

SPECIAL ISSUE ARTICLE

Referral of patients with cancer to palliative care: Attitudes, practices and work-related experiences among Swedish physicians

Karin Adolfsson^{1,2}  | Ulrika Kreicbergs^{3,4} | Charlotte Bratthäll⁵ | Erik Holmberg^{1,6} | Thomas Björk-Eriksson^{1,6} | Margaretha Stenmarker^{7,8,9}

¹Department of Oncology, Institute of Clinical Sciences, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

²Department of Oncology, Ryhov County Hospital, Jönköping, Region Jönköping County, Sweden

³Department of Health Care Sciences, Palliative Research Centre, Marie Cederschiöld University College, Stockholm, Sweden

⁴Department of Women's and Children's Health, Karolinska Institute, Stockholm, Sweden

⁵Department of Oncology, Kalmar County Hospital, Kalmar, Region Kalmar County, Sweden

⁶Regional Cancer Centre West, Western Sweden Healthcare Region, Gothenburg, Sweden

⁷Department of Paediatrics, Institute of Clinical Sciences, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

⁸Department of Paediatrics, Futurum - Academy for Health and Care, Jönköping, Region Jönköping County, Sweden

⁹Department of Biomedical and Clinical Sciences, Linköping University, Linköping, Sweden

Correspondence

Karin Adolfsson, Department of Oncology, Ryhov County Hospital, SE-551 85 Jönköping, Region Jönköping County, Sweden.
Email: karin.adolfsson@rjl.se

Funding information

Foundation for Clinical Cancer Research, Jönköping, Sweden, Grant/Award Number: 809311; Futurum - Academy for Health and Care, Region Jönköping County, Sweden, Grant/Award Numbers: FUTURUM-419721, FUTURUM-423541, FUTURUM-913371, FUTURUM-933554; FORSS, Medical Research Council of Southeast Sweden, Grant/Award Number: FORSS-657621

Abstract

Objective: This study aimed to explore the attitudes, practices and work-related experiences among Swedish physicians regarding the referral process, integration and transition between oncology care and palliative care (PC).

Methods: A cross-sectional online survey was performed with a study-specific questionnaire in 2016–2017 in south-eastern Sweden. Physicians working with cancer patients within surgical specialties, medical specialties and paediatric oncology participated.

Results: The vast majority of the 130 participating physicians (99.2%) stated that PC was beneficial for the patient and were positive about early integration of PC (65.5%). Still, only 27.6% of the participants introduced PC at an early stage of non-curable disease. However, paediatric oncologists had a very early introduction of PC in comparison with medical specialties ($p = 0.004$). Almost 90% of the study population said they wanted to know that the patient had been taken care of by another care facility.

Conclusions: Despite the physicians' positive attitude towards early integration and referral to PC, they often acted late in the disease trajectory. This late approach can

Funding

This study was funded by FORSS, Medical Research Council of Southeast Sweden, under Grant Number FORSS-657621, Futurum - Academy for Health and Care, Region Jönköping County, Sweden, under Grant Numbers FUTURUM-419721, FUTURUM-423541, FUTURUM-913371 and FUTURUM-933554, and Foundation for Clinical Cancer Research, Jönköping, Sweden, under Grant Number 809311.

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial](https://creativecommons.org/licenses/by-nc/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2022 The Authors. *European Journal of Cancer Care* published by John Wiley & Sons Ltd.

reduce the patient's opportunity of improving quality of life during severe circumstances. There is a need for in-depth knowledge of the physicians' challenges in order to bridge the gap between intentions and actions.

KEYWORDS

cancer, oncology, paediatric oncology, palliative care, physician, referral

1 | INTRODUCTION

Palliative care (PC) is still commonly associated with end-of-life care (Kaasa et al., 2018; Zimmermann et al., 2016). According to the World Health Organisation's (WHO) (2020), this care 'is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life'. Data from several randomised trials have shown benefits for patients with advanced cancer receiving standard oncology care integrated with PC early in this phase of the disease trajectory (Bakitas et al., 2009; El-Jawahri et al., 2017; Glare, 2013; Temel et al., 2010). Early referral to PC, that is, a process that facilitates an early integration of these two practices of care, can lead to improvement in quality of life, symptom control, mood, satisfaction, less aggressive therapy near the end of life, improved use of health-care resources and improved outcome for caregivers (Bakitas et al., 2009; El-Jawahri et al., 2017; Glare, 2013; Temel et al., 2010). Based on this evidence, organisations such as the American Society of Oncology and European Society of Medical Oncology recommend early integration of PC for patients with advanced or metastatic cancer as soon as patients are deemed to be in incurable phase of their disease (Ferrell et al., 2017; Jordan et al., 2018). However, the Lancet Oncology Commission concludes that in spite of the recommendations, there are no healthcare systems where this integration is completely fulfilled (Kaasa et al., 2018). The organisation and provision of PC differ within and between countries (Centeno et al., 2017; Dhollander et al., 2018; Kaasa et al., 2018). A brief description of primary PC includes basic physical and psychological symptoms, and specialised PC comprises complex care situations (Sorensen et al., 2020). There are not enough PC specialists or primary PC providers to cover all needs (Sorensen et al., 2020), and there is an overall deficit in competence in PC (Kaasa et al., 2018). Referral to PC can be delayed due to multiple factors such as organisational-, physician-, patient- and family-related aspects (Granek et al., 2013; Horlait et al., 2016). Barriers can be lack of knowledge about the content of PC (La Russa et al., 2020; Wright & Forbes, 2017), reactions related to the term 'palliative care' and the misperceptions of PC being synonymous with end-of-life care among referring physicians and patients (Horlait et al., 2016; Wentlandt et al., 2012). The timing of referral to PC also differs between medical specialties (Hui, Bansal, et al., 2015; Hui, Park, et al., 2015). Oncologists, including gynaecological oncologists, haematologists and paediatric oncologists, generally refer patients late in the disease trajectory and when the patient has uncontrolled symptoms (Lefkowitz et al., 2014; Wentlandt et al., 2012, 2014; Wright & Forbes, 2017).

