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Self-management strategies used by head and neck cancer survivors following completion of primary treatment: A directed content analysis

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Abstract

Objective: Head & Neck Cancer (HNC) survivors encounter unique challenges following treatment. This study aimed to identify self-management strategies that HNC survivors use to overcome these post-treatment challenges.

Methods: Twenty-seven individuals from four designated cancer centres in Ireland were interviewed about self-management strategies that helped them overcome challenges following HNC treatment. Interviews were audio-recorded, transcribed and analysed using directed content analysis.

Results: Twenty self-management strategy types (encompassing 77 specific strategies) were identified. The most frequently used self-management strategy types were *Self-sustaining* (used by 26 survivors), *Self-motivating* (n=25) and *Proactive problem solving* (n=25). The most frequently used specific strategies were *adaptive approaches to ongoing physical consequences of HNC and its treatment* (n=24), *customizing dietary practices* (n=24) and *maintaining a positive outlook* (n=22).

Conclusions: The study identified strategies that helped HNC survivors to self-manage post-treatment challenges. This information could inform the design/development of self-management interventions tailored towards HNC survivors.

Keywords: head and neck cancer, cancer survivorship, self-management, psychosocial intervention development, qualitative.

BACKGROUND

Self-management refers to “[one]’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition” [1,p.178]. In long-term illness, effective self-management involves monitoring one’s condition and using cognitive, behavioural and emotional strategies to maintain a satisfactory quality of life (QoL) [1]. Specific self-management strategies adopted by individuals with long-term illnesses include engaging in practices that address distinct illness needs, activating medical, psychological, social and/or spiritual resources and integrating illness/treatment consequences into daily life [2]. In cancer survivorship, self-management has been defined as “awareness and active participation by the person in their recovery, recuperation and rehabilitation, to minimise the consequences of treatment, and promote survival, health and well-being” [3,p.6]. Cancer survivors’ use of self-management strategies appears to be particularly important following primary treatment when survivors have less involvement with, and less access to, specialist health professionals [4]. This, in turn, means there is a greater need for survivors to adapt their daily routines to recurring challenges, deal with residual distress independently, adjust to late effects and understand recurrence signs and symptoms [4].

Self-management following completion of primary treatment may be particularly important to head and neck cancer (HNC) survivors. HNC and its treatment are associated with a range of specific challenges, which can disrupt survivors’ physical, social and psychological wellbeing. For instance, HNC survivors might experience difficulties in eating or communicating due to the effects of surgery or radiotherapy; issues which are associated with impaired social functioning [5,6]. Facial disfigurement resulting from surgery can also lead to elevated distress levels in this patient group [7]. Risk of recurrence is high compared with other cancers [8] and up to three-quarters of survivors experience fear of recurrence (FoR) [6]. Although some functional outcomes may improve in the initial year following treatment [9], others, like FoR, can have a profound impact on HNC survivors’ long-term QoL [10]. Persistent challenges (e.g. trismus, dysphagia and feeding tube issues) can also lead to QoL deterioration [11,12]. Such issues extend beyond the acute phase of treatment, requiring ongoing self-management.

In spite of this, little is currently known about how HNC survivors self-manage. To our knowledge, only one existing framework has been used to identify the SM strategy types that cancer survivors adopt [13], but the strategy types described therein are quite broad and relate to cancer more generally. As such, this research study aimed to identify self-management strategy types, and specific self-management strategies, that are used by purposefully-

sampled HNC survivors following completion of their primary treatment. This information could inform the development of self-management interventions to support HNC survivors to manage the post-treatment challenges they encounter.

METHOD

Study design

The study used a qualitative methodology involving semi-structured interviews to yield data that was rich and detailed, and as attentive to the context of self-management in HNC as possible. For the purposes of analysis, we used Davies and Bateup's [3] definition of cancer self-management, provided above.

Recruitment process

Ethical approval was provided by four designated cancer centres in Ireland. Ireland has a mixed public-private healthcare system and eight designated centres provide centralised cancer care within the public healthcare system; patients may also opt for private treatment in these centres. A purposeful critical case sampling strategy was used [14] following consultation with an expert advisory group. This involved targeting HNC survivors with specific functional and psychosocial impairments related to their condition (speech difficulties, swallowing difficulties, facial disfigurement and social isolation) to ensure individuals who had experienced these challenges were represented in the sample. Individuals were eligible to participate if they had completed their primary treatment for HNC, were aged at least 18 years and spoke fluent English. Individuals were excluded if they were undergoing or awaiting treatment for HNC or receiving palliative care. Potentially eligible individuals were identified by a nominated Clinical Nurse Specialist from each participating cancer centre based on their knowledge of, and familiarity with, HNC survivors who attended outpatient clinics there. These individuals were sent letters of invitation to participate, which contained an information sheet explaining the study, a reply slip and a pre-paid envelope. Interested individuals were invited to return their reply slip to the study team and provide contact details. Those who did so were contacted by the first author to arrange the interview. Informed consent was provided by all participants at the time of interview.

Data collection

Interviews were conducted by the first author; a researcher who was appropriately skilled in qualitative data collection techniques. Interviews were structured around a topic guide, including a series of open-ended questions. Participants were asked to describe challenges they encountered at any time following treatment for HNC, self-management strategies they used to help them in dealing with these challenges, how successful they felt they were in dealing with these challenges through self-management and any barriers/facilitators that they may have encountered in the use of these strategies. This article focuses on the data on self-management strategies that HNC survivors described as being helpful in dealing with challenges in the post-treatment period.

