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Qualitative exploration of head and neck cancer patient-reported experience of radiotherapy: insight on restriction anxiety and 'claustrophobia' (H&N PRER RAC)

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Abstract

Patients with head and neck cancer (HNC) who undergo radiotherapy are required to wear an immobilisation mask during treatment. The immobilisation mask is critical for treatment but can be very challenging for patients. The aims of the study were to: (1) explore patients' experience of preparing for and completing radiotherapy with the mask; (2) identify themes associated with mask-related anxiety. Semi-structured interviews were undertaken with participants treated for HNC, between six and 12 weeks after completing their radiotherapy. Thematic analysis was used to analyse interview data. At the time of their interview, participants were invited to retrospectively rate their distress during their mask-making and scans on a scale of 0 (no distress) to 10 (severe distress), using an Adapted version of the Distress Thermometer (ADT). Descriptive statistics were used to analyse ADT data. Eighteen participants with HNC provided written informed consent and completed an interview. Six themes were developed from the interviews: emotional experience of mask, physical experience of mask, information provision, coping strategies for managing mask anxiety/feelings of claustrophobia, support from others, and COVID-related issues. Of the ADT responses, 14 (78%) participants had scores over 4, a level requiring intervention; six of these (33%) participants graded their retrospective distress as a 10/10, and the remaining four (22%) scored 0/10. Participants reported diverse experiences with the mask. Interviews highlighted anxiety triggers, with common contributors being the emotional, physical, and environmental experience. Patients developed a variety of coping skills, so they were able to tolerate treatment and identified recommendations for future patients and staff. This work represents the first stage in developing a screening tool to ensure early identification of patients who may potentially experience mask-related anxiety. We see this as a crucial development, as significant mask anxiety affected 78% of participants in this study.

Keywords: Head and neck cancer, Immobilisation mask, Patient experience, Radiotherapy, Claustrophobia, Anxiety

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Introduction

Head and neck cancer (HNC) is the umbrella term used for cancers of the head and neck region and includes the sinuses, nasal cavity, lips, mouth, tongue, salivary glands, larynx, and throat[1]. Radiotherapy is one of the most effective treatments for local and regional control of HNC; however, the treatment requires the patient to wear an immobilisation device, hereafter referred to as the 'mask'. Masks are bespoke made; therefore, all patients are required to attend a mask-making session. The session takes 13 min to complete; 3 min in a warm water bath, 5 min to mould the mask around the face, neck and shoulders, and a further 5 min in place to prevent any shrinkage. The mask is made of thermoplastic material, which makes it easy to breathe. In some cases, modifications can be made such as cutting out eye holes, but the integrity and structure of the mask still needs to be maintained. Patients then need to undergo a radiotherapy planning session before they can begin treatment, when the now hardened mask is re-applied. This lasts approximately 20 min. Of note, during treatment the mask is secured to the treatment table.

Whilst the prevalence of anxiety in cancer patients is high across all disease groups[2], quality of life (QoL) and psychosocial adjustment can be particularly impaired in HNC patients[3]. HNC patients who undergo radiation therapy have been shown to experience higher levels of anxiety compared to other cancer disease groups, with up to 26% of HNC patients reporting moderate to severe distress[4].

The use of the mask can be very challenging for patients, especially those with existing anxiety problems or who experience feelings of claustrophobia[4]. Wearing the mask has been reported by patients to be a difficult event to endure[5] and has been described as one of the worst things about radiotherapy in HNC[6]. Data reporting relating to the level of disruption due to anxiety experienced by patients during scans and treatment is limited. One study reported that out of 90 HNC patients, 11% of CT sessions and 24% of the first treatment sessions were disrupted to some degree due to patient anxiety[7]. In addition to HNC radiotherapy, it is recognised that feelings of claustrophobia can have a disruptive impact on scan completion. Enders et al.[8] explored the impact of claustrophobia on patients receiving magnetic resonance (MR) scans and suggested that globally, around two million MR

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procedures a year were either prematurely terminated or could not be performed due to claustrophobia, resulting in an estimated lost productivity of approximately one billion euros a year. There remains a paucity of research into patients' experiences and strategies for screening and identification of patients most at risk and proactive management of mask-related anxiety[4,9,10].

Rachman[11] defined the concept of claustrophobia as the anticipation of negative consequences of being in an enclosed space. These negative consequences have two major components: the fear of suffocation and the fear of restriction of movement or confinement. The presence of either of these fears may be sufficient to produce claustrophobia. For a patient with HNC undergoing radiotherapy, both components are present; it is therefore understandable that this situation may trigger feelings of claustrophobia. Rachman[12] suggested that the belief 'I will lose control' is also a critical cognition in the maintenance of claustrophobia. Because of the necessity to 'lock' the patient to the treatment plinth with the mask, all these elements are potentially experienced during radiotherapy for HNC. In this paper, the term 'claustrophobia' will be used to describe one or more of the cluster of fears and beliefs described above, namely the fear of suffocation, the fear of restriction, the belief 'I will lose control' and the additional recognised concern 'fear of public shaming'[13].