Sweden is a country with about 10 million inhabitants. In 2020, sixty two thousand five hundred patients were diagnosed with cancer (The National Board of Health and Welfare, 2021a), which is the second most frequent cause of death (The National Board of Health and Welfare, 2021b). The organisation, provision and accessibility of PC vary within the country, and the care is unequally distributed, for example, regarding diagnosis and age (Axelsson, 2022). Approximately ninety thousand individuals die each year. Regardless of diagnosis, about 10%–25% of patients in end of life care have access to specialised PC units, of which around 80% are suffering from cancer (The Swedish Registry of Palliative Care, 2021). The care is tax-financed and primarily performed by public healthcare, delivered by 21 county councils. The majority of patients are cared for by staff with basic knowledge and skills in PC, in hospitals and within municipal care in collaboration with primary care and with general practitioners as medically responsible physicians (The National Board of Health and Welfare, 2016). Although the general benefits of early PC have been known for a decade, and PC is an area of healthcare prioritised by the government (Government Offices of Sweden, 2018), the strategy of integrating oncology treatment and PC for patients with advanced cancer is recommended but still not implemented as a standard of care in Sweden (Regionala cancercentrum i samverkan, 2021a, 2021b). The aim of this study was to explore the attitudes, practices and work-related experiences among physicians handling patients with cancer regarding the referral processes, integration and transition between oncology and PC in south-eastern Sweden.

2 | METHODS

2.1 | Design, participants and context

A cross-sectional online survey dealing with the referral processes to PC was performed in 2016–2017. The description of the concept of PC was defined in line with the WHO's definition (World Health Organisation, 2020). Data were collected by using a study-specific questionnaire. Participants included physicians caring for patients with cancer. These physicians were expected to handle different treatment strategies and to be responsible for giving medical oncological treatment or radiotherapy. The physicians were working as specialists and residents in oncology, haematology, pulmonology, urology, gynaecology and paediatric oncology in the south-eastern health region of Sweden. Physicians who were solely in charge of surgical oncological treatment were excluded. The region consists of three counties, with

each county having its own healthcare organisation and management. The study was approved by the Regional Ethical Review Board in Linköping, Sweden (registration number 2016/47-31).

2.2 | Study-specific questionnaire

A study-specific questionnaire was developed based on a literature review (Charlton, 2000; Glare, 2013; Smith et al., 2012; Temel et al., 2010; Wentlandt et al., 2012), clinical experience and semi-structured interviews with three qualified oncologists. The three interviews revealed that participants had different views regarding the meaning of 'introducing the concept of PC' to the patient. The concept could be equal to non-curative intention or introducing PC services based on the patient's individual needs. The interviews identified five main themes, leading to the formation of the five dimensions attitudes, practices, work-related experiences, personal experiences and the role of the organisation. A pilot study was performed with six skilled physicians working with cancer patients to ensure readability, clarity and content validity. The physicians were asked to answer the following questions: Do you understand the issues? Are the questions relevant in relation to clinical challenges within the field of cancer and PC? Do you think any issue has been left out? Are the options (Likert scale) relevant for the issues? After feedback and revisions, the questionnaire was re-tested by three physicians. Every participant stated that the questionnaire covered central themes for physicians working with cancer patients. Minor changes were performed regarding linguistic formulations. The time to complete the questionnaire was estimated at 10–15 min. Options were presented on 6-point Likert scales (ranging from 1 = *never* to 6 = *always* or 1 = *very negative* to 6 = *very positive*), multiple-choice questions (rating 'yes', 'no' and 'I partly agree' or 'very good', 'good', 'acceptable', 'bad' and 'I do not know') and freely worded answers. The final version of the questionnaire consisted of 69 questions covering the above-mentioned five dimensions and demographic data. In this study, three of the five dimensions (attitudes, practices and work-related experiences), in total 28 questions, together with demographic data are presented.

2.3 | Attitudes

The dimension of attitudes ($n = 3$) reflect aspects of the physician's approaches to PC, such as one's personal assess to potential positive consequences for the patient.

2.4 | Practices

This dimension ($n = 19$) deals with issues related to the time point for referral to PC, which terms the physician uses to explain the concept of care and how the recipient is informed about the referral.

2.5 | Work-related experiences

Within this dimension ($n = 6$), aspects of the role of feedback after referral and the process of motivating the patient are presented.

The results from the dimension of personal experiences will be deepened through a qualitative study design. In a study with patient safety focus, the results regarding the role of the organisation will be presented.

2.6 | Data collection

The survey with questionnaires was performed between November 2016 and February 2017, with four reminders. Operative managers of 28 departments in nine hospitals were informed about the study, and 27 agreed to include their units. All physicians ($n = 508$) who worked at these units were identified by the Departments of Human Resources in each county. An invitation to participate in the survey was sent by e-mail, together with an introductory letter. In this letter, a link to the survey in the web-based system, 'esMaker' (Version N3X, Entergate AB), was attached. The esMaker system automatically anonymised data. The following screening question was posted: 'Do you work as a physician within oncology, urology, haematology, gynaecology, pulmonology or paediatrics, and treat patients with cancer?' Opening and answering the survey was regarded as informed consent. To be able to access the response frequency of the target population, the operative managers at the participating hospitals were contacted to retrieve information on the number of presumptive eligible physicians in each department.

2.7 | Statistical analysis

Collected data were imported into IBM SPSS Version 24.0 (IBM Corp., Armonk, NY, USA) and StataCorp. 2019. Stata: Release 16. Statistical Software (StataCorp LLC, College Station, TX, USA). Descriptive statistics were calculated for all questions/variables, including demographic data, presenting frequencies and percentage. To facilitate the interpretation of the results, we have categorised the 6-point Likert scales into three groups, that is, *seldom* (Likert scales 1–2), *sometimes* (Likert scales 3–4) and *often* (Likert scales 5–6). One question dealing with attitudes was categorised into *negative* (Likert scales 1–2), *neutral* (Likert scales 3–4) and *positive* (Likert scales 5–6). Specialties were analysed based on three groups: paediatric oncology, medical specialties (oncology, haematology and pulmonology) and surgical specialties (gynaecology and urology). Ordinal logistic regression analysis was performed to study potential influences of independent demographic variables, defined as gender, medical career, experiences in treating cancer patients and specialties (three groups). Furthermore, analyses were performed with the three dimensions of attitudes, practices and work-related experiences. All tests were two-tailed, and p -values < 0.01 were considered statistically significant. Freely worded answers were not analysed in the present study.