Each interview was audio-recorded (with the interviewee's permission), transcribed verbatim and anonymised. Interviews lasted 35-255 minutes and were carried out in a location convenient to the participant.

Data Analysis

The data were analysed using directed content analysis [15] by the first two authors; a health psychologist working as part of a research team on the design of a self-management intervention for HNC survivors and an independent research assistant respectively. NVivo 10 for Windows was used to assist with organization and coding of data. This analysis involved three stages. Firstly, portions of the interview transcripts relevant to the research question (i.e. self-management strategies used following treatment for HNC) were extracted for analysis by the first author. Secondly, initial coding was performed by the first two authors independently to develop a coding instrument. The codes and their definitions were initially guided by self-management strategy types (e.g. *Creating a healthy environment*) identified in an existing framework describing self-management strategy types in cancer survivorship [13] and specific self-management strategies (e.g. creating and maintaining relationships with healthcare providers) identified in a systematic review of the broader self-management literature [2]. Any relevant content that could not be categorized using this initial coding instrument was assigned a new code. To ensure consistency, both authors met to discuss, clarify and refine the codes after they had independently coded blocks of 9 transcripts. The final stage of analysis involved the researchers independently coding every transcript with the completed coding instrument and counting the codes for each strategy type and specific strategy across participants. Once independent coding had been completed, any differences in assigned codes were resolved through discussion. The final author was available to resolve disagreements at each stage of the analysis and validated the interpretation of the analysis by checking the quotes and content codes to ensure that they made sense.

RESULTS

Twenty-seven HNC survivors took part. Demographic/clinical information is provided in Table 1. Twenty self-management strategy types, encompassing 77 specific self-management strategies, were identified (See Table 2): *Proactive problem solving* (encompassing 2 specific strategies), *Creating a healthy environment* (4 strategies), *Goal and action setting* (4 strategies), *Reasoned decision-making* (4 strategies), *Activity-based coping* (2 strategies), *Self-sustaining* (4 strategies), *Self-motivating* (8 strategies), *Positive appraisal* (3 strategies), *Meaning-making* (7 strategies), *Self-monitoring* (4 strategies), *Conserving physical energy* (3 strategies), *Conserving emotional energy* (2 strategies), *Acceptance* (3 strategies), *Adopting a healthy lifestyle* (4 strategies), *Behavioural avoidance* (3 strategies), *Cognitive avoidance* (3 strategies), *Managing others* (4 strategies), *Seeking normality* (5 strategies), *Using sense of humour* (2 strategies) and *Using support* (6 strategies).

In general, HNC survivors described their use of multiple self-management strategy types to deal with post-treatment challenges (range=3-19 strategy types per survivor; median=15 strategy types) and specific self-management strategies (range=3-42 specific strategies per survivor; median=24 specific strategies)¹. These self-management strategy types and specific self-management strategies were used individually or concurrently by participants. Due to the extent and range of self-management strategies used by participants, we discuss only the most frequent self-management strategy types and specific self-management strategies in the analysis and discussion which follows.

The self-management strategy types most frequently used were *Self-sustaining* (used by 26 survivors²), *Self-motivating* (n=25), *Proactive problem solving* (n=25), *Using support* (n=24), *Seeking normality* (n=23) and *Meaning-making* (n=23). The most common specific *Self-sustaining* strategy, *customizing dietary practices* (e.g. preparing food so that it is easy to swallow following eating challenges associated with cancer treatment), was used

¹Supplementary Table 1 provides definitions and frequencies for self-management strategy types and accompanying sample quotations from participants for each specific self-management strategy.

² In what follows, n values refer to the number of participants who reported using the self-management strategy type or specific self-management strategy in question.

by almost all participants (n=24). Similarly, the *Self-motivating* strategy *maintaining a positive outlook* (e.g. regarding oneself as lucky for having survived HNC) was also commonly used (n=22). The most frequently reported *Proactive problem solving* strategy was *adaptive approaches to ongoing physical consequences of HNC and its treatment* (n=24); e.g. using a hot beverage to loosen excess phlegm. *Using support* included support from healthcare practitioners and other HNC survivors but most often involved *receiving support from family and friends* (n=20); e.g. motivational support from family to manage eating challenges associated with cancer treatment. *Seeking normality* most often involved *focusing on doing normal activities* (n=16); e.g. trying to regain one's ability to perform chores like mowing the lawn. The most frequently cited *Meaning-making* strategy was *appreciating support* (n=15); e.g. appreciating the kindness of friends.

