



# Elucidating the Experience of Head and Neck Cancer Care in Focus Groups with Patients and Caregivers

when it matters MOST

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# Background

- Head and neck cancer (HNC) is associated with increased patient distress presenting as:
  - Depression
  - Anxiety
  - Stress (Calver et al., 2019)
- Patients with HNC face unique physical, functional, social, and psychosocial challenges during treatment course that impact quality of life (QOL)
- Person centered care approaches increase a team's capacity to address a patient's unique set of symptoms, mitigate distress, and improve QOL

# Study Aim

• To elucidate the patient experience of treatment of OUTCOMES & LESSONS LEARNED HNC with a focus on actionable recommendations for clinicians to improve the provision of person centered care

### Methods

- Three focus groups were held with a total of n=13 participants (9 patients, 4 caregivers)
- Focus groups were audio-recorded and transcribed verbatim
- Inductive thematic analysis of transcripts was conducted by two reviewers using NVivo Data Management Software

#### Results

hurt."

Three overarching themes emerged from the analysis:

"[...] I had someone offer me a blanket in the hallway [...] I would say consistently and overall, the empathy from the staff was unbelievable. [My family and I] never felt like we were in the hospital in this building."

#### Psychosocial Factors

- Coping Mechanisms
- Support
- Stigma

**Experience of Care** 

- Symptom Management

- Uncompassionate Care

- Compassionate Care

"I would be willing to sign up for something like [peer support]. I think something like 'hey here is my number if you want to talk.' I think that would have been helpful."

> "It's the culture to man up, that's a bloody shame."

**Patient Perception** 

- Personal Barriers

- Feedback

- Hospital System

"There should have been more information, they should have sat you down and explain[ed]. I had to do research on my own. There's stigma around it still."

(empathy, trust) - Comprehensive Care

- Communication

"The environment had a sense of compassionate and control. It had the sense [that] people knew exactly what they [were] doing, how they were doing it. What astounded me at my first chemotherapy session was the layers of security [...]"

"I didn't ask enough questions [about

chemotherapy], but I didn't know what

questions to ask either. So, the first time at

chemotherapy, I was pretty nervous [and] a little

bit agitated because I wasn't sure if it's going to

- Many patients expressed a desire to be acknowledged as part of the team rather than just "as a number" or even just "a patient" consistent with recommendations for using a PCC approach
- Importance of effective communication between patients and healthcare providers was evident across categories
- Patients reported being uninformed about the availability and accessibility of psychosocial support

# Discussion

- This study provided insight into the experiences of HNC patients and identified treatment preferences and needs
- Major themes emerged/were identified that can inform clinical practice and in turn, enhance quality of care, as defined by both patients and caregivers
- Three key that impacted quality of care for patients were interactions with healthcare providers, perceived compassionate care, and effective communication
- Actionable elements should include more opportunities for face to face interaction, and the development of effective patient-physician rapport so patients are properly informed
- Future research could involve interventions to facilitate psychological adjustment for HNC patients to improve quality of life and reduce distress