3 | RESULTS

The target population was defined as the 239 presumptive participants identified by the operative managers of participating departments, of which 130 responded to the study questionnaire, giving a response rate of 54.4%. The characteristics of the 130 participants are presented in Table 1. More than half of the participants were female (54.6%), and a majority were specialists/senior consultants (78.1%) with more than 10 years' experience working with cancer

TABLE 1 Description of the study population (N = 130)

Characteristic	N (%)
Gender	
Female	71 (54.6)
Male	59 (45.4)
Medical career	
Specialist/senior consultant	100 (78.1)
Resident	28 (21.9)
Missing	2
Experiences in treating cancer patients	
≤10 years	48 (40.7)
>10 years	70 (59.3)
Missing	12
Specialists and residents within	
Paediatric oncology	14 (10.8)
Gynaecology	38 (29.2)
Haematology	10 (7.7)
Oncology	36 (27.7)
Pulmonology	10 (7.7)
Urology	22 (16.9)
Specialties defined as	
Paediatric oncology	14 (10.7)
Medical specialties	56 (43.1)
Surgical specialties	60 (46.2)

TABLE 2 Questions covering the dimension of attitudes to PC

Items	Seldom N (%)	Sometimes N (%)	Often N (%)
When you introduce the concept of PC to a patient with cancer			
Do you think that this kind of care entails positive aspects for the patient?	1 (0.8)	25 (19.8)	100 (79.4)
When you have referred a patient with cancer			
Do you need feedback after the referral?	14 (11.7)	48 (40.0)	58 (48.3)
	Negative N (%)	Neutral N (%)	Positive N (%)
The role of early integration			
How do you feel about early integration of PC?	5 (4.4)	34 (30.1)	74 (65.5)

Note: The six-point Likert scales categorised into three groups, i.e. *seldom* (Likert scales 1–2), *sometimes* (Likert scales 3–4), *often* (Likert scales 5–6). Abbreviation: PC, palliative care.

patients (59.3%). The most common specialists were gynaecologists (29.2%) and oncologists (27.7%).

3.1 | Attitudes and practices

The vast majority of the participants (99.2%) stated that introducing the concept of PC could sometimes or often be beneficial for the patient and (88.3%) said that they appreciated feedback after referral. The general opinion about early integration of PC was positive (65.5%), and only a few (4.4%) responded that they were negative to this kind of approach (Table 2). The analysis revealed that the concept of 'PC' was often first mentioned to cancer patients in the following situations, that is, when they had a lack of symptom control (65.3%), after completing anti-cancer treatment (92.0%) or when shifting to end-of-life care (92.0%). Participants frequently used the term 'soothing' (61.1%) to describe the aim of care, while the term 'palliative' was used to a lesser extent (42.1%). The basis for the referral process to PC included a lack of symptom control (56.5%), when oncological treatment was discontinued (75.8%) or when shifting to end-of-life care (82.3%). In most cases, written documentation was the only source of information for the recipient (71.5%). The patients were regularly referred to specialised PC units (57.5%) or general practitioners for primary PC (21.3%). Only 7.5% of the responders stated that they often referred patients to early integration in PC (Table 3).

3.2 | Work-related experiences

When participants introduced the concept of PC, more than half (61.1%) said that they had a clear view of the framework of this care. PC providers commonly responded to referrals with written replies after taking care of the patient (51.6%) or used an automatic written confirmation (39.3%). Verbal feedback (8.3%) or feedback through a multi-disciplinary conference (4.2%) were unusual. Almost half of the participants found it easy to motivate the patient for referral to PC (41.9%) (Table 4).

TABLE 3 Questions covering the dimension of practices

Items	Seldom N (%)	Sometimes N (%)	Often N (%)
When do you introduce the concept of PC to a patient with cancer?			
a) Immediately when the patient is suffering from non-curable cancer	36 (28.3)	56 (44.1)	35 (27.6)
b) When the patient has lack of symptom control	13 (10.5)	30 (24.2)	81 (65.3)
c) When the disease has progressed, but there are more possible alternatives for anti-cancer treatment	31 (25.0)	54 (43.5)	39 (31.5)
d) When the dialogue about the decision to stop anti-cancer treatment is held	5 (4.0)	5 (4.0)	115 (92.0)
e) When the dialogue about the decision to shift treatment and care to end-of-life care is held	5 (4.0)	5 (4.0)	115 (92.0)
Which words do you use to explain the aim of care for a patient with non-curable cancer?			
a) Do you use the word palliative	29 (23.0)	44 (34.9)	53 (42.1)
b) Do you use the word soothing	18 (14.3)	31 (24.6)	77 (61.1)
c) Do you use the phrase 'making the tumour slow down'	22 (17.5)	39 (31.0)	65 (51.6)
When do you refer a patient with cancer to PC?			
a) When the patient is suffering from incurable cancer	38 (31.7)	56 (46.7)	26 (21.7)
b) When the patient has lack of symptom control	15 (12.1)	39 (31.5)	70 (56.5)
c) When the disease has progressed, but there are more possible alternatives for anti-cancer treatment	38 (30.9)	62 (50.4)	23 (18.7)
d) When the dialogue about the decision to stop anti-cancer treatment is held	9 (7.3)	21 (16.9)	94 (75.8)
e) When the dialogue about the decision to shift treatment and care to end-of-life care is held	8 (6.5)	14 (11.3)	102 (82.3)
How do you inform the recipient of your referral?			
a) Only by a written referral	10 (8.1)	25 (20.3)	88 (71.5)
b) Do you also inform verbally	57 (46.7)	46 (37.7)	19 (15.6)
c) At a multidisciplinary conference	78 (64.5)	32 (26.4)	11 (9.1)
To whom do you send your referral			
a) General practitioner for primary PC	42 (34.4)	54 (44.3)	26 (21.3)
b) Specialised PC unit	15 (12.5)	36 (30.0)	69 (57.5)
The role of early integration			
Do you refer patients for early integration to PC?	61 (50.8)	50 (41.7)	9 (7.5)

Note: The six-point Likert scales categorised into three groups, i.e. *seldom* (Likert scales 1–2), *sometimes* (Likert scales 3–4), *often* (Likert scales 5–6).

