

The Experience of Taste Changes during Radiotherapy for Head and Neck Cancer: A Mixed Methods Study

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Background

Problems tasting food is a common side effect of radiotherapy and chemo-radiotherapy for head and neck cancer. Up to 95% of these patients experience taste changes leading to malnutrition, increased rates of tube feeding, hospital admissions and reduced quality of life. Some patients are able to carry on eating despite taste changes whereas others report that everything tastes awful and stop eating becoming dependent upon a feeding tube for their nutrition. This study aims to understand the experience of taste changes during treatment for head and neck cancer including why some patients carry on eating when food tastes awful whereas others stop; what helps to manage their taste changes and what motivates them to continue eating despite food tasting bad.

Methods

This study uses a mixed methods approach supported by a critical realist framework to investigate the experience of taste changes during radiotherapy for head and neck cancer. The mixed methods approach has enabled a full exploration of the experience of taste changes as well as measuring their extent and when they arise during treatment. A participant self-report questionnaire, the MD Anderson Symptom Inventory-Head & Neck (MDASI-HN) and semi-structured interviews were used for data collection. Participants who scored 5 or greater for problems tasting food in week 4 were considered to have moderate to severe taste changes. Sixty-one participants completed the MDASI-HN questionnaire in weeks 1 and 4 of treatment, with a purposive sample of 21 participants taking part in a semi-structured interview to discuss their experience of taste changes. The interview focussed on their experience, timing of taste changes, how participants managed taste changes and what motivated them to continue eating if they were.

Results

Seventy-seven percent of participants having radiotherapy and 88% of participant having chemo-radiotherapy scored 5 or greater for problems tasting food. Thirty-seven percent of participants reported problems tasting their food by the end of week 1 of treatment which was earlier than they had been informed to expect them. Participants having chemo-radiotherapy for oro-pharyngeal cancer (88%) were the group most likely to experience taste changes, although participants with all head and neck cancer diagnoses reported taste changes. Females (92%) were more likely than males (75%) to experience taste changes. Participants who continued eating managed taste changes with a combination of determination, good symptom management, sharing the burden with family members and or healthcare professionals and possessing the ability to accept and adapt to their situation. Strong survival instinct, fear of losing their swallow function and avoiding tube feeding were strong motivators for those who continued eating.

Conclusions

There was no association between recording a high score for problems with tasting food on the MDASI-HN and continuing to eat. Patients with all head and neck cancer diagnoses are at risk of developing taste changes.

Patients require accurate information regarding the timing of taste changes, what they will be like, and how long their taste might take to recover, to avoid unnecessary distress. Healthcare professionals need education to provide this information.