



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



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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

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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

patient's perception of palliative care and one item regarding rehabilitation/supportive care contacts had multiple choice response options.

In order to assess and test the study specific questionnaire for face validity, a small pilot study was conducted. Six H&N patients (at different stages of disease and with a variety of cancer sites) agreed to complete the questionnaires and to comment on the relevance and their understanding of the questions. The questionnaires were handed out during an appointment at the Department of Oncology, Karolinska University hospital. Only minor issues were reported and the questionnaires were changed accordingly.

2.7. Statistical methods

Item scores of EORTC QLQ C-30 and INFO25 were transformed to a 0–100 scale (Fayers et al., 2002). Scale scores were calculated, where higher scores represent higher functioning and global quality of life, as well as higher levels of information received, higher information wishes and higher satisfaction in EORTC INFO25 (Fayers et al., 2001). However, higher scores in symptom scales represent more symptoms and a heavier symptom burden in EORTC QLQ C-30.

Descriptive statistics were used to present patient characteristics (age, educational level, gender and type of treatment received), and scale scores in EORTC QLQ C-30 and INFO25. The patient's perception of the concept of palliative care (multiple-choice question) was presented as proportions. Proportions were calculated for the binary variables and minimum, maximum, median and percentiles were used to describe the continuous variables.

The scores of EORTC QLQ C-30 and INFO25 were compared between the groups of patients reporting they had been referred to palliative care versus those who had not been referred. Patient characteristics and other items from the study specific questionnaire (written care plans, and visiting the emergency department) were also compared between the two groups (palliative care vs. no palliative care). Responders and non-responders were compared regarding age, sex, cancer site and stage. Exploratory *p*-values were calculated for the comparisons where a Pearson chi square test was used to analyze binary variables. For analysis of continuous variables (such as scores of EORTC QLQ C-30 and INFO25) a Wilcoxon rank sum test was used (a non-parametric test to assess whether the population mean ranks differed).

3. Results

Out of 290 identified patients, 203 (70%) responded. Among these patients, 135 (67%) responded electronically. The mean age was 69 years and most of the responding patients ($n = 134$, 66%), were men. About one third of the patients reported that they had received single treatment (surgery or radiotherapy alone) and about half reported having undergone multimodal treatments. The majority ($n = 153$, 75%), stated that they were in the follow up phase after treatment and one fifth ($n = 43$, 21%), reported being referred to palliative care. Less than half ($n = 91$, 45%) of the patients reported that they had been in contact with a contact nurse, and more than one third ($n = 77$, 38%) had received a written care plan. Patient characteristics are presented in Table 1. No statistically significant differences were found regarding age, sex, cancer site or stage between responders and non-responders (data not shown).

3.1. Health related quality of life, HRQoL

Median scores of the EORTC QLQ C-30 showed that the symptom with the highest score was fatigue (median score 33). Nausea/vomiting and diarrhoea were the symptoms reported with the

Table 1
Patient characteristics and patient-reported supportive care services.

Characteristics	n (%)
Age mean, (min-max)	69 (25–100)
Female	69 (34)
Male	134 (66)
Education high ^a	129 (64)
Single treatment	60 (30)
Multimodal treatment	110 (54)
Missing data (treatment)	60 (16)
Referral to palliative care	43 (21)
Had contact with a contact nurse	91 (45)
Had a written care plan	77 (38)

^a Higher education = University.

lowest scores. The median scores and spread of the scores in symptom scales is shown in Fig. 1.

Global health and the different functional scores, (highest scores reported for physical functioning, median score 87), were reported at a relatively high level (Fig. 2).

3.2. Information needs

The lowest levels of perceived information (EORTC INFO25) were reported in relation to “other services” (median score 25), “different places of care” (median score 33), and “things to do to help yourself get well” (median score 33). Data are presented in Fig. 3.

The impact of a contact nurse, a written care plan and other rehabilitation/supportive/palliative care contacts.

