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ORIGINAL ARTICLE

# Early palliative care: current status of integration within German comprehensive cancer centers

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**Abstract**
*Purpose* The aim of this study is to describe how models of early integration (EI) of specialized palliative care (SPC) are applied to German comprehensive cancer center (CCCs).
*Methods* Heads of SPC departments of the 15 German CCCs were asked by email to describe the situation of early SPC in their CCC. The responses were analyzed using MAXQDA.
*Results* Thirteen answers were allowed to be analyzed. Most of the department heads report that EI models of SPC are partially applied in the CCC (responses with "yes" or "partly," $n$ = 10). Though they often describe that the models' implementation needs optimization and depends on temporary and financial restrictions or it has a pilot character. Models compromise structures like SPC unit, inpatient/outpatient SPC consultation team, and participation of members of SPC team in tumor boards. Moreover, other EI models of SPC quoted by the participants were standard operating procedures (SOP), screening tools, and information material for physicians, patients, and their related persons.
*Conclusions* Currently, German CCC models of EI of SPC are not applied in a standardized way. Approaches are still very diverse.

**Keywords** Early specialized palliative care · Integration · Palliative care · Service · Oncology · Comprehensive cancer center

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## Introduction

Comprehensive cancer centers (CCCs) offer the most complex cancer care and lead research and educational institutions nationwide [9]. General palliative care and specialized palliative care (SPC) are essential in cancer care [10, 11]. However, level, model, and timing of integration are heterogeneous [1, 2, 4, 6, 7]. But in fact early integration (EI) of SPC is recommended by the World Health Organization (WHO) [14] and the American Society of Clinical Oncology (ASCO) [13]. The ASCO stated, that "combined standard oncology care and palliative care should be considered early in the course of illness for any patient with metastatic cancer and/or high symptom burden" [13]. This definition has been adopted by the National Guideline on Palliative Care for Patients with Incurable Cancer and hence by our working group palliative care within the network of German CCCs [3].

In 2014, a status analysis [1] outlined characteristics of SPC in the CCCs funded by the German Cancer Aid. The aim of the short survey presented here was to assess the

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current situation of implementation of models of EI of SPC within the CCC network.

## Method

In February 2016, the views of the heads of SPC departments of the 15 German CCC sites were explored regarding their models of EI of SPC via email. The heads of departments were the focus of the exploration, as they may best ensure a comprehensive view on strategic developments concerning EI of SPC. The method of a short email survey was chosen due to convenience as it was originally planned to support a presentation on the status quo of EI in German Cancer Care held on the German Cancer Conference in 2016. However, for the presentation, the results were not analyzed in detail. The exploration was designed (rational-intuitive) by a physician (FN) who is the head of a non-funded Comprehensive Cancer Center and performed and analyzed conjointly by members of the working group (JB, SS, CO).

The answers were anonymized and subsequently evaluated using an inductive method with the qualitative data analysis software MAXQDA 12.

## Results

The heads of the department for palliative medicine of 13 CCC sites (86%) responded as follows. All but one CCC had a palliative care unit which is spatially divided (93.3%). In 2014, the number of palliative care beds in the CCC network ranged from 7 to 36 (median, 10) [1]. Within one site, palliative care beds are integrated in another department. A multi-professional inpatient consultation team was available at 12 of 15 locations (80.0%).

### Have you already applied a model of EI of SPC in your CCC?

Three persons stated clearly "yes." However, the majority of respondents ($n$ = 7) argue that EI models exist, but can be optimized and adapted in the future. Two participants consented that their CCC did not yet establish an integrated model of EI of SPC.

> We have here in #location# not a concept that we can call seriously "implemented". We have already tested various constructs, but so far without a successful sustainable establishment.

*If you have applied such a model, can you briefly describe its content and structures?*

> In our hospital there is a well-functioning palliative care consultation team, and consultation hours for palliative care patients. The nucleus is our palliative care unit.

Applied structural models contain the establishment of a SPC unit, an inpatient/ outpatient SPC consultation team, participation of SPC staff in interdisciplinary tumor boards, and training and education of medical students. One CCC renamed their SPC outpatient clinic into supportive care outpatient clinic. The integration of physicians of SPC into the inpatient and outpatient oncological clinics was designated as a model of EI as well.

Process-based measures to support EI include (a) standard operating procedures (SOPs), and (b) screening, prognosis or assessment tools. Additionally, CCCs (c) provide information about SPC and other supportive measures which have been submitted to physicians, patients and relatives (advice on the SPC services, pastoral care, psychology, social work, and physio, nutrition or creative therapy).

