



**Karolinska
Institutet**

Institutionen för lärande, informatik, management och etik

Characteristics of taste and smell alterations in patients treated for lung cancer: translation of and results using a symptom specific questionnaire

AKADEMISK AVHANDLING

som för avläggande av licentiatexamen vid Karolinska Institutet offentligen försvaras i Aulan, Stockholms sjukhem, Mariebergsgatan 22, Stockholm

Fredagen den 11 oktober, 2013, kl. 10.00

Jennifer McGreevy

Legitimerad dietist

Huvudhandledare:

Med Dr Britt-Marie Bernhardson
Karolinska Institutet
Institutionen för lärande, informatik,
management och etik,
Medical management centre

Bihandledare:

Professor Carol Tishelman
Karolinska Institutet
Institutionen för lärande, informatik,
management och etik,
Medical management centre

Med Dr Ylva Orrevall
Karolinska Institutet
Institutionen för lärande, informatik,
management och etik,
Medical management centre

Betygsnämnd:

Docent Elisabet Rothenberg
Göteborgs Universitet
Sahlgrenska Akademin
Institution för medicin
Avdelningen för invärtesmedicin
och klinisk nutrition

Professor Gerd Ahlström
Lund Universitet
Medicinska fakulteten
Institutionen för hälsa, vård och samhälle

Professor Roger Henriksson
Umeå Universitet
Institutionen för strålningsvetenskaper

Stockholm 2013

ABSTRACT

Background: Taste and smell alterations (TSAs) have been found to be common and distressing symptoms for patients with cancer. TSAs may also relate to other symptoms affecting food consumption and contribute to poor nutritional intake. Evidence-based knowledge to guide healthcare staff in identification and management of TSAs is lacking. Patients with lung cancer have been reported to perceive TSAs but these alterations are poorly understood.

Aim: This thesis explores the characteristics of TSAs in a lung cancer population from data obtained using a questionnaire translated and culturally adapted for the purpose.

Methods: Two studies are included in this thesis. The first study uses a 5-step method for translation and cultural adaptation of the Taste and Smell Survey (TSS) for use in a Swedish population. The second study uses the translated TSS to explore the characteristics of TSAs reported by patients after starting treatment for lung cancer and to elucidate how patients describe their TSAs. This study also explores how TSAs relate to demographics, nutritional intake, six-month weight change and other symptoms.

Results: The process for translation and cultural adaptation of the TSS produced a robust instrument in Swedish. Each of the 5-steps contributed information enhancing the quality of the translation, emphasising the value of using a multi-step process. Using the translated TSS, 61 out of a sample of 89 patients with primary lung cancer were found to report TSAs at some stage during the study period. Patients reporting TSAs were younger and more often smokers. Gender differences were seen in characteristics of TSAs reported with more women reporting stronger sensations of sour, bitter and smell and more men reporting weaker sensations of all tastes and smell. Patients reporting TSAs commonly reported other symptoms, notably loss of appetite, nausea and early satiety. A mean six-month weight loss of 6% was seen in patients reporting both TSAs and loss of appetite. Reduced enjoyment of eating was a key feature of patients' descriptions of TSAs. Energy intakes were seen to decline with increasing number of reported TSAs.

Conclusions: The translation and cultural adaptation of the TSS allows comparisons between English and Swedish speaking populations. Gender differences are seen in characteristics of reported TSAs and how TSAs are described. This highlights a need for further investigation of this phenomenon and may indicate that different approaches for identification and management of TSAs in men and women should be considered. Patients described TSAs in terms of both sensory changes encompassing taste and/or flavour, and hedonic changes indicating that TSAs are multi-dimensional. A consistent vocabulary might therefore facilitate more clear communication about TSAs among patients, healthcare staff and researchers.

Key words: cultural adaptation, gender, instrument, lung cancer, nutrition, symptoms, taste and smell, translation.