The most frequently used specific self-management strategies corresponding to the remaining self-management strategy types are as follows. Within *Goal and action setting*, the most common approach was *setting up facilitating conditions* (n=15); e.g. carrying around a water bottle to manage dry mouth arising from radiotherapy. *Reasoned decision-making* strategies were infrequently reported by participants; the most common of these strategies, *evaluating effectiveness of SM* (e.g. deciding to stop using medications that increase drowsiness), was only used by two participants. *Creating a healthy environment* most commonly comprised *learning self-management skills* (n=11); e.g. learning relaxation techniques to alleviate anxiety and FoR. *Activity-based coping* most often involved *pursuing an existing hobby/activity* (n=13); e.g. playing a musical instrument in times of stress. The most common *Conserving physical energy* and *Conserving emotional energy* strategies were *taking a break* (n=17) and *minimising stress* (e.g. avoiding "office politics"; n=9), respectively; typically to manage cancer-related fatigue. *Positive appraisal* most often took the form of *reinterpreting negative consequences* (n=17); e.g. reinterpreting surgical scars as a symbol of survival. *Self-monitoring* included *monitoring symptoms and side effects* (n=12); e.g. continually checking one's mouth for recurrence signs. The most prevalent *Acceptance* strategy was *accepting illness and its consequences* (n=20); e.g. accepting that one can no longer perform hard physical labour due to fatigue. *Adopting a healthy lifestyle* most commonly involved *exercising* (n=13) behaviours such as going for walks. *Behavioural avoidance* most often involved *avoiding activities that may cause harm* (n=10); e.g. avoiding noisy public locations that aggravate symptoms of tinnitus arising from chemotherapy. *Cognitive avoidance* most frequently involved *avoiding thoughts about cancer and its consequences* (n=16); e.g. getting rid of clothes which reminded one of cancer treatment. *Managing others* most commonly related to *protecting others from harm* (n=10); e.g. de-emphasizing emotional and physical challenges in order to avoid burdening others. Finally, *Using sense of humour*

mostly comprised *laughing about cancer and its consequences* (n=6); e.g. taking a 'selfie' after receiving a tracheotomy.

DISCUSSION

To our knowledge, this is the first study to identify specific self-management strategies that HNC survivors use to deal with challenges they experience following primary treatment. The extent and diversity of self-management strategy types and specific strategies used by HNC survivors may reflect the burden of physical, social and psychological challenges encountered following HNC treatment [6,16]. The identification of a broad typology of HNC self-management strategies, which was informed by an existing framework of cancer self-management [13], may also be useful for categorising such strategies. While future quantitative research is needed to verify the extent and usefulness of such strategies, this typology could be adopted as a resource for practitioners (e.g., to help direct HNC survivors who may be at risk for poorer outcomes towards appropriate support) and researchers (e.g., to inform the development of interventions to promote self-management strategies that might benefit survivors' responses to specific challenges).

The self-management strategy types described herein were based on a framework that describes how cancer survivors self-manage the consequences of their illness and its treatment [13]. As the only existing framework of cancer self-management strategies, it provided a useful starting point in making sense of the data and developing a typology of self-management strategies. The following strategy types from this framework reflected key self-management strategy types used by participants and were thus included in our analysis: *Proactive problem solving*, *Goal and action setting*, *Creating a healthy environment*, *Reasoned decision-making*, *Self-motivating*, *Self-sustaining* and *Activity-based coping*. As the framework was derived from data primarily relating to breast, colorectal, lung and gastric cancers, this finding suggests that these strategy types might be common across a range of different cancers.

This study also indicates how this framework might be adapted to more comprehensively reflect the experiences of survivors of other cancers (in this instance, HNC) by including additional strategy types such as *Acceptance*, *Adopting a healthy lifestyle*, *Cognitive avoidance*, *Meaning-making*, *Conserving emotional energy*, *Positive appraisal*, *Seeking normality*, and *Using support*, none of which appeared in the original framework. *Meaning-making* appears to be commonly used by people with long-term illnesses such as type 2 diabetes and cardiovascular

disease [2]. This may be particularly relevant to HNC survivors who, due to facial disfigurement/communication difficulties, may experience a diminished self and desire to make sense of their illness [17]. *Positive appraisal* (i.e. focusing on positive aspects of one's situation) has been associated with positive outcomes such as using more active coping strategies among breast cancer survivors [18] and individuals with HIV [19]. *Conserving emotional energy* may help HNC survivors to deal with long-term challenges, such as eating difficulties and facial disfigurement, which have been found to require significant psychosocial adjustment [20-21; 6]. *Adopting a healthy lifestyle* and *Seeking normality* are broad self-management strategy types that are consistently identified in reviews and theoretical models of self-management in both long-term illness [22-24] and cancer [4]. *Using support* was also a commonly used self-management strategy type for HNC survivors in the present study; this is consistent with the emerging literature on the importance of social support following HNC treatment [6,17]. The frequently reported use of *Cognitive avoidance* to assist post-treatment self-management echoes prior research suggesting that denial and defensive avoidance can be adaptive in dealing with long-term illnesses that are particularly challenging [25-27]. Avoiding thoughts about cancer might be protective for HNC survivors, given the likelihood of recurrence and high incidence of FoR among this cohort [6,8]. It is also possible that this strategy could buffer against negative outcomes associated with FoR, such as psychological distress and diminished QoL [10]. *Acceptance* may also be important in aiding HNC survivors' psychological adjustment to persistent and potentially irresolvable challenges that they may encounter in this period, including eating/communication difficulties and ongoing medical management (e.g. feeding with a percutaneous endoscopic gastrostomy tube).

This typology of self-management strategy types could inform the design and implementation of self-management interventions for HNC survivors in future research. For instance, it could be used as a framework for research which seeks to identify the strategy types that are most effective in the self-management of post-treatment challenges in HNC. Further studies may be able to identify clusters of strategy types, such as cognitive strategy types (e.g. *Reasoned decision-making*, *Goal and action setting* and *Meaning-making*) and behavioural strategy types (e.g. *Behavioural avoidance*, *Creating a healthy environment* and *Activity-based coping*), that may be particularly useful for HNC survivors in responding to specific challenges associated with HNC treatment and its consequences.