Abbreviation: PC, palliative care.

3.3 | The role of demographic data

Ordinal logistic regressions were performed to evaluate the influence of demographic variables on participants' PC-related attitudes,

practices and work-related experiences. Significant differences concerning PC-practices and work-related experiences are presented in Table 5. No significant differences were found regarding PC-related attitudes. In the logistic regression model, medical specialty was

TABLE 4 Questions covering the dimension of work-related experiences

Items	Seldom N (%)	Sometimes N (%)	Often N (%)
When you introduce the concept of PC to a patient with cancer			
Do you have a clear view about what it means for the patient?	7 (5.6)	42 (33.3)	77 (61.1)
When you have referred a patient with cancer			
a) Do you get an automatic written confirmation that your referral has been received?	41 (35.0)	30 (25.6)	46 (39.3)
b) Do you get a written reply after assessment of the patient?	25 (20.5)	34 (27.9)	63 (51.6)
c) Do you get any verbal feedback?	80 (66.1)	31 (25.6)	10 (8.3)
d) Do you get feedback through a multidisciplinary conference?	101 (84.2)	14 (11.7)	5 (4.2)
The role of early integration			
Do you find it easy to motivate your patient for the referral?	17 (16.2)	44 (41.9)	44 (41.9)

Note: The six-point Likert scales categorised into three groups, that is, *seldom* (Likert scales 1–2), *sometimes* (Likert scales 3–4), *often* (Likert scales 5–6).

Abbreviation: PC, Palliative care.

defined as the reference group. Significant differences were found regarding when participants from the three specialties (medical specialties, surgical specialties and paediatric oncology) introduced the concept of PC; referred their patients to PC and general practitioners; regarding aspects of feedback from the recipients; as well as the role of the multi-disciplinary conference. Paediatric oncologists introduced the concept of PC immediately to their patients significantly more often than medical specialties ($p = 0.004$). Medical specialties used the phrase ‘making the tumour slow down’ to explain the aim of care for a patient with incurable cancer to a larger extent than paediatric oncologists ($p = 0.002$) and surgical specialties ($p = 0.001$). Medical specialties referred their patients to early PC significantly more often than surgical specialties ($p < 0.001$) and compared to paediatric oncologists when ending cancer treatment ($p < 0.001$) and when shifting to end-of-life care ($p < 0.001$). When paediatric oncologists referred their patient, they informed the recipient verbally ($p = 0.001$), received verbal feedback ($p = 0.001$) and got feedback at a multidisciplinary conference ($p = 0.006$) to a larger extent than medical specialties. Medical specialties sent their referral to general practitioners for primary PC to a higher degree compared to paediatric oncologists ($p = 0.003$).

4 | DISCUSSION

This study aimed to explore the attitudes, practices and work-related experiences among physicians who work with cancer patients who may be in need of early PC. The study presents data regarding the referral process, integration and transition between oncological treatment and PC in south-eastern Sweden.

The present study showed that most physicians introduced the concept of PC to the patient late in the disease trajectory, that is, when ending anti-cancer treatment, shifting to end-of-life care or

when the patient had a lack of symptom control. This late action was in spite of their overall positive attitude to early integration of PC. Paediatric oncologists differed significantly from medical specialties by introducing PC as soon as the patient was found to be suffering from incurable cancer. The majority of the physicians, regardless of their experience, thought that the concept of PC would be beneficial for the patient and had a clear view of the aim of the care.

Among the physicians in our study, educational levels and experience of oncology care varied. However, we could not find any significant differences regarding attitudes or practices to PC between residents and specialists. Still, it is important to be aware of the role of experience. Previous research has shown that physicians with a low grade of training in PC can be unprepared for the task (Axelsson, 2022), as well as the risk of developing distress and burn-out (Mougalian et al., 2013). Although younger physicians' work-related experience may be restricted, these results indicate that the residents probably had supervisors supporting their daily work with cancer patients in the palliative setting.

Previous studies have pointed out that both healthcare providers and patients often associate PC with end-of-life care and that it can increase the professionals' and the patients' sense of hopelessness (Horlait et al., 2016). It can be a challenge for the physician to make sure that the patient understands that early integration is not equal to giving up. The participating physicians seldom used the word ‘palliative’ when describing the aim of treatment for a patient with incurable cancer. To use other words like ‘soothing’ and the phrase ‘making the tumour slow down’ can be a way to avoid distress for the patient and their families, thereby conveying the message that cancer is a chronic disease that can be handled, though not cured. Studies have suggested that naming the service ‘supportive care’ could facilitate early referral (Dalal et al., 2011; Fadul et al., 2009; Wentlandt et al., 2012). From a professional point of view, paraphrases can be defined as coping strategies in severe circumstances (Stenmarker et al., 2010).