The current study aimed to: (1) explore the experiences of patients with HNC during preparation for and completion of radiotherapy utilising an immobilisation mask, (2) identify themes related to 'claustrophobia' and mask-related anxiety within this patient cohort.

Materials and methods

Ethical statements

Ethical approval was obtained for this study by the Northwest - Greater Manchester South Research Ethics Committee (Ref: 20/NW/0264), HRA, and Health and Care Research Wales. All participants provided informed written consent prior to interviews being conducted.

Study design

A qualitative approach underpinned by a contextualist epistemology was chosen for this study. This is appropriate as the context of people's experiences may vary depending on their own personal experiences either in the past or during the procedures. Semi-structured interviews were used to explore the experiences of wearing an immobilisation mask during radiotherapy in patients with HNC. Semi-structured interviews were chosen to allow discussion of key themes but also to give participants the opportunity to discuss other issues of importance and to provide a deeper understanding of their experiences during their treatment. The study was conducted and reported according to the consolidated criteria for reporting qualitative research (COREQ)[14].

There was a quantitative element to the study. At the start of the interview, patients were asked to retrospectively rate their remembered distress during the mask-making and scan on a scale of 0 (no distress) to 10 (severe distress). Demographic data were collected from the patients using a case report form.

Study site

The study site is a specialist cancer centre in NW England. The HNC Clinical Oncology service at the study site is the largest in the UK and treats patients from a wide geographical area, populated by approximately 3.2 million people. Support from the Complementary Health & Wellbeing team (also known by patients as 'the CALM team') is integrated into patient care pathways, including HNC, by referral. The team provides techniques to facilitate compliance with potentially lifesaving treatments for patients who find the situation challenging. The current service relies on staff identifying patient distress, the patient being able to share their distress/anxiety prior to commencement of treatment, or non-compliance during treatment.

Participants

HNC patients were approached to take part in the study when attending their 6- or 12-week post-radiotherapy review appointments. At 6 weeks post-treatment, patients have a review but do not find out their results, so this was the preferred time to approach them. If it was necessary to approach them at their 12-week appointment, when they would receive their results, it was checked beforehand, and only patients whose response to treatment was positive were approached to take part in the study. A purposeful sampling strategy was used to include equal numbers of participants who did and did not receive CALM support, with the mask making and treatment, to ascertain the broadest spectrum of experiences with the mask and radiotherapy treatment. This sampling approach was adopted as it was felt that experiences may differ considerably depending on whether patients had received support or not.

Patients with HNC were eligible to take part if they met the following inclusion criteria: aged ≥ 18 years; had completed radiotherapy treatment for HNC utilising a mask ≥ 6 weeks before study entry.

We aimed to recruit approximately 20 participants. Data collection would end when thematic saturation had occurred. Urquhart[15] defined saturation as when no new codes are identified in the data but replication of the same codes. Collecting additional data from this point would not be expected to lead to new codes.

Study procedure

Eligible patients were identified by either a member of the research team or a member of their clinical team, from the 6- or 12-week post-radiotherapy outpatient clinic, and asked if they would be happy to be approached regarding inclusion into the study. Patients who gave permission were sent a patient information sheet and a consent form. This was followed up with contact from a member of the research team to discuss the study. If they were still happy to be interviewed, patients were asked to return the signed consent form in a supplied stamped addressed envelope. On receipt of the signed consent form, an interview date was arranged.

Consented participants were given the choice of interview by telephone or virtually via 'Attend Anywhere'; a system used at the participating hospital to conduct consultations remotely. Participants attended the interview on their own. At the start of the interview, all participants were informed that the interviewer was there in a research context and because they had an interest in improving the quality of the patient journey.

The interview was conducted using a semi-structured interview schedule consisting of open-ended questions, developed by the research team, with input from patient and public colleagues from a service-user charity, to explore issues related to the aims of the study. There were no time restrictions put on the length of the interviews. A trial interview was conducted with a PPI contributor before participant interviews began. The trial interview was transcribed, and the transcript was reviewed and approved by the contributor. The interviews were audio-recorded and transcribed verbatim.

Demographic data, including sex, age, ethnicity, marital status, and employment status, were collected ahead of the interviews, which were conducted by members of the research team.

