind of cancer you have, you have to change your complete [lifestyle] food-wise and everything. Sometimes it's more expensive—and then if you're on prescriptions, it's two quid every bloody time you go in. [Lorcan, 61 years].*

### 3.3.2 | Access to appropriate health services

Several participants highlighted perceived challenges in accessing appropriate health services as barriers to their active self-management. Cathal described how he felt that the interval between hospital follow-up appointments was too long and led to difficulties managing uncertainty.

*Once a person walks out the door, they shouldn't be forgot for six months until the next visit, do you know what I mean? [...] It's just reassuring to say "oh, you come in in three months". I know the hospitals are very busy but six months is a long time. [Cathal, 69 years].*

Another participant reported that he had limited access to professionals with HNC-specific expertise, and felt that the lack of specialist knowledge contributed to a difficulty in effective collaboration with healthcare professionals.

*The nurses working on those wards are not oncology nurses, which is totally ridiculous. They haven't a clue how to attend to a cancer patient's needs. [...] If you want throat cancer [sic], you need to speak to that [person]; if you have prostate cancer, you need to speak to them .... How can you explain yourself to somebody that knows more about prostate cancer than they know about your cancer? It's like asking you to come and do an electrician's job here for me when you're a painter. [Rory, 61 years].*

Rory also perceived that he was unable to effectively navigate appropriate health resources because of limited access to such resources. He described that the health services responsible for his care did not have readily accessible support for emotional and medical self-management, which he felt that he badly needed.

*All I want is someone to listen to me, someone to help me badly when I need it. Someone that shows a little compassion and a little concern for their fellow human being. That is all I ask. I'd do anything for myself if I can and what I can, but I would appreciate that, a little tiny bit of help, which I have not got.*

## 3.4 | Self-evaluative barriers

### 3.4.1 | Diminished self-confidence

Some participants described increased negative views of themselves arising from "becoming a cancer patient" (eg, feelings of vulnerability and reduced self-confidence), which negatively impacted their perceived ability to manage their condition.

*[I would describe it as] more or less, not feeling that I'm in charge. I felt a lot more capable dealing with everything that might have arisen [before]. I think it's just the fact of knowing that I got cancer. I just think of myself as a cancer patient. [Victoria, 76 years].*

Similarly, Cathal described how the loss of strength he felt following treatment had made him believe that he was less able to undertake physical work he used to perform with ease.

*Things that you'd be able to do at your ease, you'd just have to stand back now and let somebody else do that now. I was up climbing poles and masts for years and all sorts of dangerous work, but now I have to get one of the young lads to sweep the chimney because you wouldn't chance going up. [...] I'd be nervous now where I wouldn't have been nervous before. [Cathal, 69 years].*

Other participants talked about their lack of confidence in communicating effectively with health care professionals, which acted as a barrier to medical and emotional self-management. Finbar described how he felt that he lacked the courage to communicate effectively with his consultant at appointments, making it difficult to find reassurance about his progress.

*I'm no good to talk to a doctor. I'm no good to ask questions. [...] I'd like to talk to [consultant] at the next appointment, or one of the other doctors, and see how I'm progressing. [...] I don't know why [I'm not good at asking questions]. Maybe I don't have the courage or what, I don't know. [Finbar, 52 years].*

### 3.4.2 | Interpersonal self-evaluative concerns

Several participants perceived that others reacted negatively towards them because they had HNC and felt that this was a barrier to self-management. Catherine, who experienced speech difficulties following primary treatment, described how her perceptions of others' attempts to "test" her speech following primary treatment prevented her from returning to work and made her feel more self-conscious in social encounters.

*It took an awful lot to go back to work. The people at work knew what happened to me and they were looking to see "Is there something wrong with her speech?" I found that hard in the months after treatment. If you were in a restaurant, if you were ordering something, if it was noisy or busy, I did find that very difficult—if somebody said "Sorry?" or they looked at you and said "I just don't get what you're saying". That might have*

*happened anyway before and I wouldn't have noticed it, but it's probably just—I was more conscious of it.* [Catherine, 33 years].

Similarly, Adrian described how he became more uncomfortable with others who he perceived to be looking at him “as if he was dying”, leading him to avoid social encounters.

*I never really wanted to see anybody ... because they would look at you like you were dying, or they didn't know what to say or they didn't feel comfortable just popping in to you. And you didn't feel as comfortable with them as you did beforehand.* [Adrian, 56 years].

Participants also described how HNC led to difficulties maintaining the relationships needed to sustain their work. Timothy (an architect) described how he had found it very difficult to obtain new clients and retain existing ones because of people's reactions towards his cancer diagnosis and treatment.

*I have found that it's more difficult to get clients now. And a few people have come to me and said, “We didn't want to bother you with the cancer.” So they went elsewhere. [...] I depend on referral and word of mouth, and when word gets out that you've got cancer and you are recovering from cancer, people, they steer clear.* [Timothy, 57 years].

## 4 | CONCLUSIONS

To our knowledge, this is the first study to identify the barriers that HNC survivors perceive to impede their ability to actively self-manage their condition following treatment. We have identified 4 key barriers in this context: emotional, symptom-related, structural, and self-evaluative barriers.