TABLE 5 Dimensions of practices and work-related experiences in relation to specialties

Dimensions/items and questions	Specialties	Seldom N (%)	Sometimes N (%)	Often N (%)	OR (95% CI)	P
<i>Dimension of practices</i>						
When do you introduce the concept of PC to a patient with cancer						
Immediately when the patient is suffering from incurable cancer?	Medical	15 (27.3)	26 (47.3)	14 (25.4)	1.0 (ref)	
	Surgical	20 (33.3)	28 (46.7)	12 (20.0)	0.74 (0.38–1.48)	0.399
	Paediatric	1 (8.3)	2 (16.7)	9 (75.0)	8.22 (2.00–33.78)	0.004
Which words do you use to explain the aim of care for a patient with incurable cancer						
Do you use the phrase “making the tumour slow down”?	Medical	3 (5.45)	14 (25.4)	38 (69.1)	1.0 (ref)	
	Surgical	16 (26.7)	19 (31.7)	25 (41.7)	0.28 (0.13–0.58)	0.001
	Paediatric	3 (27.3)	6 (54.6)	2 (18.2)	0.16 (0.05–0.52)	0.002
When do you refer a patient with cancer to PC						
When the dialogue about the decision to stop anti-cancer treatment is held?	Medical	3 (5.6)	5 (9.3)	46 (85.2)	(1.0 ref)	
	Surgical	1 (1.7)	13 (21.7)	46 (76.7)	0.61 (0.24–1.60)	0.319
	Paediatric	5 (50.0)	3 (30.0)	2 (20.0)	0.03 (0.01–0.15)	<0.001
When the dialogue about the decision to shift treatment and care to end-of-life care is held?	Medical	3 (5.4)	3 (5.4)	49 (89.1)	1.0 (ref)	
	Surgical	1 (1.7)	8 (13.6)	50 (84.8)	0.72 (0.24–2.17)	0.562
	Paediatric	4 (40.0)	3 (30.0)	3 (30.0)	0.05 (0.01–0.22)	<0.001
How do you inform the recipient of your referral						
Only by a written referral?	Medical	3 (5.6)	10 (18.5)	41 (75.9)	1.0 (ref)	
	Surgical	1 (1.7)	14 (23.3)	45 (75.0)	1.0 (0.43–2.34)	0.994
	Paediatric	6 (66.7)	1 (11.1)	2 (22.2)	0.03 (0.01–0.17)	<0.001
Do you also inform verbally?	Medical	26 (48.2)	22 (40.7)	6 (11.1)	1.0 (ref)	
	Surgical	29 (49.2)	24 (40.7)	6 (10.2)	0.95 (0.47–1.92)	0.891
	Paediatric	2 (22.2)	0 (0.0)	7 (77.8)	19.27 (3.39–109.53)	0.001
At a multi-disciplinary conference?	Medical	29 (54.7)	18 (34.0)	6 (11.3)	1.0 (ref)	
	Surgical	47 (79.7)	9 (15.2)	3 (5.1)	0.31 (0.14–0.72)	0.006
	Paediatric	2 (22.2)	5 (55.6)	2 (22.2)	3.08 (0.84–11.20)	0.088
To whom do you send your referral						
General practitioner for primary PC?	Medical	10 (18.2)	34 (61.8)	11 (20.0)	1.0 (ref)	
	Surgical	24 (42.1)	18 (31.6)	15 (26.3)	0.61 (0.30–1.23)	0.164
	Paediatric	8 (80.0)	2 (20.0)	0 (0.0)	0.08 (0.02–0.42)	0.003
The role of early integration						
Do you refer patients to early integration to PC?	Medical	15 (27.8)	33 (61.1)	6 (11.1)	1.0 (ref)	
	Surgical	39 (67.2)	17 (29.3)	2 (3.4)	0.20 (0.09–0.44)	<0.001
	Paediatric	7 (87.5)	0 (0.0)	1 (12.5)	0.07 (0.01–0.61)	0.016
<i>Dimension of work-related experiences</i>						
When you have referred a patient with cancer						
Do you get any verbal feedback?	Medical	36 (66.7)	16 (29.6)	2 (3.7)	1.0 (ref)	
	Surgical	42 (71.2)	14 (23.7)	3 (5.1)	0.84 (0.38–1.85)	0.663
	Paediatric	2 (25.0)	1 (12.5)	5 (62.5)	19.01 (3.56–101.50)	0.001
Do you get feedback through a multi-disciplinary conference?	Medical	45 (83.3)	6 (11.1)	3 (5.6)	1.0 (ref)	
	Surgical	54 (91.5)	4 (6.8)	1 (1.7)	0.45 (0.14–1.45)	0.181
	Paediatric	2 (28.6)	4 (57.1)	1 (14.3)	8.27 (1.84–37.14)	0.006

Notes: Statistical significant differences $P < 0.01$. The table presents a selection of significant variables ($N = 11$) out of 56 performed analyses regarding specialties by ordinal logistic regression. The six-point Likert scales categorised into three groups, that is, *seldom* (Likert scales 1–2), *sometimes* (Likert scales 3–4), *often* (Likert scales 5–6).

Abbreviation: PC, palliative care.

Previous research has shown that physicians have difficulty breaking bad news (Friedrichsen & Milberg, 2006; Horlait et al., 2016) and there is a risk of being 'blamed for the message' (Stenmarker et al., 2010). To introduce the concept of PC late in the disease trajectory can be a way for the physician to be sure that the patient is ready to accept the fact of having an incurable illness when there are no other remaining anti-cancer therapies. Still, the patient's unrealistic expectations of a cure can be difficult to handle and represent a well-known barrier for referral (Horlait et al., 2016). On a personal level, the doctor can struggle with distress at disrupting or harming a close patient–doctor relationship (Hay et al., 2017a; Horlait et al., 2016). In line with the literature (Lefkowitz et al., 2014; Wentlandt et al., 2012; Wentlandt et al., 2014; Wright & Forbes, 2017), physicians in the present study referred their patients to PC when they were suffering from inadequate symptom control or late in the disease course. The strategy of using symptom control as a way to introduce the need for PC has been shown previously (Hay et al., 2017b). Previous research has also shown that the timing of referral to PC differs between medical specialties (Hui, Bansal, et al., 2015; Hui, Park, et al., 2015). This is in line with the results from the current study concerning physicians caring for adult cancer patients. In contrast, paediatric oncologists introduce the concept of PC early in the disease course. In accordance with the definition of WHO (1998) regarding PC and children, it is better to introduce PC as a term describing the total care of a child with cancer and his/her family. In line with this approach (Snaman et al., 2020; Waldman & Wolfe, 2013), the basic organisational model for the majority of paediatric oncologists in this study includes being responsible for the child's care as the disease proceeds from curable to incurable stages (Waldman & Wolfe, 2013). If or when the paediatric oncologists in this study referred their patients, they primarily turned to specialised units and used verbal contact to a large extent to exchange information, in comparison with the medical specialists who used written information as the main source of communication. Different ways of communication between specialties are probably related to the fact that few children suffer from cancer with end-of-life care compared to adults. In clinical practice, this may indicate that paediatric oncologists can spend more time and effort when they refer their patients and assure themselves that the child will receive good care (Snaman et al., 2020; Waldman & Wolfe, 2013). When it comes to the role of motivation, the majority of the participating physicians from different specialties said that they found it easy to motivate the patient for referral to PC, which is in line with previous studies (Wentlandt et al., 2012). Furthermore, studies have shown that the patients, both children and adults with cancer, often express positive feelings about PC (Chosich et al., 2020; Levine et al., 2017).

