Development and validation of the Significant Other Scale for Eating in Head and Neck Cancer (SOSE-H&N)

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Abstract

Background: Emerging research has documented distress and reduced quality of life in carers of people with dysphagia following head and neck cancer (HNC). Currently, there are no tools available to health professionals to identify those carers requiring further education and support regarding the pervasive effects of dysphagia. The aim of the current study is to develop a psychometrically sound instrument to identify and measure the effects of dysphagia in HNC on carers.

Methods: A mixed-methods approach was utilised to develop and validate the Significant Other Scale for Eating in Head and Neck Cancer (SOSE-H&N). In phase 1, 38 carers took part in either individual or focus-group interviews to elucidate the most important issues regarding living with or caring for someone with dysphagia. Following phase 1, concepts identified were operationalised into the SOSE-H&N. Phase 2 involved cognitive interviews with both carers of people with dysphagia in HNC and health professionals in order to ensure preliminary face and content validity. The final phase involves the administration of the SOSE- H&N with approximately 100 carers to determine its validity and reliability.

Results: Thematic analysis in phase 1 identified five general areas of importance which included 19 categories and 26 sub-categories. These categories and sub-categories were operationalised into a 33 item instrument, the SOSE-H&N. Data collection to determine the validity and reliability is currently ongoing.

Conclusions: The development and validation of a psychometrically sound instrument will enable the identification of carers of people with dysphagia following HNC who require supportive services. This could lead to more timely services for carers and provide more targeted support for their essential role in patient care.