

Patients understanding, perceptions and experiences of head and neck lymphoedema management following treatment for head and neck cancer: a qualitative study.

Ms. Lauren J. Mullan (Ulster University), Dr Nicole E. Blackburn (Ulster University), Dr Jackie Gracey (Ulster University), Dr Lynn Dunwoody (Ulster University), Ms. Jill Lorimer (BHSCT) and Professor Cherith J. Semple (Ulster University/SEHSCT).

Contact: Mullan-L1@ulster.ac.uk



Background

Head and neck lymphoedema (HNL) is increasingly identified as a common, unintended chronic consequence following treatment for head and neck cancer (HNC).^[1,2] Post-treatment, HNL affects up to 90% of patients and is often debilitating.^[3,4] Due to the propensity and chronicity of HNL, it is important to explore how patients engage in self-management.^[5,6]

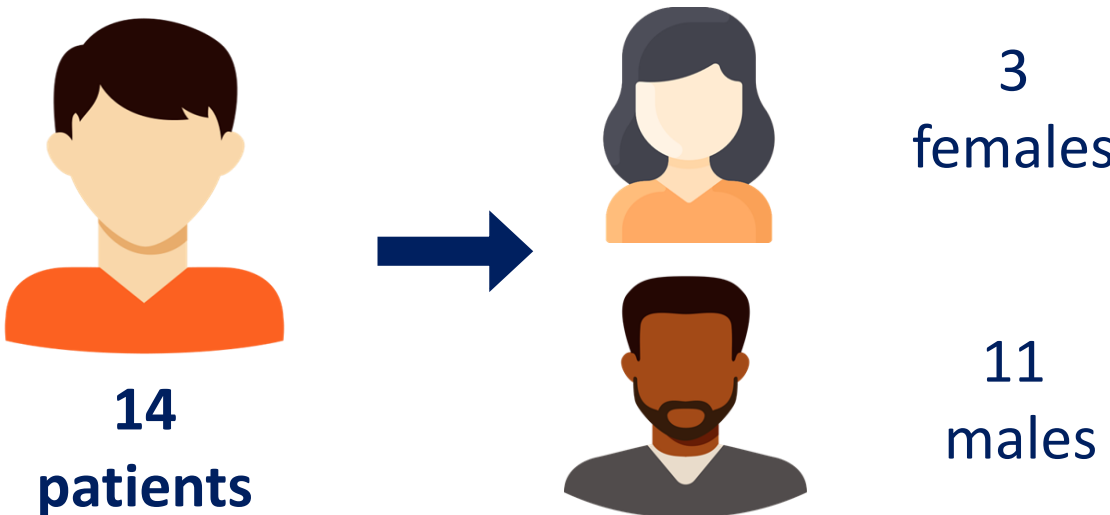
Aim

Explore patients' understanding, perceptions, and experiences of HNL management following treatment for HNC, to promote HNL self-management and adherence.

Methods



Across three healthcare trusts, 25 potential participants were identified by local collaborators. In total, n=14 provided written consent.



One-to-one semi-structured interviews were conducted (n=14) with HNL patients who had completed treatment for HNC. Key themes were developed using reflexive thematic analysis.^[7]

Results

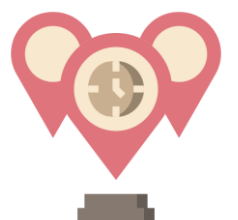
Findings were reported as **two main themes**:

THEME 1: “Maximising patients’ competency to self-manage HNL”



Lack of understanding and knowledge surrounding HNL and management.

Desire for **basic and early information** avoiding medical jargon.



Tailored information at **multiple time points**.

Patients benefitted from **reassurance** from HCPs and family.

THEME 2: “Adherence to HNL self-management – what makes a difference?”



Physical barriers: compression, discomfort, pain, and fatigue.



Objective improvements helped promote motivation.



Gratitude for being alive facilitated coping with HNL.

Establishing a routine was promoted as a coping strategy – accepting a new normal.

Timely access to a HNL specialist when concerns arose.

Conclusion

NEED for clear and consistent information, lacking medical jargon, across multiple timepoints.

DESIRE for dedicated information and resources for HNL self-management.

BENEFITS of receiving positive reassurance and information from a specialist therapist to develop self-management skills.