When comparing patients who reported having, or not having, a contact nurse, patients with a contact nurse had statistically significantly lower levels of global health ($p < 0.030$), and higher levels of symptoms (fatigue, pain, nausea and vomiting, $p < 0.003$). Having a contact nurse didn't seem to affect the perception of received information. Neither could we identify any statistically significant difference regarding knowledge of who was the main health care contact, between patients with or without a contact nurse (data not shown).

We found no statistically significant differences in HRQoL between patients reporting having or not having any rehabilitation/supportive care contacts. Neither could we identify any significant differences in perceived information between patients who reported having or not having any type of rehabilitation/supportive care contacts. However, higher scores were reported on perceived information regarding self-care among patients with a written care plan compared with patients without ($p < 0.000$).

When asking patients about their perception of palliative care (multiple choice question), the majority responded that it related to when disease was not curable ($n = 44$), end-of-life care ($n = 66$) and/or care in hospice ($n = 32$). Only 26 patients stated that palliative care also included advanced symptom management (multiple choice questions).

3.3. Patients with palliative care referral

We found no statistically significant differences in age, gender or educational level between patients referred/not referred to palliative care (see Table 2). However, patients who reported they had been referred to palliative care were more likely to have undergone multimodal treatment, to score lower levels of global health ($p < 0.003$) and higher symptom burden (fatigue, pain, nausea and vomiting), $p < 0.000$, compared with patients without palliative care referral.

Furthermore, patients referred to palliative care had lower levels

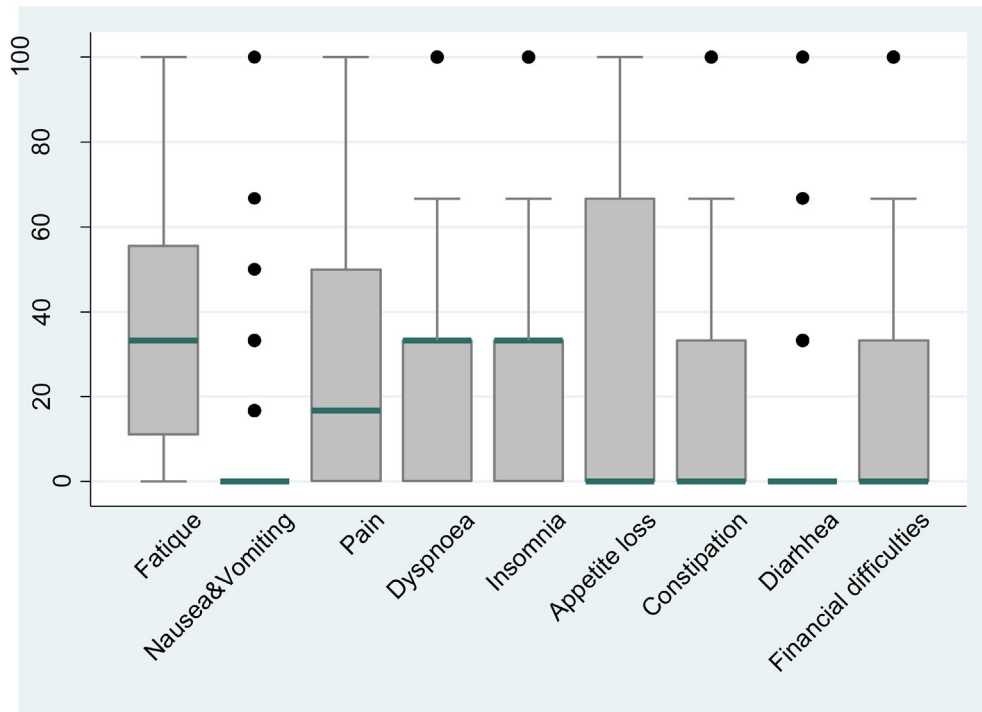


Fig. 1. Median scores and spread of European Organization for Research and Treatment of Cancer (EORTC) QLQ C-30, symptom scales.

