

Research Article

“It’s Just Being Honest, Isn’t It?” The Communication Gap on Cancer-Related Fatigue in Oropharyngeal Cancer Survivors: A Qualitative Study

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Introduction: Cancer-related fatigue (CRF) is a pervasive and debilitating symptom in patients treated for oropharyngeal cancer (OPC). This study explores communication about CRF in routine care according to patients and clinicians.

Method: This work integrated qualitative data from a secondary analysis of a cross-sectional study evaluating long-term fatigue and neurocognitive impairment in OPC patients treated with radiotherapy ± chemotherapy and a complementary qualitative service evaluation focused on exploring how healthcare professionals (HCPs) discuss CRF. Semistructured interviews were conducted with disease-free OPC survivors and HCPs experienced in managing OPC. Reflexive thematic analysis was undertaken.

Result: Thirty-one interviews (21 patients, 10 HCPs) were conducted. Mean interview duration was 40 min. Four themes were identified: (1) limited awareness and knowledge, (2) approaches to discussing CRF: proactive versus reactive, (3) impact of available time and timing of CRF discussions and (4) solution-oriented mindset and identified solutions. Both patients and HCPs described a lack of comprehensive understanding of CRF, contributing to an overall sense of vagueness and uncertainty. This led to a reactive rather than proactive approach to discussions, especially in the long term. Time, often limited amidst competing priorities in consultations, was seen as insufficient to address the complexities of CRF. In addition, no single optimal time to discuss CRF was identified, instead it may require multiple discussions. HCPs prioritised tangible solutions to address patient concerns, but a lack of straightforward strategies to manage CRF challenged this approach. HCPs proposed potential approaches, showing a willingness to engage in addressing the existing gaps.

Conclusion: While patients treated for OPC often seek validation and support for CRF, discussions are hindered by limited knowledge, time and lack of clear accessible solutions. Improved dialogue is needed to address the existing gaps in communication and inform the development of patient-centred strategies for managing CRF.

Keywords: cancer-related fatigue; communication; management; oropharyngeal cancer; radiotherapy

1. Introduction

The incidence of oropharyngeal cancer (OPC) is increasing, primarily driven by the rise in human papilloma virus (HPV)–associated OPC cases [1, 2]. Radiotherapy, with or

without chemotherapy, is standard of care [3, 4] for OPC. HPV-driven OPC is associated with an overall better treatment outcome, with a 3-year overall survival of 93% in low-risk cases [1]. Consequently, there is an increasing number of long-term OPC survivors who must live with the

long-term effects of successful treatment and face key survivorship issues.

Cancer-related fatigue (CRF) is often described as debilitating and is experienced by a significant proportion of cancer patients at diagnosis and during treatment, sometimes persisting for years [5, 6]. Indeed even years post-treatment, in head and neck cancer (HNC) survivors in general, and in OPC survivors specifically, moderate to severe fatigue is reported in 18%–20% of people, respectively [7]. This impacts on the survivors' quality of life, work productivity and mood [8]. Despite its prevalence and significant impact on quality of life, many cancer patients and clinicians appear to have a limited awareness of the issue of fatigue [9]. CRF is frequently underreported by patients during clinical consultations and is underestimated by clinicians [10–12], hindering appropriate care or support. This might be attributed to the prioritisation of discussing other HNC-specific functional impairments, such as dysphagia, dry mouth and other more visible late effects of treatment [13, 14], which often dominate the medical focus of care. Following primary treatment for OPC, patients typically enter structured follow-up lasting for at least 5 years, with intensified review in the first 2 years when recurrence risk is the highest [15]. In the United Kingdom, the exact nature of follow-up is influenced by individual institutional and clinician practices [16]. Typically, oncologists are primarily involved during the initial posttreatment phase to manage acute effects (e.g., up to 6 months posttreatment), after which follow-up is generally led by head and neck surgeons. Specialist nurses frequently support patients early in survivorship, with roles in symptom management, psychosocial support and care coordination, though their involvement tends to decline over time.

We aim to critically examine the communication regarding CRF, capturing the perspectives of both patients and healthcare providers. This deeper insight could inform the development of targeted interventions that foster more effective communication around CRF, improve the approach to CRF in clinical settings and enhance supportive services for OPC survivors.

