UNDERSTANDING THE HEALTHCARE PRIORITIES OF LIVING WITH INCURABLE HEAD AND NECK CANCER

WHY THIS RESEARCH WAS IMPORTANT

- Patients with incurable head and neck cancer can experience pain, swallowing, and speech difficulties.
- Their symptoms can be unpredictable, making daily life challenging for both patients and their families.
- Incurable head and neck cancer patients often have to attend hospital multiple times.
- They are twice as likely to have multiple emergency hospital visits compared with people with other cancers.

WHERE WE COME IN

We wanted to **understand the most pressing issues for patients** living with incurable head and neck cancer –where things do not go as planned in their healthcare journey –and try to find possible solutions

WHAT WE DID

- We interviewed **18 incurable head and neck cancer patients** every four months to understand their healthcare experiences.
- We included **family members in interviews**. Some were interviewed after the patient had died.
- We held **group discussions with 23 healthcare workers** who work in head and neck cancer.
- We **ran 3 workshops** (1 online, 2 in-person) with a mix of healthcare workers and head and neck cancer patients or carers to discuss our findings, prioritise and generate solutions to the issues.

WHAT WE FOUND

Our study found great variation in the care received. These differences affected patients' well-being, treatment experiences, and overall quality of life.

NAVIGATING THE SYSTEM

- Some patients were uncertain about who to call, especially in emergencies.
- For others, having contact information for key specialists and the option to use alternative communication methods like WhatsApp helped them navigate the system.

SUPPORT FOR FAMILY CAREGIVERS

- Many caregivers felt overwhelmed and unprepared to handle the complex care needs of their family member.
- Those who received training, emotional support and knew who to call for help felt more capable and confident in their role.

INFORMATION & COMMUNICATION

- Some patients felt they received too much, too little, or confusing information about their condition and treatment.
- Others appreciated clear, well-timed updates that helped them make informed decisions about their care and future.

GETTING MEDICINES

- Some patients faced frustrating delays and miscommunications when trying to access important medications.
- Others had a much smoother experience when processes were in place (e.g. good communication and coordination with pharmacies) to prioritise patients affected by incurable cancer.

RECOMMENDATIONS TO IMPROVE CARE

- Ensure that **every patient and family caregiver has a list of key contact information** for healthcare workers.
- This list should include **an explanation of their roles, who does what, and who to call for advice and when they are available for support.**
- **Empower Caregivers:** Provide better training and emotional support for caregivers.
- **Improve Communication:** Deliver timely and person-centred information to patients and their families when they need it.
- System level solutions are needed to address issues relating to medication supply.

NEXT STEPS

Develop research into the two priorities identified in our workshops: 1) supporting patients when they move from the hospital to their home, and 2) ways to better prepare and support family caregivers.

WOULD YOU LIKE TO KNOW MORE?

If you want more information about the study, please visit our website at https://www.sheffield.ac.uk/palliativeresearch/ii-hanc

You can also engage on our social media platform @iiHANC on X

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