

A Mixed Methods Study Exploring the Experience of Distress and Engagement in Daily Life in People with Head and Neck Cancer Beyond 5 Years Post-Treatment

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Abstract

Purpose: To understand the experience of distress and life engagement in people with head and neck cancer (HNC) in the years following treatment.

Method: Participants treated more than 5 years previously for HNC completed the National Comprehensive Cancer Network Distress Thermometer (DT) and Problem List and an interview to explore their experience of distress. Data from the DT were analysed descriptively, and interviews analysed qualitatively to extract core themes.

Results: Twenty-one participants were recruited and reported an average DT score of 3/10, with the most commonly reported problems related to physical (87%) and emotional challenges (57%). Thematic analysis of the interviews revealed three themes: (1) The experience of head and neck cancer is distressing; (2) Facilitators to adjustment and re-engagement, and; (3) "My (philosophical) approach was...".

Conclusion: Low-level distress remained an ongoing issue for people beyond 5 years post HNC. This distress is related to the challenges of the disease, treatment, and ongoing side-effects. Coping strategies and mindset philosophy enabled participants to manage ongoing side-effects with the support of practical strategies and health professional support, highlighting the importance of ongoing survivorship engagement with services to address long-term need and care.

Keywords: Distress; Engagement in Daily Life; Head and Neck Cancer; Survivorship

Abbreviations

DT: Distress Thermometer; HNC: Head and Neck Cancer; NCCN: National Comprehensive Cancer Network.

Introduction

In 2018 there were estimated to be 181 million new cancer cases worldwide [1]. In the last two decades there has been a trend of increasing survival following a cancer diagnosis [2,3], with people diagnosed now living longer with the side-effects of treatment. A meta-analysis of 94 studies across haematological, oncological and palliative care settings suggested that, of these people with cancer, at least 40% will have experienced some form of distress along the trajectory of their treatment [4]. Distress is a term that is used to describe an unpleasant experience of a psychological, social, spiritual and/or physical nature for the person undergoing cancer treatment [5]. The USA National Comprehensive Cancer Network (NCCN) Guidelines for Distress Management identify people at increased risk for moderate or severe distress as those with social

concerns, uncontrolled symptoms or communication barriers [5]. These factors are often reported by people with head and neck cancer (HNC) during and following treatment [6].

People with HNC report consistently higher levels of distress prior to treatment when compared to people diagnosed with prostate, gynaecological, pancreatic and stomach cancer [7,8], and are 2.7 times more likely to report high distress 6 months after hospital admission than those with other cancer diagnoses [8]. Furthermore, over a quarter of people with HNC who on average were 2½ years post-treatment, reported moderate or severe levels of ongoing distress [8-11]. Moderate to high levels of distress related to HNC have been associated with significantly poorer survival, when compared to moderate to high distress associated with breast and genitourinary cancer [12]. For people with HNC, distress is more often associated with a younger age, recurrent disease and perceived lack of social supports [8,10,11].

Distress in the HNC population has also been associated with the presence of tumour and treatment related physical symptoms and their impact on function. Using cross-sectional methods, a study (n=280) examining survivorship up to 5 years post-treatment found one-third of participants identified ongoing moderate to severe levels of distress and unmet needs, with the most common concerns being oral and eating problems, fear of recurrence and fatigue [13]. A qualitative study specifically exploring the oral and eating experience of 24 HNC survivors 2 years post-treatment found patient experience related to “entering the unknown”, making practical and emotional adjustments”, and “accessing supports” were reported by participants [14]. Although not specifically investigating distress, another longitudinal study of 56 participants with HNC 2-2½ years post-treatment explored the differences in how people moved on with life, and revealed four types of psychological adjustment with participants expressing that: a) they had psychologically left behind the illness; b) the cancer experience had been diluted by other events happening in life; c) cancer had made a difference in both positive and negative ways or; d) physical and/or psychological problems still predominated [15]. These studies suggest that the impact of HNC is personal, and that distress and adjustment may relate to physical, emotional, psychological, or practical issues. For this reason, it is imperative that health professionals are well-versed in the multitude of recovery trajectories following HNC, so as best to support each individual patient regarding their health care needs.