Another major finding of this study was the use of many different specific self-management strategies by participants. One key specific self-management strategy used by HNC survivors was *accepting illness and its consequences*. This echoes the findings of research in other populations, where mindfulness and acceptance-based

approaches have helped individuals to deal with long-term medical, stress and anxiety symptoms [28-30]. These are important issues for HNC survivors after treatment [6], suggesting that it may be worth assessing the presence of such symptoms and incorporating mindfulness and acceptance-based approaches as part of tailored self-management interventions for HNC survivors, where appropriate. The finding that *maintaining a positive outlook* was frequently used by participants also mirrors findings from the wider literature on dispositional optimism among HNC survivors. Dispositional optimism (i.e. a generalized expectancy for positive outcomes [31]) has been found to predict QoL and one-year survival among HNC survivors [32-33]. This, together with our findings, suggests that self-management interventions which emphasise positive thinking might assist HNC survivors in overcoming specific post-treatment challenges. Using *adaptive approaches to ongoing physical consequences of HNC and its treatment* may also help HNC survivors to overcome persistent symptoms/side-effects such as dry mouth and pain [16]. *Customizing dietary practices* may be beneficial for HNC survivors post-treatment, as they often experience functional eating difficulties and taste-related changes that require dietary alterations such as changing to a “soft diet” [20,34]. Finally, *receiving support from friends and family* has been identified as particularly important among HNC survivors in prior research; e.g. taking on survivors’ responsibilities in the home or providing personal care [17]; findings which are reflected in this study. As such, interventions which teach self-management skills to HNC survivors and their friends and family may help to maximise the benefits of such support to survivors.

Limitations

There were a number of limitations to this study. Firstly, as interviews only took place at one time-point, we did not explore change over time within individuals. Future longitudinal qualitative research could help to establish whether and how use of self-management strategies changes at different stages of the cancer trajectory. Secondly, the purposeful critical case sampling method used meant that, in some cases, only a small number of individuals with particular functional or psychosocial challenges were included. It is possible that HNC survivors without these challenges (or with different challenges) may use additional and/or different self-management strategies.

Nonetheless, the credibility of the research and sampling process is evidenced by the diversity of the sample and varied experiences of participants in the dataset as a whole. Additionally, the flexible application of the topic guide allowed participants to raise issues of importance to them, while independent coding of transcripts by two researchers ensured the analysis process was robust. It should also be noted that, although particular self-management strategies were identified by participants as helpful in overcoming their post-treatment challenges, the

use of these strategies may not have been optimally effective and participants may have varied in their success at, and ability in, implementing them.

Clinical Implications/Conclusions

This study demonstrates that a purposefully-selected group of HNC survivors use particular strategy types and a wide variety of specific strategies to deal with post-treatment challenges. These findings could inform the development of self-management interventions for HNC survivors by tailoring them to explicitly incorporate the strategies that appear to be most appropriate for their post-treatment self-management. As HNC survivors want support about managing side effects associated with their condition from peers and health professionals [35], adjustment-focused self-management interventions which provide such support and which strengthen self-efficacy in dealing with the consequences of cancer [36] may assist HNC survivors to employ more adaptive approaches to their self-care. The study points towards potentially condition-specific strategies (e.g. customizing dietary practices) that HNC survivors use in their post-treatment self-management. These may help survivors to overcome specific challenges of HNC and its treatment. As HNC survivors in this study used a variety of different self-management strategy types and specific self-management strategies, it may also be important for healthcare practitioners to identify HNC survivors' self-management needs on an ongoing basis. This could assist practitioners to support HNC survivors more effectively in managing post-treatment challenges, e.g. by directing them towards additional multidisciplinary team members (e.g. dieticians, physiotherapists and psycho-oncologists) who may be able to direct, or train, them in relation to key self-management skills. Finally, it may not always be possible for HNC survivors to self-manage independently following primary treatment and they may require on-going support from the multi-disciplinary team involved in their care.

Conflict of Interest

There is no conflict of interest to report for this manuscript.

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Table 1: Demographic/clinical characteristics of participants

<i>Variable</i>	<i>N</i>
Gender	
Male	18
Female	9
Marital status	
Single/Never married	5
Married/Cohabiting	18
Separated/Divorced	3
Widowed	1
Cancer site	
Larynx	9
Tonsils	6
Tongue	5
Oral Cavity	5
Pharynx	2
Treatment(s)	
Radiotherapy & chemotherapy	6
Surgery & radiotherapy	10
Surgery, radiotherapy & chemotherapy	11
Employment status	
Currently working	9
Not currently working	8
Retired	10
Self-reported smoking status	
Current smoker	3
Ex-smoker	15
Never smoked	8
Not reported	1
Self-reported alcohol consumption status	
Does not drink	4
Moderate drinker	18
Heavy drinker	5
Age	
25-39 years	2
40-54 years	5
55-69 years	17
70 years or more	3
Time since diagnosis	
9-12 months	1
13-24 months	13
25-36 months	10
Over 36 months	3

Table 2: Self-management strategy types and specific self-management strategies identified through content analysis