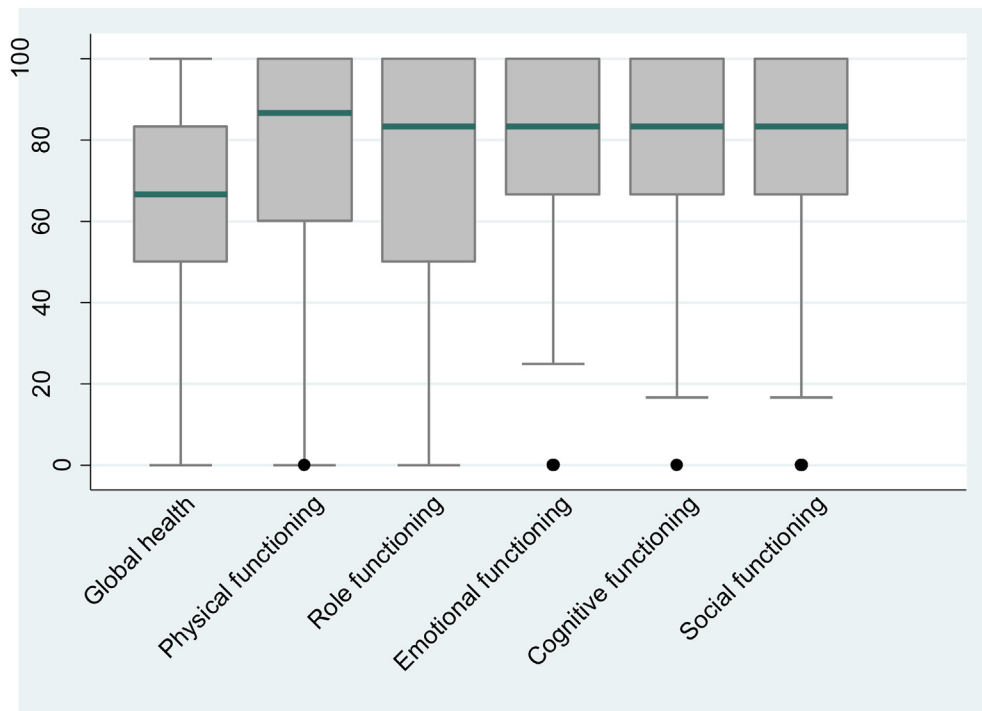


Fig. 2. Median scores and spread of European Organization for Research and Treatment of Cancer (EORTC) QLQ C-30, functional scales.

of perceived information regarding possible causes of the disease ($p < 0.00$) and the extent of (spread of) the disease ($p < 0.010$). No other statistically significant differences were found regarding perceived information between the two groups of patients (referred/not referred to palliative care).

Among the patients that had been referred to palliative care, the

majority ($n = 34, 87\%$) also reported to have had contact with a contact nurse, compared with nearly half ($n = 53, 47\%$) of patients without referral to palliative care ($p < 0.00$). We found no statistically significant difference between patients with/without referral to palliative care regarding knowledge of who was responsible for their care.