To best provide ongoing support, education and service provision, an understanding of the experience of distress and engagement in daily life in the years following treatment is needed. With improving diagnostic and treatment options available, close to 70% of people diagnosed in Australia with HNC are surviving 5 years following diagnosis [3], however their experience of distress and the factors contributing to distress remain unknown. Hence the aim of this study was to explore the experience of distress and the factors contributing to distress and engagement into daily life for the person with HNC more than 5 years post-treatment.

Materials and Methods

This study utilised a mixed methods design - combination of quantitative and qualitative methodology. The quantitative component analysed data extrapolated from the NCCN Distress Thermometer (DT) and Problem List. The qualitative component was designed with an interpretive descriptive methodology as it allows for applied research contextualised into the clinical setting [16]. The study was conducted at a single, quaternary hospital in Australia. Ethical clearance was received from the local Human Research and Ethics Committee (HREC/13/QPAH/315). Informed consent was obtained from participants.

Participants for this study were recruited from a treatment database of people who were treated for T1-T3 squamous cell carcinoma of the oropharynx with curative intent. This treatment data

base had been used for a previous study where participants were excluded if they had in-field recurrence within 2 years of completing radiotherapy [17,18]. Of the 227 potential participants listed on the current database, only 52 were eligible to contact for the current study. One hundred and seventy-five were deemed ineligible as they had been lost to follow-up (both lost to follow-up and failure to respond to previous study) or deceased. Participants received treatment between 2003 - 2011 ensuring they were beyond 5 years post-treatment at the time of data collection (February - May 2018). A time convenience sample of 38 participants were contacted and agreed to participate following written consent.

Participants completed the NCCN DT and Problem List within the week prior to the semi-structured interview [5]. The DT is a validated tool with a scale from 0-10 (0 = no distress; 10 = extreme distress) and asks participants to “please circle the number (0-10) that best describes how much distress you have been experiencing in the past week”. Previous studies have indicated a score of four or greater requires a referral for health professional support [19,20]. The DT Problem List has 39-items (within six categories: 1. practical problems [six items]; 2. family problems [four items]; 3. emotional problems [six items]; 4. spiritual/religious concerns [one item]; 5. physical problems [22 items]; and 6. other problems [as a free text area]) [5]. At the time of DT completion, participants were also provided with an interview guide to support reflection of their experience and preparation for the interview.

The semi-structured interview included open-ended questions to explore the participants experience [19], which focused on the experience of distress at the time of treatment for the HNC and in survivorship, engagement in daily life, with the last question focusing on categories reflected by the NCCN PL (Appendix 1). The questions were developed by two members of the research team (JN and BB, both >15 years clinical experience with HNC) and reviewed by a consumer advisor who was six years post-treatment, for relevance and acceptability. Interviews were conducted by the principal investigator (JN), who was not previously known to the participants. All interviews were audio-recorded and transcribed verbatim for analysis.

Data analysis

Demographics and the DT and Problem List were analysed descriptively with frequency data, means and ranges provided. The thematic analysis of the interviews was conducted by the research team using an interpretive descriptive approach by Thorne [16]. Initial thematic analysis was undertaken whilst two members of the research team concurrently listened/read the interview transcripts. The process underwent a four-step process of data analysis: comprehending the themes; finding patterns that were similar both to the individual participants and in relation to the group; re-conceptualising any patterns to these themes; and finally, how the themes moved from theoretical contexts to that of clinical practice [16,20].

Results

Participants were recruited between February 2018-May 2018. Thirty-eight participants were approached: 22 provided written consent; one subsequently withdrew due to death in the family; three declined; and 13 were lost to follow-up. Twenty-one participants completed the DT Problem List and interview. There was missing data for one participant who did not complete the thermometer component.