At the beginning of the interview, participants were asked to complete a modified version of the 'Distress Thermometer'[16]. The DT is a single-item tool where people are asked to rate their level of distress over the past week on a scale of 0 (no distress) to 10 (severe distress). The DT has been modified in previous research to specifically explore distress related to mask anxiety[4]. The 'Adapted Distress Thermometer' (ADT) asks participants to grade the level of distress they experienced during mask making and their scan, as they remembered it. DT guidance advises a score of 4 or higher as a trigger for onward referral[17].

The research team was comprised of both clinical and academic researchers with relevant experience. Interviews were conducted by three female researchers (a Clinical Research Associate [CRA], therapist and nurse consultant), who all have experience in qualitative interviewing. Participants who had received CALMs intervention were not interviewed by the researcher who was also a CALMs therapist. Coding of the interview transcriptions was initially carried out independently by the CRA and therapist researcher. These were then independently reviewed by senior members of the research team, who had not been involved in the interview process, to reduce researcher bias.

The CRA had no knowledge of the mask prior to involvement in the study.

Data analysis

Interview data

The interviews were analysed using reflexive thematic analysis[18]. Reflexive thematic analysis was chosen as it is a flexible approach, which provides a critical interpretation and engagement with the data whilst also acknowledging the subjectivity of the researchers. Data were coded inductively with codes developed iteratively through regular meetings with all research team members and through multiple readings of the transcripts. To ensure qualitative rigor, we kept a record of any analytical decisions that were made. We also engaged with reflexivity throughout by considering how clinical roles and experiences may be impacting on interpretation of the data. The key stages of reflexive thematic analysis were followed. Two researchers (AM & DH), read each transcript independently to familiarise themselves with the data. Codes were developed independently by the two researchers (AM & DH) to generate an initial code list. All transcripts were coded independently by each researcher, then they met to discuss their coding. This was an iterative process involving multiple rounds of coding and several discussions with the wider research team. The initial code list was reviewed by another member of the research team (GP) to confirm interpretation. This was followed by discussion between the original reviewers to interpret the data and actively develop themes and sub-themes from the codes. A coding tree containing the themes and subthemes was created and reviewed with additional members of the research team to ensure themes were an accurate representation of the data and reflected the entire dataset. Themes were then further refined to produce the final analysis. Direct quotes are presented in the manuscript to emphasise the depth and nuances of the data and to ensure qualitative rigour. NVivo 12 was used to store the data and manage the data analysis. Coding was conducted simultaneously with data collection.

Adapted distress thermometer (ADT)

Basic frequencies were used to summarise the ADT scores, scores were presented according to the number of participants who scored 10/10 indicating maximum distress, the number who scored the defined cut off score or above ≥ 4[17], those who scored below the cut off score and those who scored 0 indicating no distress at all. An average distress score across all participants was also calculated.

Results

Demographic information

A total of 18 HNC patients participated in the study. One patient withdrew from the study before the interview was conducted but did not provide a reason why. Eight (44%) of the participants had received additional support from the CALMs team and 10 (56%) had not. Participants had a mean (SD) age of 59 (10.8), median 55, range 34–79. Thirteen (72%) participants were male, and five were female (28%). Sixteen (89%) participants identified as British and two (11%) did not have their ethnicity recorded. Half of the participants, nine (50%) were retired, five (27%) were employed, one (6%) was self-employed, one (6%) was unable to work, and two (11%) did not have their employment status recorded. Most participants, 14 (78%), were married or in a domestic partnership, two (11%) were divorced, and two (11%) were single, never married. Twelve (67%) participants were interviewed 6 weeks after their radiotherapy, four (22%) 12 weeks after, and two (11%) 12+ weeks after (see Table 1).

Interviews and themes

The average interview length was 32 min, with the shortest interview being 13 min, and the longest 1 h and 7 min. The interviews were coded as described within the analysis section. There was a consensus between all members of the research team that data fell into six key themes as defined below.

Emotional experience of mask

Wearing the mask had a significant emotional impact on participants. The emotions experienced were varied, and descriptions alluded to both physiological and psychological reactions to having the mask made and wearing the mask during the treatment. One person described it as a surreal experience, as if it wasn't really happening to them, and felt that wearing the mask had left a lasting impact.

Table 1. Demographics.

Demographic	Category	Count
Sex	Male	13
	Female	5
Age	< 50	1
	50–59	11
	60–69	1
	70–79	5
Marital status	Married/domestic partnership	14
	Single/never married	2
	Divorced	2
Employment status	Employed	5
	Self-employed	1
	Unable to work	1
	Semi-retired	1
	Retired	8
	Not recorded	2
Ethnicity	British	16
	Not recorded	2
Time since radiotherapy (weeks)	6	12
	12	4
	12+	2

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I thought 'I'm going to wake up in a minute, this isn't happening' and then obviously when it was all complete, I just thought that's me now. I didn't feel me, that mask was me (PT09)

The terminology used by participants to describe their experience differed considerably. Some participants specifically referred to claustrophobia whereas others used terms such as being *'pinned down' (PT05,06,09,17), 'anchored down' (PT16), 'locked in' (PT05), 'bolted down' (PT13,14) 'stuck' (PT03,05,06,14,16), 'trapped' (PT01,05,09)* and *'clamped down' (PT16)* to describe feelings of claustrophobia or feeling out of control. For some participants, the experience triggered a physical reaction such as shaking, panic attacks and feelings of suffocation.