> There are a number of SOPs in which the early integration of palliative care is firmly anchored.

More than half (7/13) of respondents reported that models of EI of SPC within their CCC are tested within scientific projects for a limited time and with restricted financial resources. These projects are performed in cooperation with hospital management, pain services, and other departments. The main scientific interests of the CCCs were currently the development of screening tools for early identification of patients with SPC needs. For this purpose, the surprise question ("Would I be surprised if this patient died in the next year?") [5, 8] in combination with the "Integrated Palliative Care Outcome Scale" (IPOS) [12] is used in a running project. In a further CCC, a project was initiated to implement a check box within the mandatory electronic nurse documentation system for activating a SPC consultation.

> Currently [we have] a small pilot project with the pain service. It gives all cancer pain patients who were seen by the service, the IPOS. The bow completed by the patients is then picked up by our palliative service and [it is] examined how high are the palliative care needs. When high, we return to the station and offer a palliative consultation. But [it] runs very variable and does not work as well as desired.

In one CCC, a multi-professional, outpatient counseling team (physician, nurse, and social worker) is established. In another CCC, a four-step model of structured dialogue in each stage of disease (diagnosis, stable

situation, progression and termination of tumor-specific therapy) is planned.

The measures of EI are offered at different times. SPC first contact was conducted during the first oncology consultation, during the second cycle of chemotherapy or even 8 weeks after detection of malignant tumor.

*What kind of patient groups are targeted with this EI model?*

The reported EI models focus on patients with an incurable cancer disease. In the CCC network, patients with esophageal, pancreatic, lung, stomach, and brain cancer were targeted in particular.

**Why and for what patient groups could be useful the (development of) models for the EI of SPC?**

All respondents claimed models of EI of SPC as "useful," "important," or "necessary" for patients with incurable diseases, especially with tumors in the neck, nose or ears, bronchial carcinoma, pancreatic cancer, and young patients.

The reasons why EI models are considered useful:

- Support early and adequate symptom control (e.g., reduction of distress)
- Facilitate advance care planning
- Anticipate problems and intervene early
- Facilitate (informed) patients' access to SPC
- Relieve medical colleagues from medical wards offering primary care and it is of ethical and sociopolitical relevance

> Early integration also facilitates access to palliative care and reduces the fear of contact with the physician in palliative care [ … ]. The detailed information in the outpatient clinic often leads to the fact that patients contact us independently [ … ]. It also seems to result in a relief in the family system if it is clear that someone is well taken care at the end.

**What kind of final thoughts on "care models of EI in Germany" do you want to add?**

Currently, non-palliative care professionals and patients with long-lasting incurable cancer diseases were named as challenges regarding the implementation and application of measures of EI of SPC in funded CCCs. Time-limited projects, distinction between supportive and palliative care, lack of professionals, and scarce financial resources were mentioned as barriers for integrating models of EI of SPC.

> The establishment of such structures costs money (personnel resources, training in general palliative care) - not to implement with means of the palliative care department.

There is no doubt that early general palliative care is necessary and requires at least routine symptom and distress screening, milestone conversations about therapeutic goals and advance care planning. This should be carried out by all physicians who treat cancer patients. In more complex cases, access should be granted to the SPC.

Multi-professional SPC outpatient clinic, consultation team, SPC in day clinics, the offer of discussions, and automatically triggered activation of SPC in tumor boards should be fostered in the future.

Respondents stated that it is important to manage an adequate financial support for EI research such as the development and evaluation of screening tools for SPC needs.

## Conclusions

Currently, in most German CCCs no standardized model of EI of SPC exists. There are first attempts to integrate SPC early into the treatment process of cancer patients, though they are heterogeneous and have more or less pilot character.

There is an urgent need for a nationwide valid, empirically based, and easy to implement concept of EI of SPC in German CCCs. At present, SOPs and screening tools about SPC needs are only partly implemented.

However, time limits prevent the sustainability of the implementation which is needed. So funding of the respective structures is required.

## Limitations

Due to the fact that only physicians were asked, the perspectives of other professional groups and patients remained unseen in our exploration. The multi-professional views should be evaluated in more in depth studies in the future. However, it can be assumed that heads of palliative care departments are best informed about implementation and future plans referring models of EI of SPC.

This study is focused on the exploration of experts' views. A focus group or a qualitative interview design is recommended for further approaches. Responses to a survey via email may be limited. Nevertheless, answers were concise and the results can give an interesting overview.

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**Compliance with ethical standards**

**Conflict of interest** The authors declare that they have no conflict of interest.

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