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European Perspectives

Implementation of Best Practice Recommendations for Palliative Care in German Comprehensive Cancer Centers

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Key Words. Palliative care • Comprehensive Cancer Center • Implementation • Recommendations • Integration

Abstract

Background. From 2014 to 2017, the Palliative Medicine Working Group developed and published best practice recommendations for the integration of palliative care in Comprehensive Cancer Centers (CCCs) in Germany. To evaluate the implementation level of these recommendations in the CCCs an online survey was performed. Based on the results of this study, strategic tandem partnerships between CCCs should be built in order to foster further local development.

Materials and Methods. Directors of all CCCs were contacted by e-mail between December 2017 and February 2018. At the time of the survey, 15 CCCs were funded by the German Cancer Aid. The level of implementation of the recommendations in individual CCCs was established using a transtheoretical model.

Results. Between December 2017 and February 2018, all 15 contacted directors or their representatives of the CCCs took part in the survey. More than two thirds of the CCCs have a palliative service as well as a day clinic and palliative outpatient clinic. Regional networking and the provision of a palliative care unit were approved by all CCCs.

Conclusion. The publication of best practice recommendations was a milestone for the integration of palliative care in the CCCs. The majority of the German CCCs already fulfill essential organizational and structural requirements. There is a particular need for optimization in the provision of a basic qualification for general palliative care and emergency admission personnel. ***The Oncologist*** 2020;25:e259–e265

Implications for Practice: In 2017, the Palliative Medicine Working Group in the network of the German Comprehensive Cancer Centers (CCCs) published the best practice recommendations it had developed for the integration of palliative medicine in CCCs in Germany. In order to evaluate the level of implementation of the recommendations, an online survey of the CCC directors was established. The majority of German CCCs fulfil elementary organizational and structural requirements. However, there is still room for improvement in the provision of a basic qualification for general palliative care and emergency admission personnel.

Introduction

The fundamental aim of a Comprehensive Cancer Center (CCC) is to offer patients with cancer at all stages of the disease optimal and individualized health care based on the best available evidence [1]. A central role plays cancer research, especially in order to achieve continuous improvement of the quality of patient care [2]. In 2006, to bundle competencies, the "Comprehensive Cancer Center Initiative Germany" forum was established at the National Center for Tumor Diseases in Heidelberg [3]. Since 2009, cancer centers in Germany can apply to be labeled as a CCC funded by the German Cancer Aid. To ensure excellence, an international review process is performed. Already funded CCCs have to reapply on a regular basis, and they may lose their status.

Comprehensive cancer care includes palliative care to meet the needs of patients with incurable diseases and their families [4–6]. According to the 2002 World Health

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Organization definition, palliative care is defined as follows [7]: "Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." For the network of the funded CCCs, the following definition was specified and consented to [8]: "Palliative care at a CCC is focused on people with life-threatening cancer and aims to maintain or improve the quality of life of patients by preventing, detecting and reducing the physical, psychological, social and spiritual suffering that associated with a tumor disease. Palliative care is provided independently of the state of the disease, the place of treatment or current/planned therapy procedures. It is incorporated with foresight, but its focus is on the time during which a curation is no longer considered possible. The families of those involved are also in focus."

General palliative care is the responsibility of every clinically active member of a CCC. Specialized palliative care performed at the CCC by a qualified, multiprofessional team of physicians, nurses, social workers, physiotherapists, psychologists, pastors, and other professional groups should be involved in situations of severe symptom load and/or complex demands.

Excellent general and specialized palliative care at a CCC is based on the comprehensive observation of the latest evidence, to whose further development the structures of palliative care directly contribute via internal and cooperating research projects. Specialized palliative care staff participate in the advanced training of all professional groups in palliative issues in order to promote general and specialized palliative care in the CCC and the region. Specialized palliative care staff are involved in the curricular and extracurricular training of medical students and other health professionals [9].

Furthermore, palliative care has to follow the best possible evidence to ensure high quality. A significant contribution achieving this goal is provided by the Palliative Care Working Group within the CCC network. The overarching aims of the expert group are to assess palliative care in the individual centers, to develop common research projects, and to establish a common data basis. In addition, the Working Group has developed and continuously adapts standard operating procedures for palliative care [10–22].