The findings illustrate that the morbidity associated with HNC and its treatment (such as speech difficulties, loss of teeth and tinnitus) not only impacts upon survivors' quality of life (QoL)<sup>15,20</sup> but also impairs their active self-management following treatment. Symptoms such as taste loss, speech difficulty, dental disease, and tinnitus reduce survivors' motivation and ability to engage in medical management, may compound emotional difficulties, and may lead to social isolation. Head and neck cancer survivors who experience such issues may benefit from acceptance-training intervention components, which focus on increasing one's ability to tolerate unpleasant experiences, and have been found to assist cancer survivors to live well in the context of issues related to cancer and its treatment [eg].<sup>21</sup>

Head and neck cancer survivors also identified how negative self-evaluations could act as a barrier to their posttreatment self-management. While experiencing a “diminished self” has been described elsewhere in relation to this patient group,<sup>22</sup> this is the first study to demonstrate its deleterious effects on self-management (ie, by reducing self-confidence). Participants' perceptions of the negative views of others also highlight how perceived stigma may affect their ability to self-manage (eg, preventing them from working and socializing). This is consistent with research showing that stigma is higher among

people who are disfigured by cancer and/or its treatment<sup>23</sup> and that confronting others' negative reactions can take a substantial emotional toll among HNC survivors.<sup>24</sup> Additionally, while emotional consequences are recognised as a notable concern for HNC survivors associated with lower QoL,<sup>12</sup> this is the first study to identify how negative emotional consequences act as barriers to active self-management.

Our findings also highlight how perceived issues with access to appropriate health services can affect HNC survivors' ability to activate health resources effectively (a key self-management process<sup>25</sup>). Self-management literature recognises that effective self-management requires specialised support from appropriately trained health care professionals.<sup>26</sup> While this may not always be possible, or appropriate, for those involved in the care of HNC survivors, more innovative or effective models of delivering follow-up care and longer term support may be necessary. Furthermore, HNC survivors may need signposting to available services and support and encouragement to access these services where they already exist.

Symptom-related and structural barriers to active self-management described by participants also mirror barriers to self-management identified in other long-term conditions. Pain, fatigue, financial resources, and cognitive symptoms arising from treatment have emerged as key self-management barriers across a range of long-term conditions.<sup>3,27-32</sup> Poor communication between individuals with long-term conditions and health care professionals can impede understanding and effective collaboration in relation to medical management.<sup>3,28,33,34</sup> In the current study, poor communication resulted from HNC survivors' worries about future consequences and lack of efficacy in communicating with health professionals.

### 4.1 | Clinical implications

The barriers to self-management identified above have important implications for the design and implementation of supported self-management interventions for HNC survivors. Drawing upon a comprehensive framework by Schulman-Green et al,<sup>25</sup> it is possible to identify specific self-management skills related to the perceived barriers described herein, which may be useful to target in such interventions. For example, emotional barriers like low mood, FoR, and worries surrounding treatment consequences could be addressed by intervention components that relate to exploring and expressing emotional responses.<sup>25</sup> Head and neck cancer survivors may also benefit from support in learning to manage how they respond to others' reactions to their physical appearance and/or symptoms arising from their condition. Because redefining the self and reframing expectations of life and self<sup>25</sup> can assist HNC survivors in tackling negative self-perceptions arising from stigmatisation,<sup>32</sup> these might also represent important intervention components to tackle perceived stigma among this group following treatment. Our findings also highlight the need to target negative self-perceptions like low self-confidence; interventions which focus on confronting change and loss and accepting the “new normal”<sup>25</sup> could be particularly helpful in this regard. Adjustment-focused interventions, which facilitate the overall transition to survivorship rather than concentrating on specific functional issues, can effectively foster self-efficacy<sup>35</sup> or target key self-management processes such as learning illness needs, taking ownership of health

needs, and promoting good health within oneself<sup>25</sup> and may assist HNC survivors to address posttreatment psychosocial barriers to their medical management. To overcome low self-confidence in communication, intervention components that focus on key communication skills [eg,]<sup>36,37</sup> may be particularly useful. Additionally, following our findings in relation to financial resources, intervention components relating to financial management [eg,]<sup>38</sup> may be beneficial for HNC survivors. Because of potential issues of accessibility to services, eHealth self-management interventions may also be of particular value to this population [eg].<sup>39</sup> Finally, routine screening for QoL needs (eg, using the Patient Concerns Inventory<sup>40</sup>) may help to identify those who need to be targeted with structured supported self-management programmes.

## 4.2 | Study limitations

There were a number of strengths and limitations to the study. Firstly, as the study was cross-sectional, we did not explore whether or not participants' perceived barriers to active self-management persist in the long term. Longitudinal qualitative research could establish this and whether new barriers emerge over time in this population. Secondly, while this study identified and described the factors which survivors perceive as barriers to posttreatment self-management, further research is needed to quantify the extent to which these factors impinge upon HNC survivors' active self-management. Nonetheless, we have outlined direct parallels between challenges described by HNC survivors and those with other long-term conditions and highlighted the impact of unique challenges for HNC survivors, such as losing one's teeth. Furthermore, the credibility of the research is evidenced by the rich and varied experiences of participants contained in the dataset as a whole. Finally, the purposeful critical case sampling method meant that, although the study only comprised 27 participants, we included a diverse sample of survivors facing functional and/or psychosocial challenges particular to HNC. However, it is possible that other HNC survivors facing these, or different challenges (eg, mental health issues), may experience additional barriers to active self-management following primary treatment.

In conclusion, this is the first study to highlight how emotional, symptom-related, structural, and self-evaluative issues can be perceived barriers to active self-management following treatment for HNC. These findings have important implications for self-management research and intervention development in the context of HNC survivorship. Future interventions should be carefully designed to address these barriers. These could support HNC survivors to learn skills that facilitate self-management and enable them to live well after active treatment.

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## CONFLICT OF INTEREST

There is no conflict of interest to report.

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