



Working in silos? – Head & Neck cancer patients during and after treatment with or without early palliative care referral



Helena Ullgren ^{a, b, *}, Lily Kirkpatrick ^a, Sini Kilpeläinen ^a, Lena Sharp ^{a, c}

^a Regional Cancer Centre Stockholm-Gotland, Stockholm, Sweden

^b Karolinska University Hospital, Department of Oncology, Stockholm, Sweden

^c Karolinska Institutet, Department of Learning Informatics, Management and Ethics, Stockholm, Sweden

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ABSTRACT

Purpose: The primary aim was to describe patients with Head and Neck (H&N) cancer referred to palliative care and how the care transition from acute oncological to palliative care impacted on both Health related quality of life (HRQoL) and information. The secondary aim was to explore H&N cancer patients' HRQoL and perceived information.

Methods: H&N cancer patients were identified via the Swedish Cancer Register. Data were collected using the following questionnaires; European Organization for Research and Treatment of Cancer (EORTC) QLQ C-30, INFO25, and a study-specific questionnaire.

Key results: Out of 289 patients, 203 (70%) responded and among these, 43 (21%) reported being referred to palliative care. Global health was the lowest reported functional scale (median score = 67) and fatigue (median scores 33) the highest reported symptom (QLQ C-30). Patients with a written care plan were significantly more satisfied with information regarding self-care compared to patients without a care plan. Patients referred to palliative care were less satisfied with information regarding disease ($p < 0.000$), the spread of the disease ($p < 0.001$) and were more likely to visit hospital emergency departments (43% vs. 19% $p < 0.000$).

Conclusion: To avoid H&N cancer care in silos, a closer integration between the oncology and the palliative care team is needed. Further research on the complex situation of having oncological treatment concurrent with palliative care, is needed.

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1. Introduction

Head & Neck (H&N) cancer accounts for approximately 3% of all cancers in Sweden, which translates to 1200 new cases being diagnosed each year (The National Board of Health and Welfare (2015)). Tobacco use and high alcohol consumption are the main risk factors together with human papilloma virus infections (D'Souza et al., 2007; Mork et al., 2001).

Both the diagnosis and the intensive treatment (typically extensive surgery, radiotherapy and chemotherapy) often have a major impact on the patients' quality of life, with high risk for unmet needs (Wells et al., 2015; Henry et al., 2013). Typical symptoms include, xerostomia (dry mouth), dysphagia (difficulties

swallowing) and pain (Van der Lan et al., 2015), often resulting in severe nutritional problems, weight loss and hospitalization even before the treatment starts (Farhangfar et al., 2014).

The trajectory of care for patients with H&N cancer is often complex and involves several care transitions with many health care professions involved. In addition to nurses and physicians from different disciplines, dieticians, speech therapists, physiotherapists, dentists and social workers are often involved. Nurses have a key position in coordinating this complex care trajectory. In Denmark, it is required by law to have a primary health care contact (Danish Ministry of Health (2010)). The Swedish National Cancer Plan (Swedish Government of Official Reports, SOU, 2009:11), states that all cancer patients should be offered a main health professional contact, a contact nurse, with in-depth knowledge of cancer nursing and the patient's care pathway. The contact nurse coordinates the care and is responsible for all clinical handovers (SOU, 2009:11). One of the key components of an effective and safe handover is that the patient should be involved and receive

* Corresponding author. Karolinska University Hospital Department of Oncology, 171 76, Stockholm, Sweden.

E-mail address: helena.ullgren@sil.se (H. Ullgren).

information both verbally and in writing.

Transitional care is described in terms of actions created to ensure continuity and coordination of care, when a patient is transferred within and/or between care settings (Coleman and Boulton, 2003). A *care transition* is when a patient's care is transferred from one health care organization to another. It could also be a transfer between two teams within the same health care setting (Naylor et al., 2011). A care transition may put the patient in a vulnerable situation creating safety risks, due to insufficient information exchange between the different health care staff (Coleman et al., 2006; Forster et al., 2006). Flink et al. (2012) conclude that all healthcare organizations need to have a defined and clear process for handovers to guarantee safe care. Ko et al. (2014) found that over 50% of cancer patients had more than one care transition in the last three months of life. The patients in the study reported high symptom burden at the end of life and the authors conclude that oncology and palliative care need to be better integrated (Ko et al., 2014). Palliative care aims to improve the quality of both life and death, alleviate symptoms and involve the patient's family in the care process (WHO, 2015). Therefore palliative care is highly relevant for patients with H&N cancer, during all stages of disease, and throughout the care trajectory.