A major task of the Working Group was fulfilled with the best practice recommendations for palliative care at the CCCs [9]. The development of best practice recommendations was consensus based with three Delphi rounds. Consensus was achieved for 29 recommendations, including a palliative care ward and mobile multiprofessional specialized palliative care team [23]. In order to assess the current implementation status of the recommendations, an online survey was conducted at the CCCs. The results are presented and discussed here. Based on these findings, topic-related, strategic tandem partnerships will be formed between the sites in the future, thus strengthening palliative care in the CCCs.

Materials and Methods

The survey was addressed to the CCCs that were funded by the German Cancer Aid at the time of the survey (December 2017). The individual CCC directors, members of the Management Committee of the CCC network, were invited to the online survey by e-mail. Participation and the answers to the online survey had no influence on the evaluation procedure in the "Oncological Centers of Excellence" funding program. If possible, the answer was submitted by the CCC Management Committee or, if appropriate, by a person appointed by the CCC Management Committee.

One CCC director volunteered to pilot the survey. After that, the questionnaire was marginally modified (order of questions and definition of the total number of patients, primary cases, and relapse cases). The survey was sent out in the beginning of December 2017 with a reminder in January 2018.

To assess the degree of implementation of the best practice recommendations in each of the CCCs, the transtheoretical model was used. This primarily refers to changes in behavior ("Stages of Change") [24]. However, the concept can also be applied in the context of organizational restructuring [25, 26]. The present study raises the status quo and distinguishes between the phases of lack of intention, formation of intention, preparation, action, and maintenance, so that processes, abilities, and motivation for changes can be represented (Table 1).

Results

From December 2017 to February 2018, 15 of 15 contacted CCCs responded. The participants were six directors of a CCC, an Interdisciplinary Oncological Project Group (IOP) ambassador of palliative medicine, a senior physician in the clinic for palliative medicine, and a coordinator of the center. In two cases, the questionnaire was answered by the chief consultant of palliative medicine. Four participants did not specify their functions in detail.

Structural Features of Facts and Figures

Number of Patients

Nine CCCs reported that, in 2016, between 1,111 and 29,000 patients were treated for cancer. Six CCCs did not provide any information in this regard. Six centers did not answer the question of how many primary cases their corresponding CCC registered in 2016. Nine CCCs reported having between 111 and approximately 13,000 primary cases. For 13 CCCs, the question on the number of patients with relapsed cancer in their CCC in 2016 remained open. Two CCCs reported numbers of 111 and 284 cases.

Number of Beds

Ten out of 15 CCCs reported that the number of inpatient beds in their hospital ranged between 1,000 and 1,500 beds. Two CCCs reported a capacity of more than 1,500 to 2,000 beds, and two CCCs reported more than 2,000 beds. One CCC reported more than 500 to 1,000 beds.

European Society for Medical Oncology Certification

Five CCCs have a European Society for Medical Oncology certification.

Structural Features of Medical Care

The participating CCCs' responses to survey questions about the structural features of medical care are shown in Table 2.

Table 1. Description of the method

	Period				
Specification	**Lack of intent**	**Forming of intentions**	**Preparation**	**Action**	**Maintenance**
Comment	(Carelessness)	Awareness, intention to implement	Fixed intentions of implementation within a certain period of time	Matter of fact	Stabilization
State of implementation	Not yet discussed	It was/is discussed to initiate first implementation steps	Implementation within the next 12 months; first steps initiated	Implementation "yes"	
Consequence	No implementation plans to date	No concrete implementation plans; implementation considerations	Concrete implementation plans	Implementation completed	Permanent implementation

Source: Prochaska and Velicer, 1997 [24].

Palliative Care Unit

All 15 responding CCCs have a palliative care unit, with 14 integrating the palliative care unit as an independent, organizational, and spatial ward. In the remaining center, concrete implementation plans to create an appropriate unit are in place. In all 15 CCCs, the palliative care unit offers at least six beds. At 13 of 15 CCCs, experts in specialized palliative medicine are reachable 24 hours a day. In one center, considerations are being made with regard to implementation of best practice recommendations; one center does not have any implementation plans yet.

Inpatient Service

Eleven out of 15 CCCs provide a service offering palliative care for seriously ill patients with cancer in other departments. Two centers are already preparing concrete implementation plans for a multiprofessional specialized inpatient palliative care service. One center is discussing the issue and one center has not yet taken any action. At nine CCCs, the palliative service consists of at least three medical and nursing staff and a member of at least one other professional group and is available during regular working hours. The implementation of this more comprehensive offer of multiprofessionality is planned in four centers and being discussed in another center. One CCC has no plans to achieve this. Information on the availability of the palliative service in other specialist departments is also provided from nine CCCs. In five centers, implementation will take place in the coming months or a further discussion is in progress. One CCC has not yet initiated any reflections on this topic.

