

Exploring the psychological and psychosocial effects of facial disfigurement on the lived experience of head and neck cancer patients: A structured literature review by Lesley MacLeod

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Introduction: Living with facial disfigurement following treatment for head and neck cancer can cause significant difficulties in the everyday lives of patients; physically, emotionally, psychologically and psychosocially. This structured literature review used descriptive meta synthesis to explore the lived experience of people affected by altered appearance. It highlights the importance of open dialogue with health professionals, access to information, social support and acceptance in enabling people to adjust to their changed appearance and reintegrating into society.

Aims: to explore the psychological and psychosocial effects of disfigurement on the lived experience of head and neck cancer patients.

Method: A search of two recognised high quality databases suitable for qualitative evidence (CINAHL, MEDLINE) using search terms relevant to head and neck cancer, lived experience, facial disfigurement. Four studies were chosen for the SLR and synthesised using descriptive meta synthesis to highlight common themes and concepts.

Results: Despite the research being carried out in various geographic locations there was similar experiences in the lived experiences of the participants. As a head and neck cancer patient myself my lived experience also echoed those experiences. Three main themes were identified in the lived experience of people with altered facial appearance. The main themes common to all papers were “disease and disfigurement”, “loss of self” and the “social world”. “Disease and disfigurement” relates to diagnosis, relationship with HP, impact of disfigured and fear of recurrence. “Loss of self” relates to feeling you have lost self, stigma and rebuilding a “new self”. The last central theme is the “social world” which explores the impact of disfigurement on reintegrating into society, the reactions of others and developing coping strategies.

Conclusion: There is currently a paucity of research looking at the lived experience of HNC patients post treatment. The overall findings from the review highlight how important social support and acceptance are in helping in HNC Patients adjust quickly to their changed appearance and functional deficits such as eating and speaking. Given the complexity and range of potential difficulties experienced by patients an individualised needs assessment should be carried out in order to determine their unmet needs and to give them the opportunity to discuss concerns about their disfigurement without stigma. In addition, given the improvement in survival it is important that healthcare professionals are educated to deal with the issues that affect the everyday lives of patients.