



Exploration of family members perceptions of an online resource to provide information and support for patients with head and neck cancer and their informal carer

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Can an online resource meet the unique needs of head and neck cancer patients and their relatives: the family members perspective

Prof Cherith J. Semple & Angela McKeever



Introduction

Multi-modality treatment for head and neck cancer (HNC) results in survivors experiencing life-altering, long-term biopsychosocial issues affecting quality of life (Crowder et al 2021). Family members (FMs) are pivotal support providers; playing an integral role in delivering care, support and guidance for HNC patients.

Availability of the internet has enabled HNC patients and FMs to increasingly access more information, exploring it at their own time and pace; promoting understanding and coping (Hesse et al 2016). Current websites provide minimal patient and family-centred information to promote shared decision-making and ensure preparedness for HNC treatments (Kelly et al 2022).

Aims of the study

To explore FMs' perceptions of how an online resource could inform decision-making and provide post-treatment support for patients with HNC cancer and their relatives.

Methods

Research design

A qualitative research design was employed, using semi-structured one-to-one interviews between March-May 2022. This study was underpinned by Engel's (1977) biopsychosocial model.

Data collection

A topic guide informed by literature and developed by research steering group, guided one-to-one interviews (zoom n=3, telephone n=10). Interviews were digitally recorded and transcribed verbatim. Reflective notes were taken.

Data analysis

Using reflexive thematic analysis (Braun and Clarke, 2020), data were initially coded. Then utilising a mind mapping technique, themes were generated and refined during team discussion.

Results

A total of 13 participants were recruited, with the following sample characteristics:

Age range = 36 - 73yrs old

Gender = 10 female, 3 male

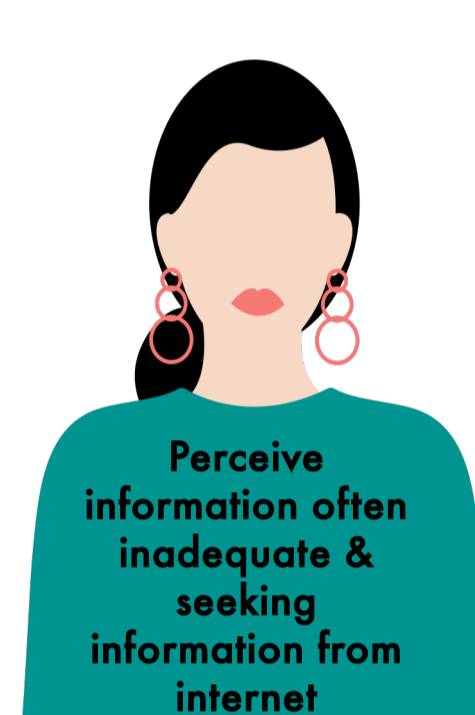
Relationship to patient = 9 spouses / 4 daughters

Primary treatment = Surgery 12 / radiotherapy (XRT) 1

Adjuvant treatment = Chemo/XRT 9

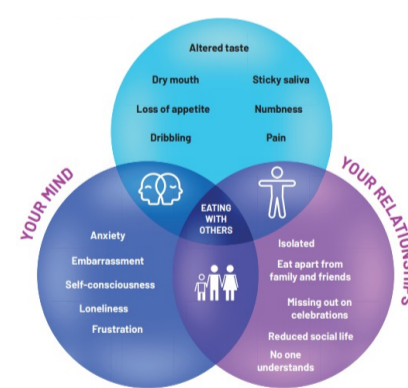


4 key findings from family members data:

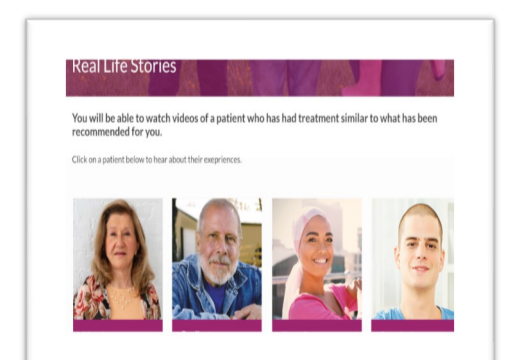


Components within an online resource

Biopsychosocial content



Psychological support



Discussion

At diagnosis, FMs desire realistic information on post-treatment expectations and prognosis to support patient decision-making. An online resource should include HNC specific information, addressing eating & drinking problems and body image.

Patient and FM video narratives were advocated to encapsulate real-life experience. FMs experience significant levels of distress and guilt, indicating a need for psychological support to be embedded within an online resource.

Conclusion

An online resource should be co-designed with patients and FMs, informed through a biopsychosocial lens. Integrating patient and FM video narratives would help contextualise information, enhance understanding, promote preparedness for treatment and encourage self-management.

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