Day Care and Outpatients

Twelve CCCs have a possibility for an interdisciplinary outpatient consultation, especially with expertise in specialized palliative medicine. One CCC has not yet debated it, and two are discussing it. At 11 centers, consultation hours are generally offered at least 4 hours per week and by appointment. An additional group of four CCCs are planning or discussing implementation. Patients also have access to specialized palliative care in 11 CCCs within day-care services of all specialist departments. The remaining four centers already have concrete implementation plans or are in the process of discussing them.

Regional Networking

In all 15 CCCs, specialized palliative home care is available via the CCC's own services and/or in cooperation with regional providers. In this context, 13 CCCs have a written cooperation agreement. Two CCCs already have implementation ideas or concrete implementation plans. At all CCCs cooperation with hospices is guaranteed. Fourteen CCCs provide hospice support for patients with incurable cancer by qualified volunteers. One center has not yet studied this topic.

Planning for the End of Life

The participating CCCs' responses to survey questions about planning for the end of life are shown in Table 3.

Living Will and Power of Attorney

In 11 CCCs, the existence of living wills and powers of attorney are inquired about and documented during the admission interview. Three CCCs are already discussing this question. One center has not considered this topic to date. Eight CCCs document the existence of living wills and powers of attorney centrally and electronically so that this information is available to all persons involved in treatment. Five CCCs have had a discussion about this issue, and two CCCs have not yet addressed it.

Registry

In nine CCCs, the palliative care services submit their data to the National Hospice and Palliative Register. Five are already pursuing concrete implementation plans, and one CCC is already discussing this issue.

Pathway for Care of the Dying

Six CCCs have a quality concept for handling dying patients. Five CCCs have not examined this issue so far, and two are already discussing it or planning to do so. Six CCCs also have a quality concept for handling death situations with the following recommended elements: steps to assess the situation of the seriously ill patient in a multiprofessional team, documentation of the decision-making process, and an information sheet for relatives and information after death. Four centers have not yet considered this topic, two are already discussing it, and three have concrete implementation plans.

Structural Features of Specialized Palliative Medicine

The participating CCCs' responses to survey questions about structural features of specialized palliative medicine are shown in Table 4.

Table 2. Structural features of medical care

Patient-centered care structures; structural features of patient care	Response of participating CCCs, *n* (%)	
	Yes	No
Palliative care unit		
Existence	15 (100)	0 (0)
Independent, organizational, and spatial unit	14 (93.3)	1 (6.7)
With at least six beds	15 (100)	0 (0)
Availability of experts 24 hr, 7 days	13 (86.7)	2 (13.3)
Specialized inpatient care service		
Existence	11 (73.3)	4 (26.7)
At least three members of staff and availability during regular working hours	9 (60.0)	6 (40.0)
Information storage in other departments	9 (60.0)	6 (40.0)
Day-care hospital and ambulance for palliative care		
Availability of an interdisciplinary outpatient palliative medical consultation	12 (80.0)	3 (20.0)
Availability on at least 4 hours per week and by arrangement	11 (73.3)	4 (26.7)
Offer of specialized palliative medicine also within daily inpatient offers of all specialist departments	11 (73.3)	4 (26.7)
Regional networking		
Presence of specialized outpatient palliative care via own service and/or in cooperation with regional and national providers of specialized outpatient palliative care	15 (100)	0 (0)
Documented cooperation with external service providers in specialized outpatient palliative care	13 (86.7)	2 (13.3)
Ensuring cooperation with a hospice	15 (100)	0 (0)
Availability of hospice support by qualified volunteers	14 (93.3)	1 (6.7)

Abbreviations: CCC, Comprehensive Cancer Center; hr, hours.

Time of Integration

In seven centers, palliative care is offered to all patients after diagnosis of incurable cancer, regardless of whether a tumor-specific therapy is used. Of the eight CCCs that do not yet offer this, two have concrete implementation plans and six have implementation considerations. In 12 CCCs, physicians inform patients during consultation hours about the possibility of consulting a specialist in specialized palliative medicine. This is still being discussed in two CCCs; one CCC has not yet investigated this topic. In 12 CCCs, information on palliative medicine is visibly presented in the waiting area of outpatient departments treating patients with cancer. Three CCCs are considering implementation of presenting information on palliative medicine in the waiting area of outpatient departments.