Participants were between 7-15 years post treatment, with an age range of 48-79 years (Table 1). The group were most commonly treated with concurrent chemoradiotherapy (52%), or definitive radiotherapy (26%), and the majority were male (90%). The majority (86%) identified as being in a relationship during their treatment, and at the time of the interview. Seventy-six percent of the group had been working at diagnosis, with 57% returning to work post treatment and 29% working at the time of the interview. No participants had developed locoregional recurrence since treatment completion.

Demographic variable	Participants (n=21) n (%)
Age	
Mean (SD)	65
Range (years)	48-79
Gender	
Male	19 (90)
Female	2 (10)
Years since treatment	7-15
HNC Medical Management	
PORT	1 (5)
POCRT	1 (5)
CRT	11 (52)
RT	6 (26)
RT Dose (Gy)	60-70
Relationship status	
In relationship at diagnosis/treatment	18 (86)
In relationship current	18 (86)
Employment Status	
Employed at diagnosis	16 (76)
Returned to employment post treatment	12 (57)
Employed currently	9 (29)
Interview mechanism	
Phone	17 (81)
Face-to-face	4 (19)

Table 1: Participant characteristics.

HNC: Head and Neck Cancer; PORT: Post-Operative Radiotherapy; POCRT: Post-Operative chemoradiotherapy; CRT: Chemoradiotherapy; RT: Radiotherapy.

The DT data revealed an average distress level of 3/10, with 35% of participants rating their distress as ≥ 4 , which is defined as clinically relevant distress and indicates a need for referral for support (Table 2) [21,22]. On the Problem List 81% of participants reported physical problems and 57% emotional problems. (Table 2). There were no descriptive patterns observed with the distress score and the items reported by participants on the problem list.

Distress Thermometer	No. participants n=20 (%)	
Distress Score (0-10) (ave)	3	
(range)	0-8	
Score 4 \geq	7 (35)	
Problem List	Number of participants n=21 (%)	Response types
Practical problems	5 (24)	Work, finance
Family problems	2 (10)	Worry about partner
Emotional problems	12 (57)	Worry, fears, sadness, depression, loss of interest
Spiritual/religious	1 (5)	Sisters funeral previous week
Physical problems	17 (81)	Swallowing, eating, fatigue, memory, appearance
Other	2 (10)	Stiffness in neck, slight swallow, sisters funeral

Table 2: Distress Thermometer and Problem List.

Seventeen interviews were conducted by phone and the remaining four face-to-face, as per participant preference. Interviews ranged in duration from 13 to 30 minutes (mean 22 minutes). Thematic analysis of interview data revealed three major themes associated with the participant experiences of long-term distress and engagement into daily life related to HNC. These themes included: (1) The experience of head and neck cancer is distressing; (2) Facilitators to adjustment and re-engagement; (3) My (philosophical) approach was.... Quotes exemplifying the key themes and sub-themes are presented in Tables 3-5.

Theme One- The experience of head and neck cancer is distressing (Table 3)

The first theme to arise from the interview data was the multifaceted, long-lasting impact HNC had on physical and emotional functioning. Participants reported seven associated sub-themes related to these challenges (Table 3). Some discussed how the first challenge was the experience of diagnosis which was described as a “shock” and “distressing”. The dominant sub-themes related to the challenge of HNC were the reminiscence of side-effects and adverse reactions experienced during the treatment where the majority of the group described nausea, not being able to swallow or