That was when it really started, panic attacks, claustrophobia, couldn't breathe, couldn't do it. I think to this day it was a miracle I got through it because the first/second day - there was no way I was doing it. (PT13)

For one participant, it was the fear of the unknown that seemed to trigger their physical reaction.

I was just put into a dark room and three nurses were moulding this on me and I didn't know what was going on. I started, yes, I was shaking, I was shaking, I was. (PT19)

For some participants, the experience triggered an unexpected awareness of claustrophobia.

I didn't realise, I was claustrophobic until they actually moulded that mask. (PT19)

Several participants described an overwhelming distress that forced them to stop one or more of their sessions. They did this, even with the knowledge that this would cause delays.

There was one point when I had to say stop and they said 'you do understand that if we stop this, we are going to have to reset it all up' but I just had to stop (PT11)

Some participants, particularly those who reported previous claustrophobia, described the heightened distress they felt if the procedures were taking longer than they expected.

If it [the Linear accelerator – delivering the radiotherapy] doesn't do what you're expecting to do as quick as you want it to do it, that's when you think oh my god something's wrong and I'm stuck in here, I'm not getting out. (PT16)

Participants were sometimes surprised by their reactions and found it hard to articulate what was happening to them.

It was just I could go into a fully panic mode for no reason at all, that's the hardest thing to explain to people. (PT16)

For other participants, the fear of cancer outweighed the fear of the mask.

My fear of claustrophobia was overridden purely by the fact that hopefully there is success at the end of it (PT05)

Some participants also expressed feelings of shame and guilt at the fact that they were finding the mask wearing difficult.

I was calling myself a baby and blah, blah, blah, and there was somebody else behind me [waiting for treatment], being messed about because I couldn't handle it, you know I was blaming myself for being stupid, but I wasn't. (PT16)

You start to think you have kept it in to yourself because you are protecting others in the family, you feel responsible, your body is doing this, you feel there are elements of shame I guess, a lot of fear, distress and a lot of unknown (PT11)

Physical experience of mask

The physical experience theme incorporates reflections focussing on physical comfort (e.g the fit of the mask), the impact of side effects (e.g. weight loss, nausea and vomiting), and environmental factors. Some participants were not troubled by the comfort of the mask.

Yes, it fit very well. For complaining about how it was done but it did fit. There was nothing wrong with what they did. (PT08)

However, most participants felt the mask was uncomfortable and tight which added to the negative experience.

No, I didn't find the mask itself comfortable at all. Once it was clipped down because it goes very tight on your face when it's clipped down, (PT16)

Weight gain or weight loss played a part in how tight the mask was. One patient described the mask getting tighter as they gained weight and feeling concerned about the impact it would have on their comfort if the weight gain continued.

It started to get tighter and tighter, and I thought 'I hope I don't put any more weight on.' I've never stopped putting weight on. (PT02)

One participant described the mask becoming looser over time due to weight loss. This made the mask more comfortable and the treatment more tolerable.

At first it was very tight but after the third or fourth week you can definitely feel there is a gap either side, slight gap appearing. (PT05)

As well as the tightness of the mask, participants reflected that side effects from the treatment contributed to concerns relating to comfort during their sessions. Many had worries around being unable to swallow, nausea, a sore neck and just all-round feeling more poorly as the treatment progressed.

I was glad I couldn't open my eyes but there were times when, if I was going to be sick because I felt quite nauseous on some days, you were like, am I going to choke to death on this bed (pt11)

The physical feeling of being restrained was difficult for people to cope with and many participants provided a very negative description of the treatment room. One participant related the mask, and the other equipment used in the room as being reflective of equipment you would find in a torture chamber, which strongly emphasises their lack of comfort.

When you are put in the mask and you are on the table, that, to me reminded me of torture chambers, medieval processes like, I once went, I think to York museum, where they used to shackle people and what they used to do to people and in some respects, it's not that far from it but it is in the fact that what they are doing and where it is going and stuff but it is that very medieval sort of thing (PT11)

Provision of information

The provision, or sometimes lack, of information about the process and what to expect had a significant impact on peoples' experiences. Most participants reported feeling unprepared for their mask making and treatment as the information they had received was reported as minimal with one patient quoting *'you will have a mask made and you will have radiotherapy' (PT11).*

Participants mentioned being unsure what to expect, particularly in relation to what the mask would look like. The uncertainties about the procedure all added to participants anxieties.