2. Methods

2.1. Study Design. This current work was informed by a paradigmatic framework of interpretivism and constructivism. We examined patient and healthcare professionals' (HCPs) subjective experiences of discussions surrounding CRF in the context of OPC treatment rather than fatigue as a symptom per se. Data were integrated from two sources. First, a secondary analysis of a cross-sectional study evaluating long-term fatigue and neurocognitive impairment in OPC patients treated with photon radiotherapy (Radiotherapy for Oropharyngeal Cancer and impact on Neurocognition [ROC-oN] [8, 17]) which received ethical approval from West Midlands Research Ethics Committee in October 2022 (22/WM/0207). Second, we added data from a separate complementary qualitative service evaluation, which was exempt from ethical approval but received institutional approval. The service evaluation aimed to

examine how HCPs discuss CRF with patients, explore the challenges HCPs encounter in addressing CRF and identify opportunities for enhancing service delivery in CRF management.

The term '*patient*' is used throughout this paper to reflect the terminology employed by both HCPs and individuals affected by OPC during interviews. While alternative terms such as '*survivor*' or '*person with a history of OPC*' may offer a more person-centred framing, the use of '*patient*' aligns with the clinical context of the study and the way participants themselves described their experiences within the healthcare system.

2.2. Settings and Participants. The parent study recruited adult patients with histological confirmation of OPC, who received primary RT ($\pm$ chemotherapy) at Leeds Teaching Hospitals NHS Trust (LTHT) or The Christie NHS Foundation Trust (The Christie) from 2010 to 2020, who were ≥ 24 months postdiagnosis, and who were disease-free at the time of recruitment. Exclusion criteria included inability to consent, limited English language proficiency and surgery prior or after RT.

The complementary service evaluation recruited HCPs, including oncologists and specialist nurses, engaged in both the acute care during treatment and the long-term follow-up phases with expertise in managing HNC patients. This approach ensured the inclusion of HCPs with relevant expertise and diverse perspectives to address the study objectives.

Purposeful sampling techniques were adopted for both projects. This is a technique widely used in qualitative research for the identification and selection of information-rich cases related to the phenomena of interest [18]. Interviews were conducted from March to June 2023 (ROC-oN) with patients and Dec 2024 to Jan 2025 (service evaluation) with HCPs. Study information was provided either in writing or verbally, and consent was obtained and recorded either in writing or verbally for all participants.

2.3. Data Collection. Semistructured interviews using an interview guide (see Supporting File 1) were conducted (by ZIE) by telephone or online video platform for both patients and HCPs, dependent on participant preference. Interviews covered HCPs approaches to discussing fatigue, including language used, perceived importance, professional role, barriers to communication, expectations from both clinicians and patients, educational materials and how discussions shift from acute to chronic stages of fatigue. The NCCN definition of fatigue was adopted "*a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning* [19]." Chronic fatigue is defined as fatigue lasting for 6 months or more [20, 21] and long-term CRF was considered present if it persisted for > 6 months post-treatment. Acute fatigue was defined as fatigue during treatment and immediately after treatment (< 6 months post-treatment) [22].

TABLE 1: Participant characteristics.

HCPs	(n = 10)
Years of experience working in HNC (median [IQR])	10 (9–13) years
Gender	
Male	3 (30%)
Female	7 (70%)
Discipline	
Radiation oncologist	4 (40%)
Nurse	6 (60%)
Employed	
Full time	8 (80%)
Part time	2 (20%)
Patients	(n = 21)
Years since completion of treatment (median)	5 (4–8) years
Gender	
Male	11 (52.4%)
Female	10 (47.6%)
Tumour subsite	
Tonsil	16 (76.2%)
Base of tongue	4 (19.0%)
Vallecula	1 (4.8%)
Employed	
Full time	6 (28.7%)
Part time	4 (19.0%)
Retired	7 (33.3%)
Not working due to health reasons	4 (19.0%)

Data collection concluded upon reaching theoretical saturation, ensuring our final samples were adequate in terms of offering depth of understanding [18, 23].

2.4. Data Analysis. This current work includes a secondary analysis of interview transcripts from ROC-oN, focussing on communication around CRF, focussing on both the acute treatment phase and long-term follow-up phase.