Sub-theme	Exemplar quote
Experience of diagnosis	PA2.18 It was a bit distressing around the uncertainty of what it was but...once I knew what was happening, I was quite comfortable with what had to be done
Thinking back on the side-effects of treatment	PA2.19: I did get some mouth ulcers, I got fairly severe pain, dry mouth, I lost all taste sensation basically and lost appetite PA5.13: I wouldn't recommend it (radiation) to anyone and I would never have it again
Ongoing impact on function	PA10.05: It's even hard to talk properly now and pronounce my words properly. I haven't been able to eat solids, I can't even eat custard and even jelly is hard and ice-cream (pause) I can't put my tongue out so I can't lick an ice-cream
Impact on relationships/intimacy	PA2.13: Well yeah kind of (pause) we still get on alright and that but you know it's different. You don't feel as close to each other I suppose would be the word PA5.12: Ah probably a bit more the closer than separate, yeah, definitely (relationship with wife)
Body Image	PA10.16: They took all my teeth out before my treatment and so... I'm embarrassed when you got no teeth PA10.05: I think I used to be attractive and now I'm not (pause) I don't feel like I am
Impact on work	PA2.44: They said I wouldn't be able to do the same sort of work but truthfully, I went back straight to what I used to do and they know what I can do and how I work PA2.13: I know when I found out that I probably wouldn't be able to work again I know it kind of got me depressed at first (pause) for a long time after that actually (pause) because you kind of have work mates and stuff like that and you just kind of loose contact with people you know
Financial toxicity	PA2.17: When I first had it, it used to cost me about sixty bucks, sixty dollars a month for chewing gum PA2.13: No that is all covered by the pension I'm on I think. I go to the dental clinic at Browns Plains

Table 3: Theme 1- The experience of head and neck cancer is distressing.

eat, requiring a feeding tube, and adverse reactions resulting in ICU admissions which contributed to distress. The other dominant sub-theme was the challenges of engaging in daily life with ongoing late side-effects described by all participants which included dry mouth, modified diets, and dental issues. Some participants, although finding side-effects challenging, were accepting of this as treatment sequelae. Whereas, a small number reported long term distress and difficulty engaging in life as they wanted: "I'm not liv-

Sub-theme	Exemplar quote
Self-initiated practical strategies	PA2.40: If I'm eating I'll just make sure I've got a glass of water or a drink handy PA5.09: I've always got water beside the bed where if I get up for a pee I sort of swish my mouth.
Health professionals support	PA2.04: Look you've just got to have total faith in the support people and the nurses PA10.12: 'I've got something like 11 specialists looking after me, in perhaps one of the best head and neck clinics in the world' I said 'I'm not flippant, I'm confident'
Family support	PA2.19: I had a lot of support from my wife PA5.12: She was very supportive (wife)
Biological strategies	PA2.21: Extremely distressing (pause) after about the first month after that I had to get tablets and medication to sort of feel a bit relaxed PA5.13: I don't take any other medication at all apart from um, well I do but depression tablets which are very mild
Stress management	PA2.08: I don't mean that everyone needs to but some sort of physical activity. That seemed to build my confidence back up PA2.04: Yoga, breathing, which I still do (pause) circular breathing and I'm aware of when the stress is approaching
Downward social comparison	PA2.1: when you went in every day for the treatment (pause) other patients there I thought "that bloke looks worse than me" so I shouldn't complain about anything
Engaging with others with cancer	PA2.37: Having that support from somebody who has been through it as a patient is pretty good

Table 4: Theme 2- Facilitators to adjustment and re-engagement.

ing normally, it's just ridiculous. I feel sorry for my family as we can never have a meal together, we can't go out together, we can't socialise and I've got no friends anymore as I can't go out with anyone as everybody is eating, you know what it's like, no you probably don't, it's disheartening and it makes me depressed" (PA10.05).

About three quarters of participants experienced a range of challenges related to changes to relationships and intimacy. A large number of participants discussed that the experience of cancer and treatment brought them closer to support people such as their spouse and children. However, a small number of participants discussed the impact of their diagnosis on their perception of sex: "for men, it's a disease that's packed on by oral sex" (PA2.08), and that sex has now "lost its innocence or something" (PA2.08).

