

Qualitative development of Head & Neck cancer Patient Reported Experience of Radiotherapy with focus on Restriction Anxiety and 'Claustrophobia' (H&N-PRER-RAC)



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Purpose/Objective

Patients with head and neck cancer (HNC) who undergo radiotherapy can experience high rates of anxiety compared to those with other cancers, with up to 26% reporting moderate to severe distress (Nixon et al, 2018). Radiotherapy immobilisation masks are tight-fitting, cover the face and shoulders and are fixed to the radiotherapy couch (see figure 1).

The use of the immobilisation mask whilst critical for treatment, can be very challenging for patients with anxiety or feelings of claustrophobia (Nixon et al, 2018). Although it is recognised that mask-related anxiety and distress can impact patients' treatment decisions and cause disruptions to treatment (Keast et al, 2018), there remains a paucity of research into patients' experience and strategies to manage mask-related anxiety.

The aims of this study were to: (1) explore patients' experience of preparing for and completing radiotherapy utilising an immobilisation mask, (2) identify themes related to 'claustrophobia' and mask-related anxiety, with a view to developing items for a short screening questionnaire.

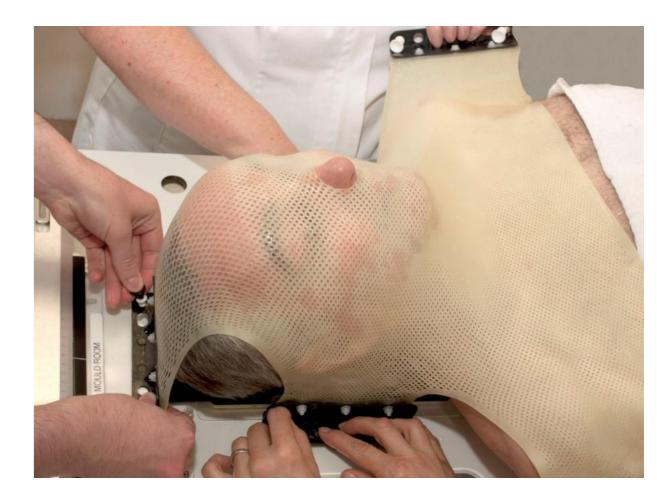
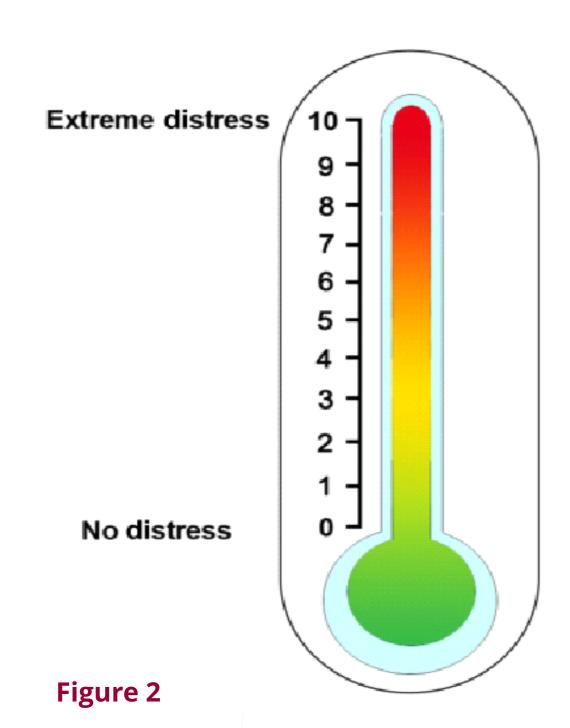


Figure 1



Methods

This was a qualitative study to better understand patients' experiences of wearing an immobilisation mask during radiotherapy. At stage I semi-structured interviews were conducted with patients who had completed radiotherapy for HNC utilising a mask completed 6-12 weeks prior to interview. At the beginning of each interview, participants were also be asked to complete an Adapted Distress Thermometer (ADT) (scaled 0 (no distress) to 10 (severe distress)) reflecting back on distress experienced during their mask making (see figure 2). The interviews captured their experiences and views pertaining to mask making, scans and radiotherapy, reported associated fears of restriction, suffocation, loss of control and fear of public embarrassment during treatment. Thematic analysis (Braun & Clarke, 2006) was conducted to analyse interviews using NVivo. An inductive approach was taken, with codes created from the data rather than using a pre-conceived coding framework. At stage II 5 cognitive interviews have been completed and analysis continues.

Results Interviews:

A total of 18 interviews were conducted (males 13, female 5; mean age 59).

6 themes were generated from the data with 28 subthemes (see table 1.)

Adapted Distress Thermometer:

Of the 18 participants, 6 (33%) graded their distress during treatment as 10/10 and 13 (72%) participants had scores of >5, with a score ≥4 acknowledged by the NCCN guidelines as requiring further management of distress (NCCN, 2019).

Conclusion

The data from the interviews has generated 6 themes, multiple subthemes and emotive quotes, which will be used to create potential items for a future screening tool for mask-related anxiety. The data from the ADT has emphasised the significance of distress as a concept for this cohort of patients. In addition to validating the importance of this field of research, distress and its management will be further explored in future work.

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Table 1

Themes	Subthemes	Example Quotes
Emotional Experience	Anxiety, Claustrophobia, Control, Panic, Fear, Thankful, Habituation, Shame, Relief	'It was just I'm trapped down here and how quickly could they get me out of it if I did reach that stage.'
Information	Desired information, Information helps, Information received, Expectations	'I didn't understand about the mask. I had no idea whatsoever what this mask meant or what it was.'
Coping	Coping strategies, 'It has to be done', Seeing the end helps, Relationship with the mask, Passive & compliant	'I just knew I had no alternative. It was a question of head down, deal with it and that's how I had to embrace it.'
Support	Advise for staff to make experience better, Informal caregiver support, Shared experience, Support provided by staff	'Again with my son's experience, my son's mask was so tight they actually had to have the eyes cut out because of the pressure above his eyes so I knew about that'
Physical Experience	Comfort, Side effects	'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'
Environmental Experience	COVID, Waiting room is 'oppressive', Treatment room made experience worse	'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'

References

1.Braun, V. and Clarke, V., 2006. Using thematic analysis in psychology. Qualitative research in psychology, 3(2), pp.77-101.

2.Keast, R., Sundaresan, P., Burns, M., Butow, P.N. and Dhillon, H.M., 2020. Exploring head and neck cancer patients' experiences with radiation therapy immobilisation masks: A qualitative study. European Journal of Cancer Care, 29(2), p.e13215.

3.National Comprehensive Cancer Network. (2019). NCCN Clinical Practice Guidelines in Oncology: Distress management. v2.2019.
4.Nixon, J.L., Cartmill, B., Turner, J., Pigott, A.E., Brown, E., Wall, L.R., Ward, E.C. and Porceddu, S.V., 2018. Exploring the prevalence of mask anxiety for the person with head and neck cancer undergoing radiotherapy. Journal of medical radiation

4.Nixon, J.L., Cartmill, B., Tur sciences, 65(4), pp.282-290.