Interviews were transcribed verbatim and analysed using reflexive thematic analysis [24, 25]. All transcripts were read and coded (ZIE), with an inductive and iterative approach employed to fully capture participant perspectives and to incorporate the insights that emerged as analysis proceeded. Analysis and coding were undertaken by both ZIE (an oncologist with 7 years of experience of working with cancer patients and 3 years of qualitative research experience) and KO (a sociologist and qualitative research expert with over 30 years' experience) using an iterative process of inductive (open) coding, analytical coding, structured (thematic) coding, annotating, and seeking coherence. This also involved regular meetings to discuss and compare the emerging themes. The team employed reflexive practice which involved continual and ongoing consideration of the relationship between researchers and participants through reflections on our positionality and professional or personal experiences [18]. This approach was implemented to ensure that different perspectives were considered, accounting for the varying disciplinary lenses of the research team members. Data analysis was conducted without the use of specialised qualitative software.

3. Results

A total of 31 interviews were conducted, with average interview duration of 52 minutes (range 41–70) for patient interview and 29 minutes (range 25–37) for HCP interview. Interviews were conducted with 21 patients (14 male and 17 female participants), median age of 61 years (IQR 56–65 years) all of whom had received chemoradiotherapy (CRT). In addition, 10 HCPs were interviewed, with a median of 10 years' (IQR 9–13 years) experience working with HNC patients. Participant characteristics are displayed in Table 1. Data were coded into four themes, covered below.

3.1. Limited Awareness and Knowledge

“how big a problem is fatigue in these patients[...] because you can't really deal with or approach a problem unless you know (oncologist)”

Overall, while HCPs were aware of fatigue, they did not fully understand it and felt ill equipped to offer help. Patients, similarly, were aware that tiredness may become an issue but did not sufficiently understand the potential impact of CRF on their lives and recovery.

HCPs acknowledged that CRF is a real and significant concern for patients, particularly during treatment and immediately posttreatment:

“we know that patients finishing radiotherapy can be very fatigued from the treatment, from coming every day, [...] it's just really tiring, isn't it?”(nurse).

Similarly, patients recognised fatigue as a possible component of their treatment experience and felt prepared for this in the acute period:

“Yeah, yeah, they told me that, they said that it affects people differently but yes, that was a great part of it” (male patient).

Although HCPs were all in agreement that CRF was relevant beyond the acute phase, awareness of the potential causes, extent and impact of long-term CRF appeared limited:

“it's a bit difficult for me to sort of say why people are tired and I guess it's quite sort of hard to quantify”(oncologist).

“I guess my problem with the fatigue is I just don't know. I honestly do not know[...] if you ask me to sort of like, say what proportion of patients have this level of fatigue? I don't know” (oncologist).

HCPs had some general knowledge of physical causes of long-term CRF such as hypothyroidism, anaemia, physical inactivity, dietary factors, pain, cancer recurrence or progression:

“when people say they’re tired, I want to make sure I’ve not missed hypothyroidism in the longer term[. . .] Is there anything treatable?”(Oncologist).

HCPs expressed a need for better education or guidance for CRF, with many HCPs expressing they did not feel equipped to effectively support patients in managing CRF:

“I’m not as well read about it than I probably should be[. . .] I could probably manage it at a basic level, but I think anything else above that[. . .] I think we probably don’t know enough about it” (nurse).

Indeed, nurses expressed a preference for addressing problems they feel equipped to solve, rather than those they feel they cannot, which can limit proactive discussions of CRF:

“It’s just that we can’t give an answer, can we? [. . .]and that is very hard with any cancer conversations” (nurse).

Together these factors may explain why patients reported having insufficient information on long-term CRF and its potential impact on daily life:

“So I never was really led to believe that fatigue was to be such a thing[. . .] because I don’t think they give you much information”(male patient).

Patients felt this long-term effect had not been adequately emphasised by clinicians *“the long-termness wasn’t, I don’t think, pushed enough maybe”(female patient)* and there is a need for more comprehensive and effective conversations surrounding this issue: *“I think they[patients] need to be told about, in the long term, how it may affect you (female patient). Patients viewed HCPs as occasionally disconnected from the lived experience of CRF, “[. . .] and he was just “oh it’s just normal, you’ll have it for the rest of your life” (male patient).*

3.2. Approaches to Discussing CRF: Proactive Versus Reactive

“my mental checklist would include, you know probably other things first[. . .]And then I might, you know, ask about it, depends on the patient.”(Oncologist)

Approaches to CRF could be distinguished into proactive and reactive approaches amongst HCPs and patients.

