The Harsh Realities of the Journey: A Pilot Study of Patients and Carers Experiences and Reflections of Advanced Head and Neck Cancer

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BACKGROUND

At the time of diagnosis of advanced head and neck cancer, the overwhelming priority for patients and carers is survival (1). Treatment for curative intent, however, is radical and the options are associated with treatment burden and toxicity. Additionally, quality of life outcomes are relatively poor and associated with many difficulties including anxiety, depression, speech impairment, swallowing difficulties and loss of social interaction (2). Physical and/or psychological distress can also be experienced by patients’ carers and be related to the care-giving responsibilities for which they are not prepared.

AIMS

To explore patients and carers experiences relating to treatment, outcomes and decision-making for advanced head and neck cancer (AdvHNC) patients having radical treatment with curative intent.

To identify information that may be used to assist future decision-making for cases of AdvHNC.

METHODS

A purposive sample of patients with AdvHNC receiving curative intent treatments, and their carers, were recruited from a tertiary centre hospital in England. Twenty-eight were approached and 8 agreed to participate. Semi-structured interviews (patients n=7, carers n=5 and 1 joint-patient/carer) detailing treatment decision-making, treatment outcome and management of care were digitally recorded and transcribed verbatim. Thematic analysis was conducted, using Colazzi’s seven step framework for guidance (3), to identify key themes emerging from transcriptions.

RESULTS

The four themes identified were:

1. Decision-making and the process of reaching this decision: degree of clarity about information given and the impact this has on joint decision-making.

2. Barriers faced when seeking timely information: depth and timing of information needed to manage treatment burden and subsequent impact.

3. The challenges to establishing effective support networks: in terms of long treatment journeys and perceived lack of support outside of specialist centres.

4. The harsh realities of the treatment journey: a range of hidden costs such as financial and emotional costs and impact on family life.

REFERENCES