As a result of the treatment about half of the participants reported an initial and ongoing challenge with life roles related to work and finances. Most of the group reported they needed time off work for treatment and were supported by their workplaces during

Sub-theme	Exemplar quote
Pragmatic response “Get on and get it done”	PA2.42: I had the attitude if it’s got to be done, it’s got to be done PA5.09: I just knew that it was a sentence and I just had to punch through it, you know
Ongoing Distress	PA2.17: Since the cancer everything has gone wrong for me PA10.05: I would tell them (pause) I would tell them not to do it in the first place (pause) I have lasted this long but don’t worry I’ve thought about it many times to do myself in and if it wasn’t for my kids I would. PA2.19: I’m in a good place now (pause) I’ll be better if this irritation in my throat isn’t anything bad but at least I’m getting a check up to find out what that is
Positive	PA2.08: I think I’m actually more sensitive... I’m more open to be affected by light, sound, wind, a baby crying, the blue in water. PA10.12: I’m an incredibly positive person. I just don’t look at things being bad, I look at the positives. Because with everything there is a positive side to it.
Thought of mortality	PA2.18: You know, if you don’t get treated, you’re not going to live.
Diminishing significance with time	PA10.34: Well that’s what I am trying hard to remember and I honestly can’t remember whether it was before or after, I cannot remember.

Table 5: Theme 3- My (philosophical) approach was....

treatment and once they were able to return to work. The majority of participants were no longer working at the time of the interviews, but this was largely related to retirement age, not physical ability. Many participants discussed the costs related to long-term dental care following treatment for HNC. At the time of the study, the health service where the study took place offered free public dental services up to 5 years post-treatment for eligible patients. A number of participants found transitioning between a free service to a fee-for-service contributed to their distress.

Theme Two- Facilitators to adjustment and re-engagement (Table 4)

The second theme, facilitators to adjustment and re-engagement, described the experiences of participants in meeting the challenges associated with long term side-effects related to HNC, and their capacity to re-engage into usual life. There were seven sub-themes describing coping strategies used by the cohort (Table 4). Practical strategies were the most frequently reported style of coping strategy, with the mention of water bottles, chewing gum, mouth moisturising products, and eating appropriate food mentioned as strategies that participants used to cope to engage in normal life. Most participants also found the support and education from health professionals valuable. They discussed the feelings of confidence in the professionalism and access to a diverse range of

health professional including medical, nursing, dietetics, speech pathology, occupational therapy, and physiotherapy. About half of the group also identified the value of family support in coping with the HNC, treatment, and engaging into usual life. Biological strategies reported as helpful during both treatment and re-integrating into usual life included prescribed pain management, anti-depressant medication, and non-prescribed suggestions by health professionals such as: “why don’t you have a few beers?” (PA2.18).

Three less frequently reported coping strategies discussed to support the distress associated with HNC long-term side-effects included: stress management strategies such as breathing techniques, cognitive techniques, physical activity, and goal setting; engaging with others who had been through or about to go through a similar experience; and, downward social comparison, which involved participants comparing themselves to others. Although not as frequently reported these strategies were reported as beneficial to a small number as a way of engaging in life.

Theme three- My (philosophical) approach was... (Table 5)

The third over-arching theme was the philosophical response and “My approach was ...” which is when the participants discussed what mental strategies, they used in the survivorship phase that helped with how they engaged into daily life. There were five sub-themes identified as approaches used by this group (Table 5). The primary emotional approach of the group was a pragmatic determination. About one-third of the participants described a positive approach to ongoing side-effects and managing these as part of their daily life. However, many discussed an ongoing distress approach, with two participants discussing that they would not have the treatment if they had known the long-term side-effects and would not recommend it to others despite understanding that they would not be alive without the treatment. A number discussed the fact that having HNC made them reflect on their mortality, with another small number discussing thoughts of recurrence, despite the fact that 7-15 years post treatment none of the group had experienced cancer recurrence.