Today, cancer is regarded as a chronic disease by WHO (Kaasa et al., 2018; World Health Organisation, 2018). The number of anti-cancer therapies and cancer survivors are growing. Therapies, including the novel immunomodulatory approach, have made the course of cancer unpredictable and the expectations of patients and physicians are high (Wiesenthal et al., 2018). In line with the results of this study, one might expect that such medical oncological improvements would result in patients being referred at a late phase

of disease. On the other hand, early integration would probably help specialists working with cancer patients to focus on tumour-directed treatment. At the same time, skilled physicians working in PC can handle the symptom management and provide local high-quality PC. Sharing responsibility for the patient's care with other colleagues may ease the transition process and enables clarification of the different roles.

Studies involving physicians from different specialties dealing with cancer patients and the transition to PC are rare. To the best of our knowledge, this is the first study among Swedish physicians examining attitudes, practices and experiences regarding referral of cancer patients to PC. The strength of this study is the regional population-based approach, and the design featuring an online questionnaire, which provides a rapid way of distribution. Limitations are primarily related to the number of participants, with relatively few physicians from some specialties, the moderate response rate, and the risk of bias with responders already interested in the subject.

In conclusion, the majority of the participating physicians declared their positive attitude towards active treatment integrated with early PC, but still they referred patients late in the disease trajectory. This approach can reduce the patient's opportunity of improving quality of life during the course of the disease. The discrepancy between the physicians' intentions and their actions might be explained by several and multifactorial reasons. The research group will strive to deepen knowledge of the physician's challenges and the role of the organisation, with a focus on the transition process.

ACKNOWLEDGMENTS

The authors want to thank all the participating physicians.

CONFLICT OF INTEREST

The authors declare that they have no conflicts of interest.

DATA AVAILABILITY STATEMENT

In accordance with the ethical approval, the authors will not be sharing the data.

ORCID

Karin Adolfsson  <https://orcid.org/0000-0001-8649-9305>

REFERENCES

- Axelsson, B. (2022). The challenge: Equal availability to palliative care according to individual need regardless of age, diagnosis, geographical location, and care level. *International Journal of Environmental Research and Public Health*, 19(7), 4229–4236. <https://doi.org/10.3390/ijerph19074229>
- Bakitas, M., Lyons, K. D., Hegel, M. T., Balan, S., Brokaw, F. C., Seville, J., Hull, J. G., Li, Z., Tosteson, T. D., Byock, I. R., & Ahles, T. A. (2009). Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The project ENABLE II randomized controlled trial. *Jama*, 302(7), 741–749. <https://doi.org/10.1001/jama.2009.1198>
- Centeno, C., Garralda, E., Carrasco, J. M., den Herder-van der Eerden, M., Aldridge, M., Stevenson, D., Meier, D. E., & Hasselaar, J. (2017). The palliative care challenge: Analysis of barriers and opportunities to