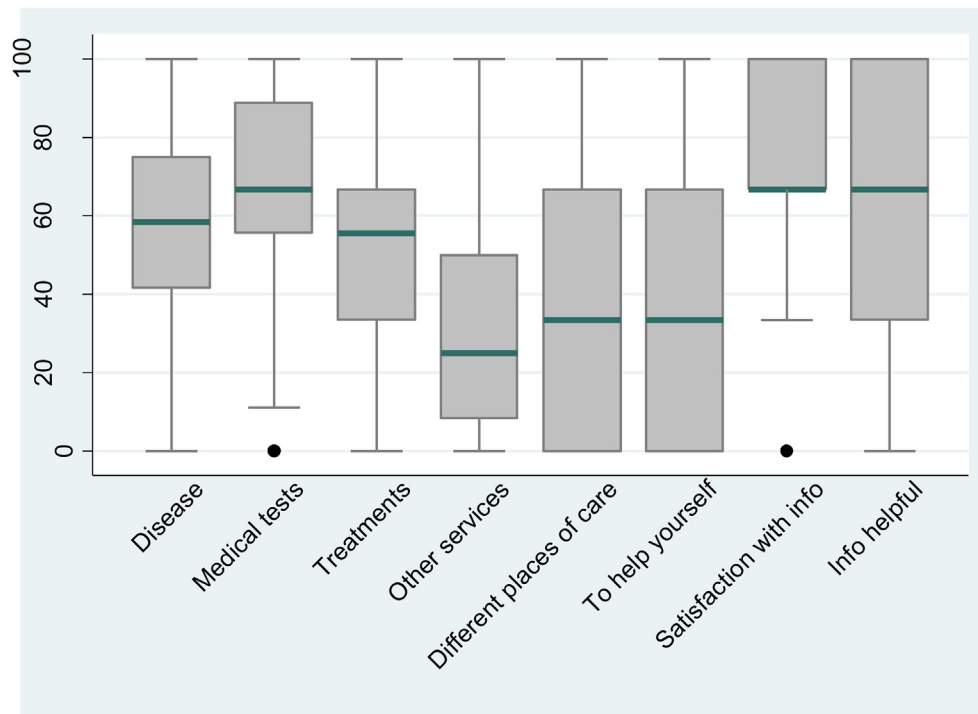


Fig. 3. Median, scores & spread of European Organization for Research and Treatment of Cancer (EORTC) QLQ INFO25.

Table 2
Characteristics of patients with/without palliative care referral.

	Palliative care n (%)	No palliative care n (%)	P value (Pearson chi square test)
All patients	43 (21)	114 (56)	
Age at diagnosis			
<54	4 (9)	11 (9)	NS
54–63	15 (35)	27 (23)	NS
>64	24 (56)	79 (68)	NS
Gender			
Male	26 (60)	82 (70)	NS
Female	17 (40)	35 (30)	NS
Treatment			
Single	4 (9)	46 (40)	p < 0.000
Multimodal	39 (91)	68 (60)	p < 0.000
Education			
High ^a	32 (76)	89 (76)	NS
Contact nurse	34 (87)	53 (47)	p < 0.000
Written care plan	31 (78)	44 (39)	p < 0.000

^a Higher education = University.

Patients referred to palliative care, reported that they visited the hospital emergency department more frequently, compared to the group with no palliative care. Out of the 42 patients referred to palliative care, 18 (43%) stated having visited the hospital emergency department once or several times versus 22 patients (19%) among those without palliative care referral.

4. Discussion

In this study a relatively large sample of H&N cancer patients reported on information needs, HRQoL, care transitions and supportive care during treatment and follow-up. The reported symptom burden was relatively low, but in line with previous published work among H&N cancer patients (Verdonck de Leeuw et al., 2014).

Patients reported satisfaction with received information in line with previous published work among cancer patients (Arraras et al., 2010). Only half of the patients reported that they had

access to a contact nurse or a written care plan, despite both these interventions being regarded as essential in the National Swedish Cancer Plan (SOU, 2009:11). In this study, we could not identify any statistically significant patient-reported benefits of having a contact nurse. The only statistically significant benefit of having a written care plan was regarding self-care strategies. These results raise many questions and we can only speculate on the reasons. The results may have been different if a larger proportion of patients had access to both a contact nurse and a care plan, since both strategies aim to improve the information exchange for individuals affected by cancer. The results may also reflect the fact that there is no clear role description for contact nurses. Each health care organization in Sweden has developed this role independently. In our study the results reflect patients' perceptions of being referred to a contact nurse, not whether they had actually been assigned a contact nurse. It is also possible that written care plans varied in content and presentation. During the time of data collection, no

general instruction regarding written care-plans was available. However, self-care strategies are important for active patient participation (Sahlsten et al., 2009).

As expected, the group of patients receiving palliative care reported significantly lower HRQoL and heavier symptom burden, which could be explained by the fact that most patients had multimodal treatment. The impact of multimodal treatment (Adelstein et al., 2000) might also explain why patients who reported to have a contact nurse also had lower global health scores and more symptoms.

One of the surprising results of this study was that patients being referred to palliative care reported significantly less information regarding their disease and the extent of the disease. One could assume that access to a palliative care team would improve the information to patients. One possible explanation could be that the main focus of palliative care is symptom management and psychosocial care (WHO, 2015) rather than discussing the disease and prognosis. Issues related to the cancer disease remain the responsibility of the oncology team even if they may have much less contact with patients after referral to palliative care. Improvements seem to be needed regarding the integration and collaboration between the two teams, with clarifications of each team's responsibilities.