Discussion

The study found that 35% people treated for HNC continued to experience distress 7-15 years after treatment. The group most frequently reported distress related to physical (81%), emotional (57%) and practical (24%) problems. Participants from this group found HNC treatment challenging and impacted on integrating back into life, with a variety of emotional responses reported, however, the group identified strategies to cope with the longer-term side-effects, and developed approaches used to engage in the survivorship phase following HNC.

The NCCN Distress Guidelines [5] recommend that there are five different categories (plus an open-ended “other”) that can contribute to the distress experienced by people with cancer and for successful engagement in daily life these areas may need ongoing sup-

port. These categories are represented in the NCCN Problem List and will be discussed in alignment with the results of the themes elicited from the participants in this study and previously published works that encompasses a broader spectrum of people who have been treated for HNC to generate discussion about considerations for clinical practice for this long-term survivorship phase.

Physical

Ongoing physical side-effects were reported on the DT Problem List by 81% of participants with all discussing long-term physical side-effects at 7-15 years following treatment for HNC. Some accepted that ongoing side-effects were part of the treatment sequelae: "It's better than the alternative", however a small number felt that: "this was not a worthwhile way to live life". In a systematic review of 37 studies of quality of life at 12 months post HNC treatment ongoing issues included xerostomia, sticky saliva and social eating [23]. A number of studies have shown that the more physical side-effects post treatment up to 2 years, the greater the distress of the participants [10]. This study has found all participants experienced long-term physical side-effects at 7-15 years following treatment for HNC. Although the majority of the participants were able to discuss practical strategies such as always having water with them, just under half of the group reported ongoing distress impacting their day to day life during the interview process. A systematic review of HNC people 12 months post treatment recommends those with physical challenges would benefit from ongoing professional support to assist with the usual integration into daily life [23]. The results from this study would suggest that people 7-15 years post-treatment may also benefit from this ongoing support. Potential models for further study could investigate health professional engagement via a shared care model/General Practitioner support, or community support options.

Emotional

Fifty seven percent of this group reported ongoing emotional challenges at 7-15 years post completion of treatment for HNC on the DT Problem List, most notably worry, fears, sadness and loss of interest in activities. Of these 35% scored four or greater on the DT which is a recommended cut-off for a referral for health professional support [5]. Previous studies have suggested a link with distress and well-being at 12 months post treatment [24], with other studies suggesting that a more passive coping style can contribute to greater distress following treatment for HNC [11]. The results of this study would suggest that distress and engagement in daily life can still be a challenge at 7-15 years post treatment. Although reporting ongoing distress, participants discussed a range of emotional responses they had used in the survivorship phase, with the dominant ones being pragmatic approach of just getting on and getting it done. However, just under half of participants expressed some regret about having had treatment as they experienced ongoing distress and depression as a consequence. These results indicate that distress is an ongoing challenge at this long-term survivor phase, however the person's coping strategy may also influence the ability to engage in day-to-day life. In a clinical context

it may be beneficial to identify those at higher risk of distress and support this group with emotional coping strategies to maximise the ability to engage in life in HNC survivorship or increase pathways to community support options.

Practical

In the current study 24% reported ongoing practical issues contributing to distress which they primarily identified related to work and finances. Financial toxicity is an area that has only recently started to generate an interest due to the costs placed on the person with cancer. In a cross-sectional survey of 447 participants with HNC of which 58% were more than 5 years post treatment, those with worse physical and social emotional functioning reported to experience worse financial burden, with the most notable financial costs reported by the study as: petrol to access treatment; change in the type of food; and, loss of earnings due to challenges with change to work [25]. In another study conducted in Denmark, known for its highly supportive social system, Kjaer, *et al.* (2013) [26] found factors that contributed to people not returning to work were more related to lower levels of education, lower disposable income and living alone, rather than the type of treatment the person had undergone for HNC.