- integrate palliative care in Europe in the view of national associations. *Journal of Palliative Medicine*, 20(11), 1195–1204. <https://doi.org/10.1089/jpm.2017.0039>
- Charlton, R. (2000). Research: Is an 'ideal' questionnaire possible? *International Journal of Clinical Practice*, 54(6), 356–359.
- Chosich, B., Burgess, M., Earnest, A., Franco, M., Runacres, F., William, L., Poon, P., & Yoong, J. (2020). Cancer patients' perceptions of palliative care. *Support Care Cancer*, 28(3), 1207–1214. <https://doi.org/10.1007/s00520-019-04917-8>
- Dalal, S., Palla, S., Hui, D., Nguyen, L., Chacko, R., Li, Z., Fadul, N., Scott, C., Thornton, V., Coldman, B., Amin, Y., & Bruera, E. (2011). Association between a name change from palliative to supportive care and the timing of patient referrals at a comprehensive cancer center. *The Oncologist*, 16(1), 105–111. <https://doi.org/10.1634/theoncologist.2010-0161>
- Dhollander, N., Deliëns, L., Van Belle, S., De Vleminck, A., & Pardon, K. (2018). Differences between early and late involvement of palliative home care in oncology care: A focus group study with palliative home care teams. *Palliative Medicine*, 32(7), 1275–1282. <https://doi.org/10.1177/0269216318774676>
- El-Jawahri, A., Greer, J. A., Pirl, W. F., Park, E. R., Jackson, V. A., Back, A. L., Kamdar, M., Jacobsen, J., Chittenden, E. H., Rinaldi, S. P., Gallagher, E. R., Eusebio, J. R., Fishman, S., VanDusen, H., Li, Z., Muzikansky, A., & Temel, J. S. (2017). Effects of early integrated palliative care on caregivers of patients with lung and gastrointestinal cancer: A randomized clinical trial. *The Oncologist*, 22(12), 1528–1534. <https://doi.org/10.1634/theoncologist.2017-0227>
- Fadul, N., Elsayem, A., Palmer, J. L., Del Fabbro, E., Swint, K., Li, Z., Poulter, V., & Bruera, E. (2009). Supportive versus palliative care: what's in a name?: A survey of medical oncologists and midlevel providers at a comprehensive cancer center. *Cancer*, 115(9), 2013–2021. <https://doi.org/10.1002/cncr.24206>
- Ferrell, B. R., Temel, J. S., Temin, S., Alesi, E. R., Balboni, T. A., Basch, E. M., Finn, J. I., Paice, J. A., Peppercorn, J. M., Phillips, T., Stovall, E. L., Zimmermann, C., & Smith, T. J. (2017). Integration of palliative care into standard oncology care: American Society of Clinical Oncology clinical practice guideline update. *Journal of Clinical Oncology*, 35(1), 96–112. <https://doi.org/10.1200/jco.2016.70.1474>
- Friedrichsen, M., & Milberg, A. (2006). Concerns about losing control when breaking bad news to terminally ill patients with cancer: physicians' perspective. *Journal of Palliative Medicine*, 9(3), 673–682. <https://doi.org/10.1089/jpm.2006.9.673>
- Glare, P. A. (2013). Early implementation of palliative care can improve patient outcomes. *Journal of the National Comprehensive Cancer Network*, 11(Suppl 1), S3–S9. <https://doi.org/10.6004/jnccn.2013.0212>
- Government Offices of Sweden. (2018). [Long-term orientation for the national work with cancer services]. Retrieved from <https://www.regeringen.se/informationsmaterial/2018/05/langsiktig-inriktning-for-det-nationella-arbetet-med-cancervarden/>
- Granek, L., Krzyzanowska, M. K., Tozer, R., & Mazzotta, P. (2013). Oncologists' strategies and barriers to effective communication about the end of life. *Journal of Oncology Practice/ American Society of Clinical Oncology*, 9(4), e129–e135. <https://doi.org/10.1200/jop.2012.000800>
- Hay, C. M., Lefkowitz, C., Crowley-Matoka, M., Bakitas, M. A., Clark, L. H., Duska, L. R., Urban, R. R., Chen, L. M., Creasy, S. L., & Schenker, Y. (2017a). Gynecologic oncologist views influencing referral to outpatient specialty palliative care. *International Journal of Gynecological Cancer*, 27(3), 588–596. <https://doi.org/10.1097/igc.0000000000000893>
- Hay, C. M., Lefkowitz, C., Crowley-Matoka, M., Bakitas, M. A., Clark, L. H., Duska, L. R., Urban, R. R., Creasy, S. L., & Schenker, Y. (2017b). Strategies for introducing outpatient specialty palliative care in gynecologic oncology. *Journal of Oncology Practice/ American Society of Clinical Oncology*, 13(9), e712–e720. <https://doi.org/10.1200/jop.2017.020818>
- Horlait, M., Chambaere, K., Pardon, K., Deliëns, L., & Van Belle, S. (2016). What are the barriers faced by medical oncologists in initiating discussion of palliative care? A qualitative study in Flanders, Belgium. *Support Care Cancer*, 24(9), 3873–3881. <https://doi.org/10.1007/s00520-016-3211-5>
- Hui, D., Bansal, S., Park, M., Reddy, A., Cortes, J., Fossella, F., & Bruera, E. (2015). Differences in attitudes and beliefs toward end-of-life care between hematologic and solid tumor oncology specialists. *Annals of Oncology*, 26(7), 1440–1446. <https://doi.org/10.1093/annonc/mdv028>
- Hui, D., Park, M., Liu, D., Reddy, A., Dalal, S., & Bruera, E. (2015). Attitudes and beliefs toward supportive and palliative care referral among hematologic and solid tumor oncology specialists. *The Oncologist*, 20(11), 1326–1332. <https://doi.org/10.1634/theoncologist.2015-0240>
- Jordan, K., Aapro, M., Kaasa, S., Ripamonti, C. I., Scotte, F., Strasser, F., Young, A., Bruera, E., Herrstedt, J., Keefe, D., Laird, B., Walsh, D., Douillard, J. Y., & Cervantes, A. (2018). European Society for Medical Oncology (ESMO) position paper on supportive and palliative care. *Annals of Oncology*, 29(1), 36–43. <https://doi.org/10.1093/annonc/mdx757>
- Kaasa, S., Loge, J. H., Aapro, M., Albrecht, T., Anderson, R., Bruera, E., Brunelli, C., Caraceni, A., Cervantes, A., Currow, D. C., Deliëns, L., Fallon, M., Gómez-Batiste, X., Grotmol, K. S., Hannon, B., Haugen, D. F., Higginson, I. J., Hjermstad, M. J., Hui, D., ... Lundebyt, T. (2018). Integration of oncology and palliative care: A Lancet Oncology Commission. *The Lancet Oncology*, 19(11), e588–e653. [https://doi.org/10.1016/s1470-2045\(18\)30415-7](https://doi.org/10.1016/s1470-2045(18)30415-7)
- La Russa, M., Zapardiel, I., Zalewski, K., Laky, R., Dursun, P., Sukhin, V., Lindquist, D., & Lindemann, K. (2020). Assessment of palliative care training in gynaecological oncology: A survey among European Network of Young Gynaec-Oncologists (ENYGO) members. *BMJ Supportive & Palliative Care*, 1–4. <https://doi.org/10.1136/bmjspcare-2020-002233>
- Lefkowitz, C., Binstock, A. B., Courtney-Brooks, M., Teuteberg, W. G., Leahy, J., Sukumvanich, P., & Kelley, J. L. (2014). Predictors of palliative care consultation on an inpatient gynecologic oncology service: Are we following ASCO recommendations? *Gynecologic Oncology*, 133(2), 319–325. <https://doi.org/10.1016/j.ygyno.2014.02.031>
- Levine, D. R., Mandrell, B. N., Sykes, A., Pritchard, M., Gibson, D., Symons, H. J., Wendler, D., & Baker, J. N. (2017). Patients' and parents' needs, attitudes, and perceptions about early palliative care integration in pediatric oncology. *JAMA Oncology*, 3(9), 1214–1220. <https://doi.org/10.1001/jamaoncol.2017.0368>
- Mougalian, S. S., Lessen, D. S., Levine, R. L., Panagopoulos, G., Von Roenn, J. H., Arnold, R. M., Block, S. D., & Buss, M. K. (2013). Palliative care training and associations with burnout in oncology fellows. *The Journal of Supportive Oncology*, 11(2), 95–102. <https://doi.org/10.12788/j.suponc.0001>
- Regionala cancercentrum i samverkan. (2021a). [National guidelines for palliative care of children]. Retrieved from <https://kunskapsbanken.cancercentrum.se/diagnoser/palliativ-var-d-av-barn/>
- Regionala cancercentrum i samverkan. (2021b). [National guidelines for palliative care]. Retrieved from <https://kunskapsbanken.cancercentrum.se/diagnoser/palliativ-var-d/>
- Smith, T. J., Temin, S., Alesi, E. R., Abernethy, A. P., Balboni, T. A., Basch, E. M., Ferrell, B. R., Loscalzo, M., Meier, D. E., Paice, J. A., Peppercorn, J. M., Somerfield, M., Ellen Stovall, E., & Von Roenn, J. H. (2012). American Society of Clinical Oncology provisional clinical opinion: The integration of palliative care into standard oncology care. *Journal of Clinical Oncology*, 30(8), 880–887. <https://doi.org/10.1200/jco.2011.38.5161>
- Snaman, J., McCarthy, S., Wiener, L., & Wolfe, J. (2020). Pediatric palliative care in oncology. *Journal of Clinical Oncology*, 38(9), 954–962. <https://doi.org/10.1200/jco.18.02331>