Table 3. Planning for the end of life

Planning for the end of life	Response of participating CCCs, *n* (%)	
	Yes	No
Patient directive and health care proxy		
Ask in the physician-patient consultation whether a proxy and/or patient directive is present	11 (73.3)	4 (26.7)
Central electronic documentation if a proxy and/or directive is in existence	8 (53.3)	7 (46.7)
Documentation of the palliative unit in the National Hospice and Palliative Register	9 (60.0)	6 (40.0)
Treatment pathway for dying people		
Existence of a quality concept for managing dying patients	6 (40.0)	9 (60.0)
Our quality concept for managing death situations at the CCC contains the following recommended elements: steps to assess the situation of the seriously ill patient in a multiprofessional team, documentation of the decision-making process, an information sheet for relatives and information after death	6 (40.0)	9 (60.0)

Abbreviation: CCC, Comprehensive Cancer Center.

Inclusion of Specialized Palliative Medicine in Interdisciplinary Decision-Making Processes

Specialized palliative medicine is involved in ten CCCs in the Management Committee. At one CCC there are no implementation plans. Three are discussing implementation, and at one CCC there is a concrete implementation plan.

Symptom Assessment

At five CCCs, symptoms and psychosocial stress of all patients with incurable cancer are measured using validated detection tools. Six centers are considering implementing such an aim. Three centers already have concrete implementation plans, and in one case this issue has not been addressed so far.

Research and Teaching Activities

The participating CCCs' responses to survey questions about research and teaching activities are shown in Table 5.

Research

In 12 CCCs, palliative medicine is integrated in the research structures of the CCC. One center has not yet studied this issue, one center is discussing it, and one center has concrete implementation plans for the next 12 months. The research performance of the palliative medicine department is regularly evaluated in seven CCCs. Concrete

Table 4. Special features of specialized palliative medicine

Special features of specialized palliative medicine	Response of participating CCCs, *n* (%)	
	Yes	No
Time of integration: Offer of palliative care to all patients after diagnosis, regardless whether a tumor-specific therapy is performed or not	7 (46.7)	8 (53.3)
Inclusion of special palliative medicine		
Integration of specialized palliative medicine in the Management Committee	10 (66.7)	5 (33.3)
In all patients with incurable cancer, detection of symptoms and psychosocial burden with validated detection tools	5 (33.3)	10 (66.7)
Information from oncologically working physicians to patients about the possibility of consulting a palliative medicine specialist during office hours	12 (80.0)	3 (20.0)
Visible information on palliative medicine in the waiting area of outpatient clinics treating tumor patients	12 (80.0)	3 (20.0)

Abbreviation: CCC, Comprehensive Cancer Center.

implementation plans are in progress at one CCC. This topic is still being discussed in three CCCs, and four CCCs have not yet made any considerations in this regard.

Education and Teaching

In ten CCCs, there is a structural concept to support research and teaching in the field of palliative medicine. Five CCCs are already working on implementing this. In all CCCs the offer of courses for palliative medicine is evaluated annually.

In the case of only one CCC, every person involved in the general palliative care of a patient with a noncurable cancer has a basic qualification in palliative care, which is acquired through training or further education (course further education, 40 hours of instruction). Two CCCs have concrete implementation plans in this context, four CCCs are discussing this topic, and eight are not currently following any implementation plans. Only one CCC employs medical and nursing staff in the emergency department with a basic palliative care qualification (course further training, 40 hours of instruction) that is updated regularly. Out of the 14 CCCs that are unable to provide this recommendation, ten have no implementation plans to achieve this so far. Three centers are discussing this issue, and one center already has specific implementation plans. Two CCCs are explicitly inviting emergency room personnel to in-house training courses on the subject of care and advice for incurable patients. Seven are not currently aiming to implement plans, whereas five centers are considering implementing them, and one CCC already has concrete implementation plans (Table 5).