Self-management strategy type	Specific self-management strategy
Activity-based coping	Taking up a new hobby/activity Pursuing an existing hobby/activity
Adopting a healthy lifestyle	Adopting a healthy diet Exercising Meditating Reducing negative health behaviours
Creating a healthy environment	Acquiring knowledge about condition and available support Collecting materials to aid self-management Learning self-management skills
Reasoned decision-making	Relationship-building with health practitioner Considering pros and cons of self-management Evaluating effectiveness of self-management Thinking objectively about negative health behaviours Thinking objectively about negative thoughts and emotions
Goal and action setting	Planning daily activities Priority-based planning Setting up facilitating conditions Setting future goals
Self-monitoring	Monitoring emotions Monitoring general health more Monitoring relationship with health professionals Monitoring symptoms and side effects
Proactive problem solving	Acting to prevent further complications Adaptive approaches to ongoing physical consequences of HNC and its treatment
Self-motivating	Employing a determined attitude Drawing on spiritual resources Encouraging oneself Focusing on milestones of survivorship Maintaining a positive outlook Persevering with healthy behaviours Rewarding oneself Treating illness as a project
Self-sustaining	Following health practitioner's advice Incorporating self-management behaviours into daily routine Maintaining medical equipment Customizing dietary practices
Using support	Companionship from pet Receiving formal support Receiving support from family and friends Seeking formal help Seeking support from family and friends Drawing support from similar other
Conserving physical energy	Reducing activities Reducing workload Taking a break
Conserving emotional energy	Caring less about what others think Minimising stress
Cognitive avoidance	Avoiding finding out too much Avoiding thoughts about cancer and its consequences Distracting oneself by keeping busy
Behavioural avoidance	Avoiding activities that may cause harm Avoiding contact with others for possible infection Avoiding uncomfortable social encounters

Managing others	Being assertive in social encounters
	Keeping others happy
	Being open with others about cancer and its consequences
	Protecting others from harm
Positive appraisal	Benefit finding
	Downward comparison
Meaning-making	Reinterpreting negative consequences
	Appreciating health more
	Appreciating the importance of family
	Appreciating life more
	Appreciating support
	Becoming more altruistic
	Changing one's image
	Finding meaning in work
Seeking normality	Focusing on doing normal activities
	Focusing on getting back to work
	Maintaining independence
	Testing oneself
	Trying to fit in
Acceptance	Accepting illness and its consequences
	Accepting new health behaviours
	Accepting social difficulties
Using sense of humour	Finding humour in others' reactions
	Laughing about cancer and its consequences

Supplementary Table 1: Self-management strategy type definitions, frequency of participants reporting particular self-management strategy types and specific strategies, and accompanying participant quotes

<i>Content codes for strategy types and specific strategies</i>	<i>Strategy type definition</i>	<i>N</i>	<i>%</i>	<i>Sample quote</i>
Activity-based coping	Use or uptake of hobbies or activities to manage one's emotional well-being	15	56	
Taking up a new hobby/activity		4	15	HNCP09: I used to be a bit of a hermit, I used to stay in the house, or I might go across the road or I might go and see some relation, but that's all. But now I'm out every night, I'm out every day. I'm on Facebook and I take photographs of the town and I put them on Facebook. I write little things about history and things like that, and I really enjoy myself.
Pursuing an existing hobby/activity		13	48	HNCP05: Any time I had ever trouble in my life, you know, like everybody has their worries, I'd go off and play the guitar. I just did it to sort my head out, you know. If I just had a rough day, I'd go down and play my guitar. And it was great, it was a great release. [...] Now I go down there and I play, you know. I can't play at 200mph an hour like I used to, but I can play. And that's great, and that gets me through a lot.
Adopting a healthy lifestyle^a	Adopting generic health behaviours to boost one's general physical and/or emotional well-being	20	74	
Adopting a healthy diet		10	37	HNCP06: I became very food conscious, what I ate. I eat what I consider good foods for everybody, you know, liver, eggs, fish, chicken. That's about it.
Exercising		13	48	HNCP07: Once my chemotherapy was finished, I actually started training at home with very, very light weights. [...] It was very, very light weights, but [as a result], I'd say six or seven weeks after my treatment was finished, I was out playing golf.
Meditating		1	4	HNCP19: One thing that I have taken up, which I had never done prior to getting sick, but I've been doing for the past couple of months, I'm lucky enough, as I told you earlier, to spend a lot of time in [location removed]. There's a Buddhist monastery close to us [there]. I go there for meditation classes. It is absolutely wonderful.
Reducing negative health behaviours		6	22	HNCP20: Ah yeah, sure I have [reduced my drinking]. Sure I wouldn't be able; I wouldn't even try now, you know?

Creating a healthy environment	Attempts to create an environment which enables effective self-management	17	63	
Acquiring knowledge about condition and available support		3	11	HNCP13: After you have the surgery, you begin to eat and you get this pain in your head, you feel like your head's going to explode. Nobody tells you about it. Onto the internet; and it's all of the liquids that your body produces to help you eat are still being produced, but there's no drainage to take them away, so they pool here in the back of your head.
Collecting materials to aid self-management		4	15	HNCP03: I have a phone system [in place] that if anything's wrong, to be able to ring them [sic].
Learning self-management skills		11	41	HNCP06: I got the nurse to show me how to use [the suctioning machine] once, because I'd say it would be invaluable.
Relationship-building with health practitioner		7	26	HNCP15: [It's important to] try to have manners with the staff, manners with the doctors and nurses, and every one of them, manners and respect of people, which I did.
Reasoned decision-making	Objective decision-making strategies relating to HNC survivor self-management	6	22	
Considering pros and cons of self-management		1	4	HNCP14: I don't particularly want to be taking things or putting gels in my mouth, when it's not that bad. I think that maybe, in a couple of years' time, if it gets a lot worse, I would do it.
Evaluating effectiveness of self-management		2	7	HNCP02: I tried putting a little scarf over [the tracheotomy] once, but all you are doing is choking off your air. And I've no intention of choking myself for the sake of saving somebody, you know
Thinking objectively about negative health behaviours		2	7	HNCP04: Both Sandra and I knew that financially we had to stop [smoking] and for health reasons we had to stop. If there's something that shows up, I'm going to be put to the back of the list if they see that I'm still smoking.
Thinking objectively about negative thoughts and emotions		1	4	HNCP13: If you start dwelling on it and thinking about it, and getting negative, what's the use? What do you gain out of that? You don't really gain anything by being negative.
Goal and action setting	Use of planning or goal-setting self-management strategies	19	70	
Planning daily activities		4	15	HNCP04: Day-to-day living, it's just a case of getting up, doing what I'm able. I try and plan out a day the night before. And it was always something of mine – write a list. If you cross the list - if you start going down your list, you feel good about yourself and that gives you that extra bit of motivation.