The way CRF was conceptualised by HCPs and discussed within clinical settings often reflected a reactive approach, with the topic being inconsistently approached. HCPs often viewed CRF as a secondary symptom, viewing it in relation to underlying conditions or treatment effects rather than as a primary concern:

“It’s never just fatigue, it’ll be that they’re generally tired, they’re struggling with taste or swallowing or other side effects” (Oncologist).

The implicit understanding amongst HCPs that fatigue early in treatment is normally translated into a proactive approach to fatigue in the acute period:

“I always ask them, you know how tired they are feeling, what their energy levels are like[. . .]”(nurse).

However, long-term CRF was conceptualised differently with a shift towards a reactive approach as patients transitioned to the recovery phase:

“So it might not be something that I specifically asked about for every patient” (oncologist).

This distinction contributed to inconsistencies in how and when CRF was raised. HCPs were more likely to discuss CRF if the patients prioritised it, especially if they explicitly raised it as a concern:

“So it depends how important it is to them, because we would always try and prioritise the things that are more important to them to talk about”(nurse).

Patients generally demonstrated greater proactivity than HCPs in initiating discussions about long-term CRF. They also emphasised the need for more transparent and candid discussions, and that these could enhance patient awareness of the potentially prolonged nature of CRF, thereby better preparing them for its ongoing impact and management:

“So had I had more kind of in-depth “well this is what you may expect, you could get over your fatigue, it could last for 5, it could last for 10 years, or you may never be the same”, you know, that kind of thing”(female patient).

HCPs reported that addressing patient’s expectations was not always easy as they had to continuously gauge how much a patient could process during each encounter and ensure patients were neither overwhelmed nor left underinformed.

“It’s just being honest, isn’t it? And just what to expect. I think you’ve got to assess the patient, how much information they can tolerate” (nurse).

However, HCPs recognised that as a result, patients with low expectations, more accepting of long-term CRF and/or less inclined to voice complaints may not have CRF acknowledged or addressed in clinical interactions:

“I think people do come to terms with that and I think it’s the same with a lot of their side effects they have from the treatments. . . they’re forced into accepting it in a way, I don’t know how they truly feel whether they think that we could be doing more and they just kind of accept it to appease us[. . .]”(nurse). The language used to discuss CRF further reflected inconsistencies, with HCPs often being ambiguous:

“usually, we’re kind of it’s very vague because everyone seems to be so different, so we are quite vague with what we tell them”(nurse).

This ambiguity, coupled with the balancing act between empathetic listening and efficiency in clinical settings, appeared to hinder proactive engagement with patients about CRF. HCPs recognised that open and transparent dialogue is crucial for a proactive approach, enabling early identification of CRF rather than relying solely on patient-initiated discussions:

“I think all we can be is frank and open, and allow it to be discussed and be honest that there are limitations, but also there are things that we can explore”(nurse).

3.3. Impact of Available Time and Timing of CRF Discussion

“they have limited time to talk about these things.”(nurse)

The distinction between time and timing is essential when engaging in discussions about CRF. Time, a finite resource, often felt insufficient (amidst competing priorities) to address the complexities of CRF. However, timing, which explored the deliberate choice of *when* to prioritise deeper discussions on CRF in the patient trajectory (e.g., during their initial consultation, during radiotherapy or during follow-up) varied. Allocation of time to discussing CRF and timing of discussion was influenced by perceived and evolving patient and HCP priorities and expectations.

HCPs reported that appointments were typically short, and CRF was often deprioritised during consultations due to limited time:

“There so many things to go through. That something like that doesn’t get an awful lot of focus [...]”(oncologist).

Patients similarly reported a need for longer appointments to facilitate discussions about side effects, including CRF, which they felt were not adequately addressed within the constraints of standard consultation times:

“you pop in for half an hour, meet your oncologist and he goes, “how are you feeling?” And they go, “well, a bit tired or a bit this.” But they don’t dig down to say, “whoa, hang on a minute, you’re really suffering, we need to help you.”(-male patient).