As mentioned, multimodal treatment is expected to lead to more side effects (Adelstein et al., 2000). The majority of the patients in the palliative care group received multimodal treatment with curative intent and we do not know whether their referral to palliative care was based on the type of treatment and side effects they experienced, rather than on a person-centered, holistic approach (Alharbi et al., 2014), focusing on the patient's individual needs.

Most patients in this study reported that palliative care signified end-of-life and hospice care. Even though palliative care has been well established in the Stockholm region for many years, these results indicate that patients have limited knowledge of some of the aspects of care that are included in the concept of palliative care. Charalambous et al., 2014, found similar results both in the general public and amongst health care professionals, suggesting that there are misconceptions about what palliative care means. The patients' perception of palliative care is important. Palliative care may also be important during the curative stage of disease (WHO, 2015). Misconceptions of the meaning might create insecurity and a lack of trust, resulting in missed care and support.

Another interesting finding from this study was that many of the patients with palliative care were still visiting the university hospital's emergency department (some on several occasions). Although it is possible that some palliative care patients might be in need of emergency care, this finding indicates insufficient collaboration between the different health care providers involved. A study by Hjermstad et al. (2013) included patients in the later stages of disease and concluded that collaboration was the key to successfully limiting visits to the acute hospital. One of the purposes of referral to palliative care is for the patient to receive care at home, even those with complex care needs (Blackhall et al., 2016). Our findings stress the importance of providing information about palliative care and its purpose for this group of patients. The study also suggests that information exchange and collaboration needs to improve between different teams and disciplines to reduce the risk of unnecessary visits to emergency and/or oncology units (Hjermstad et al., 2013).

It is possible that improved communication and information exchange between the oncology and palliative care teams could reduce visits to emergency care for this group of patients. As previously mentioned, there is a growing body of evidence showing benefits for early palliative care (tBlackhall et al., 2016; Scibetta

et al., 2016), but there is still limited research on the nature of palliative care and the challenges of having shared responsibility, as well as the exact timing and structure of early palliative care. In a survey, (Davis et al., 2014), showed that most of the larger cancer centers provided palliative care services, but the structure varied. Some had inpatient consultation teams, outpatient palliative care clinics, dedicated palliative care beds, and some provided hospice care. This current study investigated mainly patients referred to a palliative home care unit, organized independently from the cancer centers. To date, no dedicated palliative care services are available within the acute care departments in the region.

Patients in palliative care were more likely to have a contact nurse and therefore it might be assumed that they would have better access to symptom management and coordinated care. However, when patients are referred to palliative care, the contact nurse (most often a part of the Oncology team) does not follow the patients to the same extent, and symptom management is handed over to the palliative care team (even during curative treatment). The contact nurse could play a key role in the effective information exchange between the oncology and the palliative care team, but no systematic handover system has, so far, been established. It could be argued that this could affect the patients negatively, because treatment related problems in the first year after treatment are associated with long term survivorship problems and poor quality of life, it is important to ensure that these are addressed early on (Funk et al., 2012; Cohen et al., 2016), therefore an integrated approach between the oncology and palliative care teams is crucial.

Among the strengths of this study are the relatively large sample and high response rate, population-based data and, when possible, the use of validated questionnaires. However, our conclusions are based on a small proportion of patients who were referred to palliative care. One limitation may be that we did not use any H&N specific instruments, for example EORTC QLQ-H&N35, which probably would have given a more comprehensive description of the symptom burden. Supportive care strategies, such as access to a contact nurse and written care plans, are not fully implemented in our region. These are important results from our study but also, makes evaluations difficult.

5. Conclusion

To avoid H&N cancer care in silos, a closer integration between the oncology and the palliative care team is needed. This could possibly improve the care transition, and enhance satisfaction with information in patients with H&N cancer. Better coordination of care between teams and departments may also reduce unnecessary emergency admissions and lead to more optimal survivorship care. Further research on the complex situation of having oncological treatment concurrent with palliative care is needed.

Conflicts of interest

The authors have no conflicts of interest to declare.

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