Priority-based planning		2	7	HNCP04: But the key thing at the moment is to stop the drink. Then I'll tackle the smoking.
Setting up facilitating conditions		15	56	HNCP25: You can't just go somewhere and not worry about it. I've got to have a certain amount of things with me all the time to make sure that my mouth is [moist enough] that I'm going to be able to talk.
Setting future goals		8	30	HNCP18: I was on the drugs, on the pills, until the December, and I decided and I said, "In New Year, I will start without that pills [sic]."
Self-monitoring^b	Active self-monitoring of one's health, well-being and ongoing care	17	63	
Monitoring emotions		9	33	HNCP24: Oh, yeah – sure I feel [upset] now, if you think about it, you know? It's not that – I said to you earlier – it's not that I'm shutting that out. I think [crying]'s a release, it's [an] emotional response, it's how you feel, you know? It's important to get it out.
Monitoring general health more		4	15	HNCP07: Now I have to really look after my weight, because it just seems that if I look at food now I'm putting weight on.
Monitoring relationship with health professionals		1	4	HNCP13: Sometimes when project managers report, they want to give a good impression. [Laughter] So I had to catch myself once or twice, and say to [consultant], "You know the last time I told you this? Well..." She'd be laughing at me.
Monitoring symptoms and side effects		12	44	HNCP19: I began to test the improvement [in speech] myself by recording myself on my phone. That was great for the bit of confidence, because whilst I wouldn't have been that clear initially, I could actually hear the improvement.
Proactive problem solving	Active attempts to solve problems in-the-moment arising from the consequences of HNC cancer and its treatment	25	93	
Acting to prevent further complications		4	15	HNCP01: And having to cut the grass; in case I get pollen grains off the grass, I had to wear a face mask.
Adaptive approaches to ongoing physical consequences of HNC and its treatment		24	89	HNCP05: Like, [when] we are going out for a meal, you know, myself and my wife and kids or some friends, everybody is sitting in the restaurant ordering their meal and I've got to look at the softest thing on the menu.

Self-motivating	Strategies which help to motivate oneself to effectively self-manage	25	93	
Employing a determined attitude		16	59	HNCP23: You just have to get through it meself [sic]. It's as simple as that, you know?
Drawing on spiritual resources		5	19	HNCP15: I pray a good bit. I pray twice a day. It's not that I pray an awful lot, but I do pray. [...] But it has kept me going anyway.
Encouraging oneself		11	41	HNCP05: You'd, kind of, talk to yourself when you were feeling bad. You'd say, "Look, this guy has given me the all-clear."
Focusing on milestones of survivorship		2	7	HNCP13: You have to get through the first year, because your chances of recurrence are very high. [...] The outcome is never very good if it recurs. So when I got to the first year mark, I was like: "I'm at the first year mark." Now, I'm looking to the second year mark.
Maintaining a positive outlook		22	81	HNCP08: I feel, sort of, I'm a kind of philosophical person. I, sort of, felt to myself, "Well, I've got to this stage in life without any major illness, so it's not too bad if something happens now, you know."
Persevering with healthy behaviours		15	56	HNCP14: I'm not great on chewing steaks; so you just take longer, drink more. Get on with it.
Rewarding oneself		2	7	HNCP06: Whenever I see anything I like and I can afford, I'm getting it. Whereas before the cancer I'd say, "I'm not paying that kind of money for that," as if I was going to be around forever and a day.
Treating illness as a project		1	4	HNCP13: I basically project managed this, because project management is what I do. I project manage big, big projects for the bank. [...] So I sort of project managed this illness and this system.
Self-sustaining	Strategies which enable one to implement self-management strategies consistently in one's daily life	26	96	
Following health practitioner's advice		11	41	HNCP06: [Consultant]'s he's the one that recommended that [medication]. Because yesterday was my first day taking it, and by evening I was fine and there was no phlegm. [...] But I can feel it's so much better today. So by another few days I should be fabulous.
Incorporating self-management behaviours into daily routine		17	63	HNCP13: I do [mouth exercises] all the time. My trigger is: I'm driving the car, red traffic lights, I do my exercises. So that's it: brush my teeth, do my exercises; brush my hair, do my exercises; red traffic lights, do my exercises.

