The healthcare experiences of people with head and neck cancer: A scoping review

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Introduction*

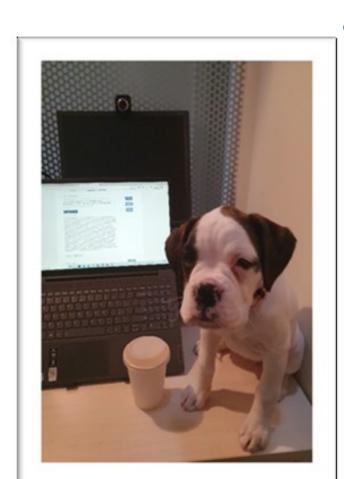
Over the last 20 years, there have been significant developments in head and neck cancer (HNC) practice including transoral robotic surgery, increased understanding of HPV-mediated disease, and advances in non-surgical treatments. Parallel to these advances, there a growing focus on patient healthcare experience, emphasising patientcentred care. Patient experience covers interactions with the health system, shaping patients' perceptions of healthcare. Good patient experience enhances safety, effectiveness, and service outcomes. Given changes in HNC treatments and patient demographics, updating our understanding of HNC health care experience is crucial. Components like pretreatment intervention, connection with professionals, education, and needs assessment shape this experience. The 'Optimal Care Pathway For People With Head And Neck Cancer' outlines the health care pathway for people with HNC in Australia. The pathway supports patients and carers, health systems, health professionals and services, and encourages consistent optimal treatment and supportive care at each stage of a patient's journey. Patient perspectives play a key role in improving patient experience, yet what is known in terms of people with HNC healthcare experiences is yet to be synthesised.

Aims

The primary aim was to review literature on self-reported HNC patient experiences. The secondary aim was to describe the source and breadth of qualitative research on this topic.

Methodology

- Followed methods for PRISMA Scoping Reviews
- Searched databases for articles on HNC + healthcare experiences + Qualitative
- Extracted data on:



Database assistant fuelled by coffee

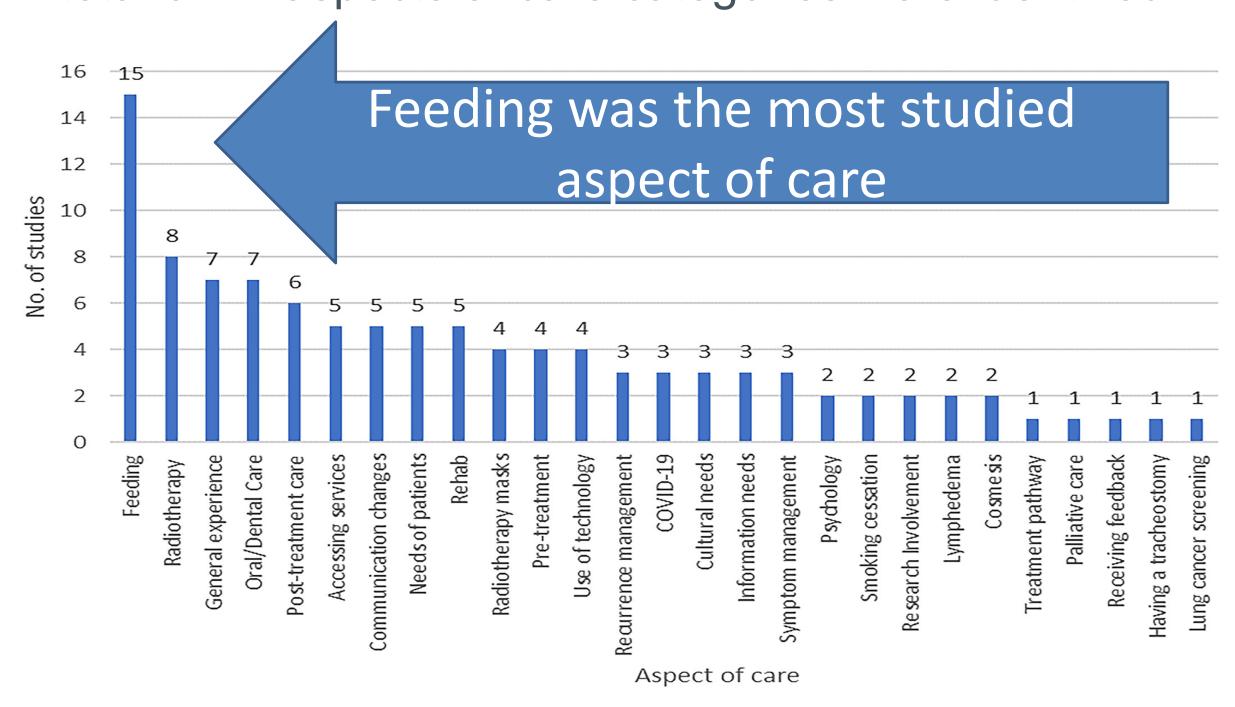
Study demographics (e.g., country/author profession)
Participant demographics
Where the study occurred in the *HNC optimal care pathway* (e.g., pre-tx, during, post-tx etc)
Aspect of care the study focused on (e.g., PEG/Xerostomia/radiotherapy/smoking cessation etc)

Methodology/methods used

Results

A broad range of studies (n=95) showed:

- Most studies looked at treatment phases but not many on pre-tx, post-tx or palliative care
- Most studies (n = 91) were conducted in hospital services, including ambulatory care and private clinics
- Mostly from developed countries
- Generic qualitative research design predominated (60%) with interviews as the main method of data collection
- A total of 27 aspects of care categories were identified:



Only two studies had a specific aim of investigating the health care experience of people with altered communication, in fact more studies reported excluding people with significant communication issues:

- Excluding people with communication changes from research studies limits our capacity to understand how this group, with their associated additional vulnerability in the health care system, experience their HNC specific health care.
- This is particularly important as HNC impacts significantly on communication.
- People with communication difficulties may value different or additional aspects of health care.

So what's next?

We are currently conducting with EMF support:
Interpretative Phenomenology Analysis research on the healthcare experiences of people with HNC and communication changes, their families, and healthcare professionals. This body of research will help us understand the HNC Australian healthcare experience when people have communication changes to make recommendations to enhance care for this population.



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