Patients and HCPs tend to focus on other acute issues or treatment-specific concerns:

“I think when they come to clinic to see us[...]the first is just telling them about the cancer. ... and then you tell them hundreds of side effects[...] And then during the treatment, you’re just really getting them through.”(oncologist).

This leaves little room to explore long-term CRF. HCPs also emphasised that patients may struggle to process all the information provided to them, particularly when delivered within a relatively short timeframe.

“I’m just very conscious that our patients get very overwhelmed, a lot of patients are already quite overwhelmed”(nurse).

“patients might be told but choose to forget[...] they’ll remember the pain or sticky saliva, but you know the fatigue[...]they don’t remember as such”(nurse).

Additionally, HCPs noted that early in the treatment trajectory, patients may not be receptive to discussions about fatigue. Their focus was often on navigating the acute phase of their care, or covering immediate concerns related to treatment:

“they don’t pay a lot of attention to when I say you’ll be tired. It’s not something that they seem particularly concerned about in the beginning”(oncologist).

Immediate posttreatment consultations were thought to be similarly challenging for addressing long-term CRF, as these meetings can be dominated by the emotional impact of treatment outcomes, leaving little opportunity for discussions about tiredness:

“I think often that at that stage their priority still, is often sort of being cured.[...] So, I think they’re quite accepting of things like fatigue” (oncologist).

Patient interviews echoed that emotions could hamper effective communication about CRF. Information provided during consultations could feel overwhelming to patients, leading to difficulties in retaining or prioritising discussions about CRF:

“I think because you just hear the words illness and the treatment, I don’t think I even looked at anything else really, do you know? [...]there was a broad spectrum of things that were told to me, I think you lose it along the way somehow. Or not lose it but just not focus as much on it” (female patient).

Although HCPs acknowledged that fatigue becomes increasingly relevant over time, they reported that at the point at which it is most pressing, patients may no longer be in regular contact with their oncology team:

“And then I’ll discharge them. So I don’t know what the other people [clinical teams] do about the tiredness [...]”(oncologist).

In contrast, nurses, who saw patients later in the treatment pathway, were more likely to engage in conversations about long-term CRF when it became a more apparent issue:

“when you’re following up patients for sort of five years, it [CRF] does crop up with them. It can be sort of a long ongoing problem with them”(nurse).

This underscored the importance of addressing CRF at multiple points along the patient-care pathway:

“So we can always pick things up again then. So, it’s not like it’s a one-time only thing[. . .]” (nurse).

3.4. Solution-Oriented Mindset and Identified Solutions

“I like to give or for patients to retain hope[. . .]”(oncologist)

HCPs often approached patient care in general with a strong solution-oriented mindset, focussing on providing tangible interventions to address patient concerns. While CRF lacks straightforward solutions, HCPs proposed strategies to improve the current practices and management approaches.

To gain more insight into the scope and severity of CRF in their patients, HCPs advocated for the integration of patient-reported outcomes (PROs) for CRF into routine clinical care:

“[. . .]if we’d had a patient reported outcome, you know, like a PROMS that that highlights it [CRF] and then they could get sent Information [. . .]”(oncologists).

Still, HCPs often perceived CRF management as outside their scope, citing a lack of actionable solutions, *“it’s not something I hugely dwell on because I haven’t really got an awful lot to offer”(oncologist).*

Amongst HCPs, oncologists viewed the management of CRF as less aligned with their role:

“I think it would be better managed by and it’s probably something that needs much more [. . .]somebody who’s got much more time to think about all of the things that can impact on it. . .”(oncologist).

HCPs recognised the importance of managing patient expectations around CRF:

“I think sometimes if you give people more realistic expectations, they manage that better[. . .]”(oncologist).

HCPs expressed that educating patients better on CRF, its causes, and potential strategies for management could help patients cope:

“I think more information would be helpful or just kind of something that they can link back to if they do have questions, a resource that they know they have there[. . .]. I think it would be helpful”(nurse).

However, HCPs acknowledged that they too would benefit from education on CRF to facilitate more effective communication and support:

“having additional knowledge on it would be useful because it would help you sort of support them better, and that that’s something that we don’t have”(nurse).