Maintaining medical equipment	7	26	HNCP20: I had the trachea [sic] in as well [after finishing treatment] and that was a devil. You had to take that out and clean it maybe three times a day, do you know what I mean?
Customizing dietary practices	24	89	HNCP04: I do find that I have to over-salt food, whereas [before] I'd always be very careful of how much salt went on at the table regardless of what went on whilst it was being cooked or spread. And to this day, I still have to over-salt food to be able to taste.
Using support^a	24	89	
Companionship from pet	2	7	HNCP23: I'd be lost without him, you know, being honest. You know, if you haven't got a dog or something, you know, when you live on your own, you get lonelier.
Receiving formal support	16	59	HNCP16: Oh yes, [dental surgeon] gave me gels, and stuff, as well that they recommend. Actually, it was her more than anyone else that looked after the oral side of things, after the whole radiotherapy and the operation. She was very good. Really good, you know.
Receiving support from family and friends	20	74	HNCP18: [My husband] was the huge support. He was with me all the time. The bigger support. This was my husband of course. I can say great man [sic]. For a year, he handled everything with the home—kids, work, cleaning, shopping, everything—so I have time to recovery myself [sic], time for lying on the bed. That's great.
Seeking formal help	10	37	HNCP27: I went through so much pain [that] I had to call me GP on several occasions and get pethadine, not morphine; because morphine, for whatever reason, wasn't worth a shit to me. It never killed my pain. Pethadine did and that's a strong pain killer. I was up to this [makes high motion with hand] in Solpadol© and Ponstan©; anything I could get my hands on.
Seeking support from family and friends	5	19	HNCP06: If I can't walk up to the bus, I can get somebody to ring a cab. So there are ways.
Drawing support from similar other	9	33	HNCP20: I actually played a game of golf last July 12 months and there was three of us sitting at the same table after having a game of golf and the presentation and the three of us had cancer. Three men that were there. One had prostate and the other had the blood thing, what do you call that? [Leukaemia] But the three of us played golf. [laughs] So that was – that was reassuring as well, you know? [...] It is nice to have a chat with some people who have gone through something similar anyway, yeah.

Conserving physical energy^c	Strategies which enable one to conserve physical energy in order to better self-manage one's condition	20	74	
Reducing activities		4	15	HNCP08: I didn't have the energy [for playing golf] for about six months.
Reducing workload		15	56	HNCP01: Of course, I wasn't doing as much [gardening maintenance]. I did it when the energy was sufficient to do what I had to do. The rest of the time I left it there, you know.
Taking a break		17	63	HNCP04: I feel I need to sit down, otherwise I drop down.
Conserving emotional energy^c	Strategies which enable one to conserve emotional energy in order to better self-manage one's condition	11	41	
Caring less about what others think		6	22	HNCP02: I've no intention of choking myself for the sake of saving somebody, you know, seeing my tracheotomy and my little Swedish nose at the end of it; so I just let it all hang out, left in view and let people deal with it.
Minimising stress		10	37	HNCP07: I was told to be as stress-free as possible. So you try your best to be as stress-free as possible. So I try not to get annoyed. I don't let things bother me anymore. You just try your best.
Cognitive avoidance^a	Strategies involving the avoidance of thoughts concerning the negative consequences of HNC and its treatment	20	74	
Avoiding finding out too much		5	19	HNCP02: One thing I learnt not to do, or stop doing very early on, was my own little research online. Because those websites just frighten the life out of you. Everybody should be warned about them. [...] You know, once you are getting through your treatment, and you do a little google, get into all of these sites, and you read somebody, "Oh yes, my husband, this is his fourth time getting radiotherapy and it keeps coming back". And it just panics you. And you learn to stop it.
Avoiding thoughts about cancer and its consequences		16	59	HNCP15: I'd hope [the cancer doesn't come back]. I've not been thinking about it. [...] No, I have it in my mind to bury that. I got the all-clear. I'm clear of it. That gets rid of a lot of distress. I'm clear of it. I don't want to see that again.

Distracting oneself by keeping busy		10	37	HNCP06: I do get depressed, of course I do. But generally, I'm strong enough minded that I'm able to say, "Well, I'll do this or I can do this"; some little job and it's far from urgent but it breaks the concentration of [thinking], "That's it, I'm finished." It breaks that. And if you can break that effect... if you can break it for a moment, you're in for a little while of okay.
Behavioural avoidance^a	Behavioural strategies which minimise one's contact with threats to one's physical and/or emotional well-being	16	59	
Avoiding activities that may cause harm		10	37	HNCP01: [I stopped using] household sprays, sprays for pesticides and herbicides and stuff like that, and pollen off flowers and everything, we were restricted, we weren't supposed to... [...] So as that you wouldn't get any pollen down your neck.
Avoiding contact with others for possible infection		3	11	HNCP02: The one thing I did was avoid crowded places, because I wanted to avoid infection, colds and flus. Which I think is advised anyway.
Avoiding uncomfortable social encounters		9	33	HNCP06: I won't sit down for coffee [in a coffee shop] because I don't want anyone to talk to me, because you go through all the explaining. Jesus, you ruin your own day. You ruin theirs as well. So what's the point?
Managing others^a	Active attempts to effectively manage one's social relationships following cancer treatment	15	56	
Being assertive in social encounters		4	15	HNCP09: When I came home first, people didn't understand me. And I said, "You don't understand what I said?" They said, "No, I didn't, [HNCP09], but I don't want to..." I said, "Look, if you don't understand me, please tell me, and I'll repeat it." And everybody, I have to do that to says, "Sorry, [HNCP09], I didn't get that." "I'll give it to you again," I said. And I loved that.
Keeping others happy		2	7	HNCP13: [My mother]'d be making me stuff I couldn't touch. [Laughter] But I'd try a spoon to keep her happy.
Being open with others about cancer and its consequences		6	22	HNCP24: I think people always need to get it out and discuss it, right? And I have no problem saying to people that I'm in cancer recovery, you know, that's the way I see it and I'll probably be saying that in 10 years' time – hopefully, [in] 20 years' time.
Protecting others from harm		10	37	HNCP19: Even to this day, particularly my youngest sister, she'd be ten years younger than me; every time I ring her, which I make a habit of doing a lot, because her first thing was always - she almost puts me into patient