Work plays a critical role in providing financial security and a significant life role for people under the age of 65 [27]. Reasons given for change in employment status at the 7-15 years post treatment was mostly related to retirement age, however a small group reported they had not been able to return to work after the treatment due to ongoing side-effects. In a previous study of 666 people with HNC, 239 were employed prior to diagnosis, and of that group 38% did not return to work following completion of treatment [28]. The five most frequent reasons given for not being able to return to work included eating, speech, appearance, pain, and fatigue [28], which is consistent with the reported long-term physical side-effects of this group. The practical aspect of financial challenges and returning to work is an ongoing challenge for some people in re-engagement into daily life following treatment for HNC, however it should be noted that the HNC alone may not be the sole contributor to this situation.

Family

Family was identified as a low contributor to distress in this group at 7-15 years post completion of treatment for HNC. A large proportion of this group were in a relationship and with support at time of diagnosis and ongoing post treatment and had made multiple references in the interviews to the value of support from family. One participant commented that it had been challenging going through treatment without a support person. A systematic review of 37 studies with heterogeneous HNC cohorts found social supports were a significant predictor of increased QoL at 12 months post-treatment [23], this is supported by the participants of this study who discussed the value of having a significant person supporting them. Although not identified by the group one potential strategy in a clinical context would be for those without social supports to access increased health professional support.

Spiritual/religious

Only one person in this study commented on spirituality in the problem list, and there was no mention of this as a coping strategy in any participant interviews. Sherman and Simonton [29] examined 149 participants with heterogeneous HNC diagnose and found that patients with advanced disease used a variety of coping strategies, of which putting their faith and trust in God/religion rated highly. The NCCN recommendation is that spiritual support be offered for those with HNC [6]. In light of our results it may be more prudent to explore the person's desire for such support first and indicate that this is available if desired.

Limitations

The small group and single centre design determine that this report should be used as preliminary information only, as it may only reflect the treatment experience from one centre and geographical area. Due to time limitations of the research group the first 38 eligible participants only were offered the opportunity to participate, which may reduce the experience representation of these findings. From this group, no participants had experienced recurrence, which may also change the representation of the distress experience.

It is worthy to note that the medical management of HNC has undergone change in the last 7-15 years [30]. With advances in technology, precision of RT delivery to tumour cells, while avoiding healthy tissues has improved, with potential of less long-term side-effects [6]. This would be a consideration if comparing this study group to people currently undergoing treatment for HNC.

Conclusions

In the long-term post treatment for HNC, challenges engaging into daily life were experienced by people, and were related to ongoing physical, emotional and practical contributing factors. Although the majority of survivors report ongoing challenges, most participants found coping strategies such as a combination of practical approaches and health professional support to manage the ongoing side-effects and were able to engage in daily life.

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Conflict of Interest

The authors declare that they have no conflict of interest.

Appendix 1: Interview Questions

Thank you for your time today. I am hoping to further explore your experience of the side effects of head and neck cancer treatment and how this impacts your everyday life now that you are X years after completing treatment. In particular, I want to ask you some questions about what things you found challenging or distressing about any ongoing side effects, and what things you found helpful.

1. Can you tell me a little bit about your cancer journey (Prompts – at diagnosis, during treatment, after treatment)?
2. Tell me about the emotional challenges or distress you experienced related to your HNC
3. Can you tell me a bit about the side-effects you experienced? (Prompts- when did it start, what made it worse, what made it better)
4. Tell me about the side effects and how you experienced them emotionally at the time? What about now?
5. How have you managed these side effects? (Prompts - what treatment/supports have you had for these side effects? What has been helpful? What has not been helpful?)
6. Tell me about your everyday life, and what parts have been affected by your treatment for head and neck cancer? (Explore the response eg work, leisure, self-care, relationships, sleep)
7. Tell me about how you experienced these life changes emotionally. What about now?
8. What would you tell people who are about to start the treatment that you have been through?
9. Is there anything else you think we need to know to help other people having similar treatment to what you have?

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