At the time I didn't know whether it was like a hockey mask and then when they said there was going to be fastened to the table, I wasn't quite sure, I couldn't visualise what that looked like. … but once they showed me, it was ok. It's not knowing what you don't know but once you've seen it, then it becomes reality, it takes away that apprehension. (PT17)

I hadn't been to the mould room, and I didn't know what to expect. I thought a mask—what sort of a mask—I couldn't get my head round it. (PT13)

Some participants reported receiving information, but they did not feel this was an accurate representation of what they actually saw when they arrived at the hospital. This again led to heightened feelings of anxiety

I'd just not been told the right information, I'm not sure but it was quite alarming when I arrived at 'the hospital' in a little room. (PT18)

Whilst most participants described a need for more information, some participants felt that if they had been given more information, this would have caused more distress leading up to the radiotherapy treatment.

I fully appreciate it wouldn't work for everybody. The main fact you're going to tell certain people they're going to be bolted down would really, really raise their stress level. (PT14)

I didn't want to. I didn't want to read anything. Even Googling I never did anything like that. (PT09)

Visual aids were suggested as potentially useful tools to help people feel more prepared and let them know what to expect. For example, participants felt if they had seen the radiotherapy machines (PT17, PT11), the radiotherapy room (PT11, PT19) and the mask before (PT17), it would have made the mask making easier.

Coping strategies for managing mask anxiety/feelings of claustrophobia

Participants described a range of coping strategies they used to help them cope with their treatment. Music was commonly used by participants as a distraction technique, and the times music was not being played were often *'very distressing'* (PT13) for participants. Music gave them something else to focus on and allowed them to mentally escape from their treatment.

Things like music helped, they allow you to put music on you know. It puts you in a different place, if you see what I'm saying, just for a minute or two. You have to concentrate on the music or the radio or whatever is on to get through it. (PT05)

Familiar songs were helpful as participants found it easier to engage with them, and they also helped to give them a sense of time during treatment and allowed them to focus on the treatment endpoint.

It helps if you know the tune and you just try to sing along to it... you say to yourself, well I know this song takes a couple of minutes so you sing along with it and at the end of it you think to yourself 'right it's coming off now.' (PT05)

… I could judge two songs and I was going to be finished, it would give you a reference point in time. If you're just in the room and it's just the machine wiring round you lose track of how long you've been in there. (PT17)

Participants described becoming familiar with the mechanical noises of the machinery and could link different noises to different parts of the treatment. This again gave them a sense of time so they could anticipate when their treatment would end which helped them to cope with their anxiety.

I could tell by clicks on the machine when it was actually going to start the process, now once it had gone one way, I was fine then because I knew it was coming back again in a second or two and that's it, I'm out of here. (PT16)

Beyond music and the sounds in the room, other coping strategies included cutting the eyes or nose out of the mask, breathing techniques, counting fingers and toes, progressive muscle relaxation exercises and taking their minds elsewhere.

I found if I could take deep breaths and think I was somewhere else, that would work sometimes because I'm an avid sea fisherman so a lot of the time I was catching fish at Holyhead. The music helped. (PT16)

The CALMs team provided patients who received additional support with a soft, 5-point, star-shaped prop that fits in the palm of the hand. Patients are guided in creating links between the star and empowering mental resources (e.g., each point symbolising someone important in their life to be beside them through their treatment), as well as providing a sense of control, movement and freedom. All patients who received the star found it a helpful tool to assist with breathing regulation, relaxation and something to focus on other than the mask.

The stars: I don't know if they give the stars to everybody, but it would certainly be an idea because when pressing them you certainly can regulate your breathing. (PT14)

Support from others

Support from others was universally reported as a key component in helping participants comply with treatment. All participants reflected the need for support in some form, with many reporting that having someone with them throughout the treatment helped. Some participants were treated during COVID-19 so had to attend appointments alone. These participants felt having their loved ones there would have helped make the experience easier.

I think you should have a family member with you, because sometimes when Dr was talking or people you can't take it all in at the time because I was like an emotional wreck, so having someone there to take notes. You listen to someone, and two different people can pick up different amounts of information, so I think having a family member there is quite good. (PT17)

Peer support, particularly conversations with people going through a similar experience, were reflected by participants as providing them with information, support and comfort.

You've been sitting, you're on your own, speaking to other people, that may have helped me get through it because I was speaking to other cancer patients and a lot of people in my own position. (PT5)

The support from staff was consistently described by participants in a positive way, The care they provided was described as *'top-notch' (PT12)*, and they provided a sense of safety and comfort for participants.