				mode. “How are you?” Again, she still needs, I suppose, a bit of reassurance.
Positive appraisal^d	Focusing on positive aspects of one’s immediate situation	22	81	
Benefit finding		10	37	HNCP02: The plus side is I’ve dropped from 113kgs down to 95kgs. So I’m fitting into clothes that were in the back of the wardrobe for years.
Downward comparison		16	59	HNCP13: Other people have huge tinnitus problems. I had tweeny little ones.
Reinterpreting negative consequences		17	63	HNCP14: If I’ve had wine and I haven’t been eating, then my mouth will get dry. But that happens to everybody. I can’t say that it’s particular to me because of that, but it probably is.
Meaning-making^e	Interpreting HNC and its consequences in the broader context of life as a whole	23	85	
Appreciating health more		3	11	HNCP21: Well, I think my health especially [is more important than work], after what I went through.
Appreciating the importance of family		8	30	HNCP04: You know, [the family] are the prime movers. They are the reason I’m here and the reason I’ve wanted to get things done.
Appreciating life more		8	30	HNCP07: It actually makes you appreciate what you have and the little things that you have.
Appreciating support		15	56	HNCP12: I don’t think I would be around, only for the team up in [location removed]. There’s no way in the world would I be around.
Becoming more altruistic		10	37	HNCP22: I kind of feel like I’m a better person now in some ways. [...] I suppose I’d be more obliging with neighbours and – I do good turns. Well, I did them before but I do more now than I used to.
Changing one’s image		2	7	HNCP05: I was too old and fat to be vain, but I, kind of, didn’t want people looking at me like, “oh you poor devil” [after treatment]. So what I did, I didn’t say to my wife, I got a taxi into town and I went to a tattoo parlour and I got my ear pierced, which looked entirely ridiculous for a guy my age. I had no hair anyway. And I got this little hat and, kind of, turned it round, wore it back to front and I thought, you know, I’d rather somebody look at me saying, “Would you take a look at that idiot trying to be 21,” than look at me and think, “Oh the poor devil.”
Finding meaning in work		1	4	HNCP05: [It’s important to] try and get working with people just to feel like you are contributing again.

Seeking normality^a	Active attempts to return to normal living following HNC treatment	23	85	
Focusing on doing normal activities		16	59	HNCP17: Any decision-making as regards the household, anything, to begin with, I didn't deal with it. What people ate for dinner; I didn't want to have the decision. I left that to everyone else. So, when I got better, I had to gradually go back into that, whereas now I do these things.
Focusing on getting back to work		8	30	HNCP05: I tried very hard to get back to work. That was a big thing for me. Because it's another financial strain when you are ill, it is a big financial strain.
Maintaining independence		9	33	HNCP26: I want to be independent; I don't want to be depending on [family] all the time. But I go out and I carry that [coal bucket] in now.
Testing oneself		1	4	HNCP21: I built the wall anyway in that heat and I didn't give in. And I knew that I was able to. [...] And I plastered it meself. The whole lot. And it took no effect and I wasn't getting weak in the evening. I was better than before – better I started getting in the evening. I wasn't tired then. So I knew then that this is it. I have meself tested out. If I wasn't able for this, I'd nothing to be doing. Because I would know meself. I wouldn't be able to throw them [bricks]. I'd get someone else to do it, to hell with it. But I got it done and there was no problem and it made me stronger and better.
Trying to fit in		6	22	HNCP06: I always, of course, wear a scarf [when I'm out]. So I get by with it like that. [...] It has a sense of normalcy.
Acceptance^a	Accepting functional, lifestyle and social changes following HNC treatment	22	81	
Accepting illness and its consequences		20	74	HNCP12: It's like when you'd be playing football or hurling, you know, you get to a certain age where you have to stop. You just have to accept it and carry on.
Accepting new health behaviours		8	30	HNCP21: Well, I didn't like [feeding with a percutaneous endoscopic gastrostomy tube] at the start but I got used to it and it was no problem.
Accepting social difficulties		12	44	HNCP02: That's the one thing, people are very fearful of cancer. And you meet a lot of that. You've got to learn how to put up with their fears.
Using sense of humour^a	Use of humour to manage emotions associated with the negative consequences of HNC and its treatment	8	30	

Finding humour in others' reactions	1	4	HNCP17: Initially you would see people looking at you alright. I knew they were looking. I found it a source of entertainment at times, because I knew people were trying to figure out, "What happened to her?" I was saying to my mum, "They really don't know what happened to me."
Laughing about cancer and its consequences	6	22	HNCP02: In fact the first thing I did [after getting the tracheotomy] was: I had my phone and I took a selfie of me with the hole in my throat. You, kind of, get a little bit... I don't know, kind of, gallows humour, I suppose.

^aThese strategy types were added to the content codes following content analysis.

^bSelf monitoring expanded from Reflecting in [14].

^cEnergy conserving from [14] has been divided into Conserving physical energy and Conserving emotional energy.

^dPositive appraisal expanded from Positive reframing in [14].

^eMeaning-making expanded from Life value pursuing in [14].