



# A supportive nursing care clinic: Conceptions of patients with head and neck cancer

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## KEYWORDS

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Nutrition;  
Nurse clinic;  
Support;  
Trajectory of care;  
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## Summary

Patients with head and neck cancer have complex long-lasting physical and psychosocial needs due to illness and treatment, and studies have shown deficiencies concerning support in these respects. The purpose of this study was to describe how head and neck cancer patients with eating problems conceived the significance of a supportive nursing care clinic before, during and after completion of radiotherapy. Thematic interviews were carried out in an open dialogue with 12 patients treated with radiotherapy for head and neck cancer. The phenomenological method was used in the analyses. The findings showed that the nurse clinic could meet head and neck cancer patients' needs of safety and security, which was especially important before and after completion of treatment when no other regular contacts in the health care system existed. The significance of the nurse clinic varied depending on where in the trajectory the patients were, what needs and problems they experienced, and how severe these were experienced by the individual patient. The supportive nursing care clinic could meet these patients' needs of knowledge, care and support both concerning practical measures related to the disease and its treatment, and emotional needs. This way of organising the care can contribute to these patients' health and wellbeing.

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## Zusammenfassung

Aufgrund ihrer Krankheit und der Therapie haben Patienten mit Kopf-Hals-Tumoren vielfältige und dauerhafte Bedürfnisse im körperlichen und psychosozialen Bereich. Studien haben gezeigt, dass die Patienten diesbezüglich keine ausreichende Hilfestellung erhalten. Das Ziel dieser Studie bestand darin, zu untersuchen, ob Patienten mit Kopf-Hals-Tumoren, die an Essproblemen leiden, eine supportive Behandlung in einer Pflegeklinik, welche vor, während und nach einer Strahlentherapie stattfindet, als sinnvoll erachten. In einem offenen Dialog mit zwölf Patienten, die wegen eines Kopf-Hals-Tumorleidens eine Strahlentherapie erhielten, wurden thematische Interviews durchgeführt. Für die Analysen wurde ein phänomenologischer Ansatz gewählt. Die Ergebnisse zeigen, dass eine Pflegeklinik dem Wunsch von Patienten mit Kopf-Hals-Tumoren nach Sicherheit und Geborgenheit entgegenkommt. Dies war um so wichtiger, als vor und nach der Behandlung innerhalb des Gesundheitssystems keine anderen regelmäßigen Kontakte stattfanden. Die

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Bedeutung, die der Pflegeklinik seitens der Patienten beigemessen wurde, war davon abhängig, in welchem Zustand sich die Patienten befanden, welche Bedürfnisse und Probleme die Patienten hatten und wie intensiv diese Bedürfnisse bzw. Probleme empfunden wurden. Eine Pflegeklinik könnte in der Lage sein, den Bedarf dieser Patienten an Information, Pflege und Unterstützung zu befriedigen; dies gilt sowohl für praktische Maßnahmen, die mit der Erkrankung und ihrer Behandlung zusammenhängen, als auch im Hinblick auf einen erforderlichen emotionalen Beistand. Eine Pflege, die dieses leisten kann, kann einen entscheidenden Beitrag zum Wohlbefinden des Patienten leisten.

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## Introduction

Patients with head and neck cancer have complex long-lasting physical and psychosocial needs. These malignancies and associated treatments have a huge impact on daily life for those afflicted due to their impact on an area of the body, central for a person's identity and fundamental functions such as speaking, breathing, eating and drinking (Dropkin, 2001; Langius et al., 1993; Larsson et al., 2003; Wells, 1998). Planning, preparation and treatment are complicated and demanding for the individual patient and require multidisciplinary care (Sharp et al., 2002; Whale, 1998). The majority are treated with radiotherapy 5 days per week for up to 6 or 7 weeks, either alone or in combination with surgery, brachytherapy or chemotherapy (Rose-Ped et al., 2002; Zackrisson et al., 2003). In Sweden, radiotherapy is carried out by specialist nurses and the scheduled time is approximately 20 min on each occasion. The limited time makes it difficult to both carry out treatment and deliver needed nursing care in a therapeutic nurse-patient relationship (Larsson et al., 2005a; Wengström and Häggmark, 1998). The patients' contacts with the health care system in Sweden during the follow-up period usually consist of revisits to physicians, mainly with the focus to monitor disease (Larsson et al., 2005b; Reizenstein, 2001).

Recent studies have shown that eating problems and nutritional status deficiencies in these patients are common before the onset of treatment (Larsson et al., 2005b; Lees, 1999). Since, radiotherapy causes acute side-effects in the mouth and throat, such as mucositis, xerostomia and taste loss (Shih et al., 2003; Stone et al., 2003), patients often experience different complications which further compromise eating ability and nutritional status (Langius et al., 1993; Larsson et al., 2003, 2005b; Rose-Ped et al., 2002). Emotional stress and existential crisis caused by the cancer diagnosis may also reduce nutriment intake (Capra et al., 2001; Cunningham and Bell, 2000; Gatson Grindel et al., 1996). As severe, acute side-effects often become chronic and late side-effects appear months or years after treatment (Dörr and Hendry, 2001; Stone et al., 2003), many patients have eating problems for a considerable period of time and some will never return to normal eating (Beeken and Calman, 1994; Larsson et al., 2005b). Hence, the risk for progressive malnutrition is evident.

These patients have also been found to experience losses and threats at different levels in daily life due to eating problems, such as loss of togetherness and sociability (Larsson et al., 2003), which may have a negative impact

on psychosocial well-being. Moreover, research shows that depressive symptoms are common among these patients during the whole trajectory of care (de Graeff et al., 2000; de Leeuw et al., 2000; Hammerlid et al., 2001). The disease and its treatment have been found to impact negatively on the patients' quality of life for months and years after treatment (Bjordal et al., 2001; Bjordal et al., 1994; Gritz et al., 1999). Thus, it is obvious that patients with head and neck cancer need extensive support during a long period of time that takes the patients' complex physical, practical and psychosocial needs into account. In spite of this, recent studies have shown that support to these patients is often insufficient (Larsson et al., 2005a; Sanson-Fisher et al., 2000).

There is a growing body of literature describing nurse-led clinics in cancer care. The findings often show that the care provided in such clinics is both holistic and safe (Cox and Wilson, 2003), but in studies concerning patients undergoing radiotherapy they are restricted to the treatment period (Campbell et al., 1999; Loftus and Weston, 2001). In addition, most nurse-led clinics during and after treatment are a doctor-nurse substitution (Corner, 2003). There is a lack of studies focusing on nurse clinics which act as a complement to regular care aimed at supporting patients with head and neck cancer during the whole trajectory of care. In addition, only a few studies have been found describing patients' experiences of such services.

## Purpose

The purpose of this study was to describe how head and neck cancer patients with eating problems conceived the significance of a supportive nursing care clinic before, during and after completion of radiotherapy.

## Method

In order to acquire a description of conceptions of a supportive nursing care clinic, a qualitative study with a phenomenographic approach was carried out (Marton, 1981; Marton and Booth, 1997; Uljens, 1989, 1993). Within phenomenography it is assumed that whatever phenomenon or situation people encounter, it is possible to identify the limited number of qualitatively different and logically interrelated ways in which this is experienced, conceived or understood (Marton and Booth, 1997). According to Marton (1996) the words experience, conception and perception are synonyms. The conceptions vary not only

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