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Title: Patients understanding, perceptions and experiences of head and neck lymphoedema management post-treatment for head and neck cancer.

Body: Background

Head and neck lymphoedema (HNL) affects up to 90% of patients following treatment for head and neck cancer (HNC) and is often debilitating. Due to the propensity and chronicity of HNL, it is important patients engage in self-management. This study explores patients understanding, perceptions and experiences of HNL management to promote self-management and adherence to HNL interventions.

Methods

Fourteen one-to-one semi-structured interviews were conducted with patients following HNC treatment. Using reflexive thematic analysis, key themes were inductively developed.

Results

Themes established were: (1) Maximising patients' competency to self-manage HNL" and (2) "Adherence to HNL self-management: What makes a difference?". Participants advocated for basic information early, with tailored instructional support as HNL presented, enabling self-management. For initial skills training, patients relied on positive reassurance, informed by objective assessment, from specialist HNL therapists, fostering motivation and adherence. Key barriers included lack of understanding towards causation and appropriately timed, tailored educational opportunities.

Conclusion

There is a need to raise awareness of HNL and its chronicity, to promote motivation regarding self-management. Development of a range of tailored HNL educational resources addressing variation in patients' learning styles, grounded by patients' perspectives, presented at multiple time-points is required to

Authors: Ms. Lauren J. Mullan (1), Dr Nicole E. Blackburn (2), Dr Jackie Gracey (2), Dr Lynn Dunwoody (3), Ms. Jill Lorimer (4), Professor Cherith J. Semple (1,5).

Affiliations: 1 - School of Nursing, Institute of Nursing and Health Research, Ulster University, Belfast, United Kingdom. 2- School of Health Sciences, Institute of Nursing and Health Research, Ulster University, Londonderry, United Kingdom. 3- School of Psychology, Faculty of Life and Health Sciences, Ulster University, Londonderry, United Kingdom. 4 - Physiotherapy Department, Cancer Centre, Belfast Health and Social Care Trust, Belfast, United Kingdom. 5 - Cancer Services, South Eastern Health and Social Care Trust, Belfast, United Kingdom.