The heavy burden of H&N cancer and treatment often leads to extensive support needs (Henry et al., 2013; Fingeret et al., 2012; So et al., 2014). Recently published studies, evaluating patients with different types of cancer, found that early referral to palliative care could lead to both improved quality outcomes (lower rates of inpatient care, less time in intensive care, fewer visits to the emergency department) and reduced costs at end of life (Scibetta et al., 2016; Blackhall et al., 2016).

There is no consensus on the definition of the concept *early palliative care*. Several researchers define it as referral within 3 months before death (Baktitas et al., 2015; Blackhall et al., 2016; Scibetta et al., 2016), while Temel et al. (2010) define it as referral within 8 weeks after diagnosis (concurrent with active treatment). In studies of the impact of early palliative care, the care settings and interventions vary greatly, including for example, consultations by a palliative team from acute hospital care (Temel et al., 2010; Bakitas et al., 2015), palliative home care, dedicated palliative care clinics (Scibetta et al., 2016), or a mixture of different settings (Blackhall et al., 2016).

In this current study, palliative care was provided by specialized palliative home care teams, not integrated with the acute hospital, as this is the way palliative care is organized in the Stockholm region. Some of these palliative teams also have access to in-patient care in specialized units, often located at hospices rather than hospitals. The primary aim of this study was to describe H&N cancer patients referred to palliative care, and how the care transitions from acute oncological to palliative care impacted on satisfaction with information and HRQoL. The secondary aim was to explore H&N cancer patients' HRQoL and perceived information regarding disease and treatment.

2. Material and methods

2.1. Design

This descriptive, cross-sectional study was part of a wider study evaluating baseline data before a planned intervention. The intervention consists of the implementation of a new nursing role, the coordinating contact nurse, with the aim of improving care transitions in the Stockholm-Gotland region. The wider study also included patients with gynecological cancer, upper gastrointestinal cancer, and hematological malignancies. In this current study, baseline data from H & N cancers were analyzed. The study was

approved by the Regional Ethics Board (DNR 2016/5:4).

2.2. Patients

All patients ≥ 18 years old, diagnosed with H&N cancer in the Stockholm-Gotland region (approx. 2.3 million citizens) during 2014 (January 1 to December 31) were identified through the Swedish National Cancer Register. This register includes approximately 99% of all cancer cases in Sweden, clinically reported and morphologically verified (Barlow et al., 2009).

2.3. Data collection

Before the questionnaires were sent, a cross-reference with The Swedish Population Register was performed on the same day, to avoid sending questionnaires to deceased patients. Three questionnaires (described below) were sent to the identified patients via regular post. A pre-paid envelope and a cover letter, with information about the study and contact details of the research team if more information was required, were also included. The letter also had a web link for participating patients who preferred to reply electronically. One reminder was sent three weeks later to patients who had not yet responded, using the same cross check with the Swedish Population Register. Patients not wishing to participate could avoid the reminder, by sending back a blank questionnaire.

The questionnaires returned via regular post were manually registered in a database, developed especially for the study.

2.4. Health related quality of life, HRQoL

HRQoL was measured by the European Organization for Research and Treatment of Cancer (EORTC) questionnaire, QLQ C-30. This validated instrument is widely used and has 30 items with 5 functional scales, consisting of physical, emotional, social and cognitive functioning, as well as three symptom scales, fatigue, pain, nausea and vomiting. There are also 6 single items regarding financial impact, symptoms and global quality of life (Aaronson et al., 1993). Responses are reported in 4 categories with 1 being "not at all", and 4 "very much". Two items regarding global health status are reported as 1 being "very poor" to 7 "excellent" (Aaronson et al., 1993).

2.5. Information needs

The patient's perception of received information regarding treatment and care was measured by EORTC QLQ INFO25. This instrument is also validated and includes 4 items on disease, 3 on medical tests, 6 on treatment, and 4 items about "other services". It also includes 8 single items regarding self-care, care settings, written information, information on CD or tape, satisfaction with information and how useful the information has been. Responses ranging from 1 to 4, where 1 is "not at all" and 4 is "very much". Four items have "yes" or "no" options (Arraras et al., 2010).

2.6. Study specific questionnaire

The study specific questionnaire, developed by the research team, included 58 items in the following five sections; general questions on demographics and treatment (8 questions), questions on the cancer work-up process (11 questions), information exchange and patient participation (20 questions), palliative care, and coordination of care including care transitions (18 questions). Most items were Likert-type questions with four response options ("not at all", "a little", "quite a lot" and "a lot"). Two items in the general section, two in the cancer work-up section, one item regarding the

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