HCPs also highlighted the need to empathise and the importance of validating patient experiences:

“I would hope to try and at least make them feel that they’ve been listened to and that they, you know, their concerns were acknowledged as real [. . .]”(oncologist).

“it’s probably reassurance that it’s not abnormal to be feeling how they’re feeling. [. . .]I think it is reassurance [. . .]”(nurse).

However, HCPs emphasised the need for practical interventions or sources of support, to address CRF more effectively, beyond merely being aware of it or validating experiences:

“Day-to-day advice and maybe kind of links into support groups, who to talk to and community support, and how they access that[. . .]”(nurse).

Group support was offered as a solution, where patients can share experiences, exchange management strategies, and better navigate their new realities with peers:

“some people might do really well with a group,[. . .] I think groups are really good because it makes you realise you’re not the only one, it’s more cost effective. And it might in itself address some of the issues that could be contributing [to CRF], like low mood and not getting out [. . .]”(oncologist).

HCPs felt their role involved empowering patients to self-manage CRF by providing guidance, resources and support:

“Our role should really be empowering patients in terms of educating them if they have got fatigue, which is related to their cancer or treatment”(oncologist).

HCPs did recognise that individual patient capabilities and circumstances may influence their ability to effectively engage in self-management:

“So I think there’s some patients for whom self-management would be perfect. Highly motivated patients have means, whereas for some of them,[. . .]they can’t really manage themselves”(oncologist).

The establishment of a life after the cancer treatment group, including allied health professions, or dedicated survivorship clinics was also proposed to address complex and ongoing needs, providing dedicated opportunities to address long-term issues such as long-term CRF:

"[...]you almost need a dedicated clinic don't you?"(oncologist).

HCPs however acknowledged that this was dependent on securing both financial and senior management support.

"I think it's funding, I think almost of all of us would like to run a late toxicity clinic[...] It's a finance issue,[...] I think most of us would like to be involved, because we know it's [late effects] is a big issue"(oncologist).

4. Discussion

This study synthesises insights from a secondary qualitative analysis of a cross-sectional study on long-term fatigue in patients treated for OPC postradiotherapy, alongside the findings from a complementary service evaluation examining how HCPs approach conversations about CRF. In HNC, CRF is insufficiently recognised and inadequately addressed in clinical practice, potentially leading to sub-optimal support and management of this prevalent and debilitating late effect [10]. Themes identified in this study include limited awareness and knowledge among stakeholders and a predominant reliance on reactive rather than a proactive communication approach. Additionally, the study underscores the critical role of time and timing in addressing CRF, identifying there is no single optimal time to discuss CRF and that instead, it may require multiple discussions. HCPs possess a solution-oriented mindset and proposed some actionable strategies to improve communication and management of CRF. Although many of these interventions have been previously explored, their universal adoption and full integration into routine clinical practice remain limited.

Our results underscore the need for enhanced education among HCPs and patients on CRF and its effective management. In general, cancer patients are typically informed about treatment-related fatigue but are less informed of the potential of long-term CRF [26]. A German study, recruiting 2508 cancer patients approximately two years postdiagnosis through a cancer registry, revealed that over 58% of participants felt inadequately informed about fatigue [27]. A key recommendation of the European Society for Medical Oncology (ESMO) guidelines for CRF is the provision of information and counselling to patients and their caregivers to enhance understanding of CRF [28]. The National Comprehensive Cancer Network (NCCN) also recommends that patients be educated regarding typical patterns of fatigue during and after treatment [29]. However, HCPs often lack the confidence, knowledge, and skills to support cancer survivors with CRF, limiting the implementation of CRF management guidelines in practice [30]. Our findings support that HCPs would also benefit from additional education on CRF and its management. This would enhance their knowledge and better equip them to support patients in managing the condition effectively. It is important to recognise that the lack of preparedness reported by patients is not unique to CRF but reflects a broader pattern encompassing other psychosocial late effects [17, 31, 32].