The staff were so reassuring everywhere I went, they really were. (PT16)

Communication during treatment, particularly over the intercom, from the radiotherapists (RADs) or CALMs team, was particularly reassuring for patients. In some cases, it did not matter what they were saying, it did not have to be related to the treatment, but just hearing someone's voice meant that the patients did not feel alone or that they *'had been forgotten about' (PT03).*

It helped with the radiotherapists saying right we are going to start the second scan because then I knew there was 2 min to go. The communication was quite key for the radiotherapists to be talking to me. (PT17)

Specialist support from the CALMs team was especially valued by those who accessed it. The CALMs team taught patients coping strategies to alleviate their feelings of anxiety and panic. For many, their support was crucial in helping them to complete their treatment; *'wouldn't have been able to do it without them'* (PT19). Participants highlighted the value of the CALMs service and described it as an essential support service that should be available to all patients.

I think there should be some provision for anyone who is having a mask made that they should be spoken to by somebody from the CALMs team. (PT14)

Like I said if it wasn't for the CALMs girls, I don't think I would have done the first couple of weeks. I don't think I could have... please get support from the CALMs team. Please get support. (PT19)

All participants who had received CALM's support felt that it helped them tolerate treatment.

Impact of COVID-19 on participants' experience

For those patients who received treatment during COVID-19, this added another layer of complexity to the emotional and logistical experience of treatment. Most participants felt that COVID-19 had a negative impact on their experience as they were unable to be accompanied by a loved one. One participant disclosed that her frustration at having to undertake appointments alone was shared by her husband.

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Yes, I had to because of COVID so I did it all on my own. Right from being told I've been on my own … He just kept saying he was going to come. He said, 'I am going to let them throw me out.' (PT08)

Other participants explained COVID-19 caused longer waiting times, which increased their anxiety about the mask.

The amount of time they are waiting around, if they are anxious won't help in any way, shape or form and anxiety will build. (PT01)

Other participants felt that having their treatment during the COVID-19 pandemic made them feel more isolated in all aspects of life. They felt they missed out on the support from loved ones during the mask making and scans that they would have otherwise had.

You have COVID on top and so you are not able to share any of this with any of your family, so it feels even more lonely. (PT11)

There were a small number of participants who felt COVID-19 helped them to cope with the mask. One participant explained that because he was on his own waiting, it forced him to speak to other patients in the same position that he was in, which he wouldn't usually do, and this helped him a lot. *(PT05)*

Adapted distress thermometer

Of the 18 participants, 14 (78%) reported elevated distress during their mask making and scan as defined by the DT clinical cutoff points (≥ 4) (17); six (33%) of these graded their distress as 10/10, and the remaining four (22%) participants scored their distress as 0/10. The average score was 6.5.

Discussion

This study was designed to explore the experiences of patients with HNC during preparation and completion of radiotherapy utilising an immobilisation mask and identify key themes related to mask anxiety within this patient cohort. It is evident that wearing a mask throughout treatment was an extremely distressing and anxiety-provoking experience for participants. Their stories demonstrate how they used coping techniques to help them manage this distress. These experiences can be understood through the Transactional Model of Stress and Coping[19]. The model suggests that distress or anxiety occurs when people feel threatened and are unsure how to manage the threat. Although the mask was a necessity for treatment, participants saw it as a source of distress and confinement and therefore a threat. Patients had to reframe their experience by using coping techniques or engaging with available support.

Many participants reported feelings of distress anxiety, and claustrophobia whilst wearing the mask. This resonates with data from Forbes et al.[9], who reported 'being clamped to the bed' was a main cause of anxiety for participants. Timing was a concern for participants, as often longer periods in the mask triggered greater anxiety. This was particularly apparent for those who experienced claustrophobia. Some participants knew prior to their treatment that they were claustrophobic and therefore were already distressed about the mask, an experience which has been highlighted in previous literature[20]. Some of our participants had never experienced claustrophobia until their treatment. The need to stop treatment sessions has been previously reported[7], but this was less apparent for most of the participants in this study. Even though participants felt distressed, they knew they needed curative treatment, and the fear of cancer outweighed the fear of the mask, helping them to override their anxiety, a finding previously identified by Forbes et al.[9].

The majority of participants reported elevated distress on the ADT. As participants scored their experience retrospectively, no automatic onward referral was made. However, to be left with such a significant memory of distress, can be an indicator of underlying post-traumatic stress disorder (PTSD), so should not be underestimated[21]. A systematic review and meta-analysis found that people with HNC report considerable anxiety and depression even before starting radiotherapy treatment and, for many these feelings continued into follow-up[22]. Participants in this study who reported a high ADT score were offered additional support if they felt it would be helpful, although none of the participants accepted the offer.