- Sorensen, A., Le, L. W., Swami, N., Hannon, B., Krzyzanowska, M. K., Wentlandt, K., Rodin, G., & Zimmermann, C. (2020). Readiness for delivering early palliative care: A survey of primary care and specialised physicians. *Palliative Medicine*, 34(1), 114–125. <https://doi.org/10.1177/0269216319876915>
- Stenmarker, M., Hallberg, U., Palmérus, K., & Márky, I. (2010). Being a messenger of life-threatening conditions: Experiences of pediatric oncologists. *Pediatric Blood & Cancer*, 55(3), 478–484. <https://doi.org/10.1002/pbc.22558>
- Temel, J. S., Greer, J. A., Muzikansky, A., Gallagher, E. R., Admane, S., Jackson, V. A., Dahlin, C. M., Blinderman, C. D., Jacobsen, J., Pirl, W. F., Billings, J. A., & Lynch, T. J. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. *The New England Journal of Medicine*, 363(8), 733–742. <https://doi.org/10.1056/NEJMoa1000678>
- The National Board of Health and Welfare. (2016). [National guidelines - Evaluation 2016 - Palliative care in the end-of-life. Indicators and grounds for assessments]. Retrieved from <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/nationella-riktlinjer/2016-12-12.pdf>
- The National Board of Health and Welfare. (2021a). Statistics on cancer incidence 2020a. Retrieved from <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/statistik/2021-12-7701.pdf>
- The National Board of Health and Welfare. (2021b). Statistics on causes of death 2020b. Retrieved from <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/statistik/2021-6-7454.pdf>
- The Swedish Registry of Palliative Care. (2021). Annual report 2020. Retrieved from <https://palliativregistret.se/media/ydvnookr/%C3%A5rsrapport-2020.pdf>
- Waldman, E., & Wolfe, J. (2013). Palliative care for children with cancer. *Nature Reviews. Clinical Oncology*, 10(2), 100–107. <https://doi.org/10.1038/nrclinonc.2012.238>
- Wentlandt, K., Krzyzanowska, M. K., Swami, N., Rodin, G., Le, L. W., Sung, L., & Zimmermann, C. (2014). Referral practices of pediatric oncologists to specialized palliative care. *Support Care Cancer*, 22(9), 2315–2322. <https://doi.org/10.1007/s00520-014-2203-6>
- Wentlandt, K., Krzyzanowska, M. K., Swami, N., Rodin, G. M., Le, L. W., & Zimmermann, C. (2012). Referral practices of oncologists to specialized palliative care. *Journal of Clinical Oncology*, 30(35), 4380–4386. <https://doi.org/10.1200/jco.2012.44.0248>
- Wiesenthal, A. C., Patel, S. P., LeBlanc, T. W., Roeland, E. J., & Kamal, A. H. (2018). Top ten tips for palliative care clinicians caring for cancer patients receiving immunotherapies. *Journal of Palliative Medicine*, 21(5), 694–699. <https://doi.org/10.1089/jpm.2018.0107>
- World Health Organisation. (1998). Cancer pain relief and palliative care in children. In. Geneva: World Health Organization.
- World Health Organisation. (2018, 01 Dec 2018). Noncommunicable diseases. Retrieved from <https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases>
- World Health Organisation. (2020). Palliative care. Retrieved from <https://www.who.int/news-room/fact-sheets/detail/palliative-care>
- Wright, B., & Forbes, K. (2017). Haematologists' perceptions of palliative care and specialist palliative care referral: A qualitative study. *BMJ Supportive & Palliative Care*, 7(1), 39–45. <https://doi.org/10.1136/bmjspcare-2014-000689>
- Zimmermann, C., Swami, N., Krzyzanowska, M., Leighl, N., Rydall, A., Rodin, G., Tannock, I., & Hannon, B. (2016). Perceptions of palliative care among patients with advanced cancer and their caregivers. *CMAJ*, 188(10), E217–E227. <https://doi.org/10.1503/cmaj.151171>

How to cite this article: Adolfsson, K., Kreicbergs, U., Bratthäll, C., Holmberg, E., Björk-Eriksson, T., & Stenmarker, M. (2022). Referral of patients with cancer to palliative care: Attitudes, practices and work-related experiences among Swedish physicians. *European Journal of Cancer Care*, 31(6), e13680. <https://doi.org/10.1111/ecc.13680>