This study provides evidence supporting the need for a more proactive and systematic approach to addressing CRF, emphasising the need for routine integration into clinical assessments and patient-provider communication. Addressing fatigue in the acute phase improves treatment adherence [33]. In the chronic phase, CRF impacts work capacity and financial security [17, 34], therefore addressing CRF could improve patients' quality of life [35, 36]. This reinforces the need for a shift towards a more proactive approach in both discussing and managing CRF. There does not seem to be an optimal time for discussing CRF; instead, it should be revisited multiple times throughout the course of the patient's care. While the focus of these discussions may shift over time, ensuring consistent engagement on the topic across the treatment trajectory could help bridge gaps. Especially given that the literature suggests patients typically retain only 20%–60% of the information provided by their physician during a consultation [37]. This may be partially explained by patients feeling overwhelmed during consultations, particularly when confronted with large volumes of complex or emotionally charged information [38, 39]. This further emphasises the need to deliver CRF-related information in a structured, paced, and patient-centred manner throughout the treatment and follow-up trajectory.

Our results suggest that roles in fatigue management remain unclear, with ambiguity around responsibility, expertise and time allocation impacting discussion of CRF. This is supported by the findings from a study that evaluated barriers and enablers to implementing fatigue guidelines at an Australian comprehensive cancer centre [11], where defining roles, having appropriate expertise and sufficient time were highlighted as issues. To promote self-management of CRF, it is essential that HCPs and patients have a clear understanding of their respective roles in management of CRF, fostering a sense of shared responsibility [40]. There is also a need for a common language [41] to promote precise communication regarding the nature of CRF, its impact on daily life and the various management strategies. Clarity in communication is essential for enhancing patient engagement and adherence to self-management strategies.

The need for provision of designated survivorship services to address late effects, including CRF, was highlighted during our HCP interviews. Head and neck survivorship care should be managed within the scope of a multidisciplinary team to ensure comprehensive and coordinated care [15]. There is also evidence to suggest that the survivorship needs of HNC patients are best addressed in a head and neck survivorship clinic [42]. Comprehensive survivorship care plans and survivorship clinics allow a more holistic approach to care [43] and would allow further exploration of CRF, incorporating educational series, fitness programs and links with patient support groups. A Cochrane review identified that educational interventions may mildly reduce CRF intensity and its interference with daily life, with a moderate effect on fatigue distress. Such interventions should be considered alongside other interventions [44]. Aerobic exercise has been found to be beneficial for CRF in patients with solid tumours during and post-cancer therapy [45–47]. Furthermore, the National Institute for Health and Care

Excellence (NICE) recommend physical activity programs, cognitive-behavioural interventions and education as first-line strategies [48]. However, despite these findings and recommendations, there is inconsistent application of CRF management guidelines, with many healthcare providers not fully integrating these recommendations into their practice. Furthermore, the integration of CRF guidelines is often hindered by a limited availability of services capable of delivering the recommended interventions.

This study has several strengths. It offered nuanced insights into the challenges of addressing CRF in HNC at various stages of cancer treatment and survivorship, highlighting the need for effective communication and support. It also underscores the importance of individualised communication strategies, where oncologists engage with patients not only on the medical aspects of their care but also on emotional responses, readiness for self-management and overall quality of life. It is important to acknowledge that patient interviews were not conducted specifically for the purpose of investigating communication about CRF. As a result, the insights into communication practices from the patient's perspective were indirectly derived, which may limit the depth of understanding achieved. Furthermore, the study was limited to patients treated for OPC and HCPs working in busy tertiary cancer centres. As such, the findings may not be generalisable to patients treated for other types of HNC or to HCPs working in different healthcare settings. However, it is important to recognise that qualitative studies do not aim to produce generalisable findings.

5. Conclusion

There is a communication gap in the discussion of CRF in patients with OPC. This gap may hinder patient awareness and understanding of CRF, as well as potential strategies for its management. Bridging this gap requires a more individualised approach, with consistent, proactive and longitudinal communication strategies that align with patients' readiness and expectations. Enhancing education for both patients and healthcare providers, fostering shared responsibility and designated survivorship programs could lead to improved patient engagement, better management outcomes and greater satisfaction with care.

Data Availability Statement

The data supporting this study are not publicly available due to participant confidentiality. Requests for access to anonymised data should be directed to the corresponding author.

Conflicts of Interest

The authors declare no conflicts of interest.

Author Contributions

Louise Murray and Florian Boele contributed equally to this work.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section. (*Supporting Information*)

Interview guide.

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