Physical experience of the mask was a key theme throughout the interviews. Physical discomfort was a factor identified by participants in this study as contributing to mask anxiety, thus validating data reported by Forbes et al.[9]. In line with other literature, many participants found the mask tight, painful, and uncomfortable. Mulla et al.[23] observed that participants experienced more tightness and pain with a closed as opposed to an open mask. For most participants, the uncomfortable nature of the mask got worse with time, as the side effects of their treatment worsened; these are similar findings to those highlighted by Keast et al.[20]. The biggest issue of concern relating to physical discomfort identified by participants was the fear of choking, with linked worries of feeling sick—particularly towards the end of treatment and inability to swallow. Once again, these findings mirror those reported in previous studies[9,20,24]. As other research has found[9,10], participants' image of the treatment room also contributed to the negativity of their treatment; described by one participant using the analogy of a torture chamber.

A theme that was frequently shared as contributing to anxiety was when participants did not feel prepared for the mask, due to a lack of information received. Participants felt they were going into the 'unknown' and the mask was not what they expected. In keeping with previous research[9], participants felt that if they had been provided with more accurate information, this would have alleviated their anxiety. It was clear that the amount and type of information received varied between participants, as well as when they received the information, which is again consistent with previous literature[20]. Several recommendations for preparing patients for treatment emerged from our participants, such as videos of the mask and room, tours of the room, and being able to see and feel the mask ahead of having their own prepared.

Participants also shared their recommendations regarding the use of coping strategies; offering this information was a key theme within the interviews. In line with previous work[20], participants reported a diverse range of coping strategies, including breathing exercises, daydreaming, and listening to music. As in this study, Forbes et al.[9] found that music was the most cited coping strategy and helped to mitigate anxiety. Some of our participants also commented on the selection of music played; in line with previous literature[25], if they liked the music or knew the song, there was a greater positive impact. Participants did not all use the same coping strategies, and some were more effective than others. In this study, a number of participants received support from the CALMs team, meaning they were offered props (e.g. squeezy, yellow stars), and taught coping strategies (e.g. progressive muscle relaxation and breathing techniques), which participants reported as helpful in managing the situation. Another technique, which could be employed to reduce patient anxiety, is the use of open instead of closed masks. Especially as there is evidence to suggest open masks can significantly improve patient comfort whilst maintaining the level of accuracy required[26].

As well as coping strategies, participants emphasised the importance of having support. In alignment with previous research[10,20], our participants shared that having friends and family accompany them to

appointments provided comfort. Others found reassurance in sharing similarities in experiences with fellow patients in the waiting rooms, a finding supported by Forbes et al.[9]. As in other studies, many participants expressed gratitude to the staff for their continual reassurance and support, which was needed to cope with treatment[27]. Our participants reported specifically that having either the RADs or CALMs team speaking to them over the intercom was important in alleviating anxiety whilst having the mask in place, which has been previously reported[4]. Of those participants who received specialist support from the CALMs team, many of them expressed they would not have been able to get through the treatment without this intervention. Other researchers[20] have reported patients receiving support from the clinical team or psychological intervention[28,29]. This validates the importance our participants placed on the support they received from professionals whilst undergoing radiotherapy with the mask, as does the recommendation from Nixon et al.[30], that patients who require an immobilisation mask for treatment should have access to healthcare professional intervention.

Although not applicable to all the participants interviewed for this study, some went through their treatment during COVID-19, which added an extra layer of anxiety to their experiences. Whilst, in line with previous research[31], participants did not feel their treatment and care was impacted by COVID-19, several reported their struggle with not being allowed a loved one with them during appointments and treatment. This further emphasises the points made above regarding the importance of support and is consistent with prior research[32], plus isolation and loneliness have previously been reported to have been a problem for cancer patients during the pandemic[33].

Our findings add additional information to highlight the experiences and significant impact of using an immobilisation mask during HNC treatment, and in particular the potential for this impact to be long-lasting. Applying the Transactional Model of Stress and Coping[19] in practice offers several opportunities to reduce distress. Pre-treatment interventions such as providing more information about what patients should expect could potentially help to alleviate some of the patients' concerns. Similarly, providing patients with coping techniques ahead of their treatment would also be beneficial. Our participants have identified several recommendations, which could be put in place to improve the experience of future patients and are shown in Tables 2 and 3.

As has been highlighted by previous researchers[34], the availability of a screening tool would facilitate identification of patients who may struggle with treatment and would therefore benefit from additional interventions. The screening tool would include questions to help identify latent claustrophobia in patients who may not have experienced it before. The Transactional Model of Stress and Coping[19] emphasises the need for constant re-appraisal as patients' experiences may change over the course of their treatment. It highlights that patients' experience with the mask is not fixed and can change depending on the coping techniques they use and the support provided. Interventions currently offered at the study site include stress management techniques, use of 'squeezy stars' and exploration of the process of the mask making. Lack of perceived control can trigger a claustrophobic response/mask anxiety, so ensuring that the patient understands that they are in control and can 'pause the process' at any time is important. Reassurance that patients will be able to breathe wearing the mask and inviting them to 'choose to be still' rather than focusing on the immobilisation aspect of wearing the mask have also been identified as important to the patients. At present, support offered is on an organisational level, with no national standards of care.

Table 2. Patient recommendations to help reduce distress during mask making and treatment.

PT ID	Patient recommendations
PT 03, 11, 17, 18, 19	Staff talking over the intercom
PT 03, 11, 13	Staff letting a patient know the precise time they have left
PT 05	Cutting open the mouth and nose holes if possible
PT 05, 09, 11, 12, 13, 16, 17, 18	Provide music for patients
PT 05	Counting your fingers and toes
PT 08, 11, 12, 13, 17, 18	Take a loved one with you
PT 09, 18, 19	Bigger treatment room with windows
PT 09, 14, 17, 18, 19	Using the yellow stars
PT 14, 17, 18, 19	CALMs team for everyone having a mask
PT 17	Heated tables/blanket (cold on the table)

Table 3. Patient recommendations for improving the information they receive about mask making and treatment.

PT ID	Patient recommendations
PT 05, 08, 11, 19	Videos of the mask making
PT 05,18	Leaflets of the mask
PT 05	Videos of patients who have claustrophobia and manage to get through the treatment with the mask
PT 08, 17, 19	See a mask before treatment
PT 08, 11, 13	Staff to take more time to explain what is happening
PT 11, 17, 19	See the radiotherapy machines
PT 11, 19	Video/seeing the radiotherapy room

Limitations

It is acknowledged that in qualitative research, personal biases cannot be eliminated. However, we maximised impartiality and increased methodological robustness. The mean age of the study cohort was 58.8 years, 72.2% were males and 88.9% were of British ethnicity, thus limiting the generalisability of our results. Recruitment of a more diverse sample group may have strengthened our findings; however, the sample was reflective of the clinical cohort of patients. A further limitation is the potential for recall bias; interviews were conducted 6–12+ weeks after the end of their treatment, meaning participants' memories, feelings and perceptions may have changed.

Future work

The data presented here and that from previous studies would indicate there needs to be increased focus on improving and standardising supportive care offered to HNC patients undergoing radiotherapy. Development of educational packages for staff and patients addressing the concerns and suggestions highlighted in this data, for example, would facilitate improved standards of care across organisations and be of significant value within this field.

Of equal importance is the identification of patients at high risk of experiencing significant levels of distress due to mask anxiety, prior to the commencement of treatment. Despite recognition of the issue, there is minimal literature focused on addressing the problem. There is a need for a screening tool so that patients who may struggle to tolerate treatment can be identified prior to radiotherapy and appropriate support can be put in place. The next stage of our work, item generation and initial reliability and validity testing for such a screening tool using data from this study, is currently underway. The aim of the next study will be to look at the reliability and validity of the resultant tool, in a larger study.

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Conclusions

Our findings provide important insights into patients' experiences of wearing the immobilisation mask throughout their course of radiotherapy and validate the findings of others. We identified potential anxiety triggers, including emotional and physical contributors, a range of coping strategies and the need for support. Participants provided us with recommendations to make their experience less traumatic (see Tables 2 and 3). Pre-identification of anxiety triggers and patients vulnerable to higher levels of anxiety is essential to enable support and interventions to help people get through their treatment. This study is the first step in developing a screening tool to do this and thus facilitate more consistent and timely interventions.

Ethical statements

The study was conducted in accordance with the Declaration of Helsinki, and the protocol was approved by the Greater Manchester South Ethics Committee (Identification Number: 20/NW/0264, Approval Date: 07/07/2020). Written informed consent was obtained from all participants prior to enrolment. Participant data were anonymised and handled in compliance with applicable data protection regulations

Author contributions

The authors confirm contribution to the paper as follows: study conception and design: Mehrez A, Stringer J, Yorke J; data collection: Mehrez A, Hopper D, Stringer J; analysis and interpretation of results: Mehrez A, Hopper D, Punett G, Stringer J, Yorke J, Taylor S; draft manuscript preparation: Mehrez A, Hopper D, Punett G, Stringer J. All authors reviewed the results and approved the final version of the manuscript.

Data availability

The datasets generated and/or analyzed during the current study are available from the corresponding author on reasonable request.

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Conflict of interest

The authors declare that there is no conflict of interest regarding the publication of this article.

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