Table 5. Research and teaching activities

Research and teaching activities	Response of participating CCCs, *n* (%)	
	Yes	No
Research		
Integration of palliative medicine in the research activities of the CCC	12 (80.0)	3 (20.0)
Regular evaluation of the research performance of the palliative medicine department of the CCC	7 (46.7)	8 (53.3)
Teaching		
Existence of a structural concept to support research and teaching in the field of palliative medicine	10 (66.7)	5 (33.3)
Annual evaluation of the curriculum for palliative medicine	15 (100.0)	0 (0)
maintaining a basic qualification for all persons involved in the general palliative care of a patient	1 (6.7)	14 (93.3)
Basic palliative medical qualification of the medical and nursing staff of the emergency department	1 (6.7)	14 (93.3)
Invitation of emergency room personnel to in-house training courses on the topic of care and counselling of incurable patients	2 (13.3)	13 (86.7)

Abbreviation: CCC, Comprehensive Cancer Center.

Discussion

General palliative care (skills that all clinicians should have) and specialized palliative care (skills for managing more complex and difficult cases) [27] are increasingly accepted as integral within comprehensive cancer care. This is also consensus within the German CCC network. With the aim of making this overarching demand more concrete, minimal standards for the network were conjointly defined, consented to by the board of CCC directors, and published. This set of best practice recommendations represents an important milestone in optimizing the integration of specialized palliative care in the CCCs funded by the German Cancer Aid.

This survey presented here provides insight into what extent those consented recommendations are implemented in the German CCC network and in which sites and areas further development is needed. The data show that many of the recommendations have already been implemented. In particular, some aspects of specialized palliative care are

well in place, for example, palliative units: all CCCs are equipped with a palliative unit with at least six beds. However, other aspects of the context of specialized palliative care are underdeveloped. Although nine institutions state that they provide a genuine multiprofessional palliative service including members from at least three different professions, it is surprising that a total of six CCCs do not (yet) have such an offer. The multiprofessional support provided by such a service on the oncological ward is an important part of the treatment and care of critically ill patients [28, 29]. Palliative care is well known to have a positive outcome on pain, symptom control and anxiety in patients with cancer [30–33] and that it may have a cost-saving effect [34–37].

Potential for improvement may be seen in the integration of a quality concept for the management of dying patients and death situations.

With regard to education and teaching in specialized palliative medicine, a sustainable basis for improving the understanding of palliative medicine should be considered here. The aim is to provide participants with a basic qualification in palliative care. In addition, medical and nursing staff in the emergency department should also acquire a basic qualification that should be updated regularly. In any case, emergency room personnel should be explicitly invited to in-house training courses for the care of incurable patients.

The thematic tandem partnerships are intended to establish a good network between CCCs that have already implemented certain recommendations and CCCs that wish to implement them. For this purpose, we need to record the existing limits for establishing a basic qualification in general palliative care and for the nursing and medical staff of emergency departments in their practical work. There is already a CCC in place to be a pioneer in providing assistance to all other CCCs. Although the support seems to be connected with great effort, it is not impossible. Therefore, it is of enormous importance to understand the requirements of the CCC network and to make them available to everyone in further publications. In this context, an exchange with emergency departments is also necessary to gain an impression of the problems involved in raising awareness of palliative medicine.

Benefits for the establishment of validated assessment tools for symptoms and psychosocial burden should be made more obvious, especially for those performing documentation. An example of an instrument widely used in German palliative care is the Hospice and Palliative Care Evaluation (HOPE) basic tool with a validated symptom and problem checklist [38]. Its contents can be directly transferred to the National Hospice and Palliative Register. The use of a validated assessment tool called HOPE may support patient care and identify opportunities for reducing costs.

The keyword “Early Integration” in the best practice recommendations means that palliative care is offered to all patients after diagnosis of incurable cancer, regardless of whether a tumor-specific therapy is performed [9]. The definition and implementation of “Early Integration” is already being discussed as an important topic in a sub–working group of the CCC Palliative Medicine Working Group [39, 40]. Early involvement of palliative care in patients with advanced cancer has a positive effect on quality of life and symptom intensity [41].

With all CCCs involved, the results of the survey were extremely precise and representative. However, only the current state of implementation of the recommendations was assessed and not the conditions or barriers responsible for the current state. As part of the tandem partnerships, these conditions and barriers are to be identified later on. The survey is a sample of CCCs; no other clinics providing basic and specialized palliative care with a different geographical location were included in the survey. Therefore, the recipients of the survey were only clinics with maximum care. Given the novelty of the development of the survey and the small number of respondents, a mixed method approach with qualitative research methods in addition to the structured survey tool would have enriched the data. Because of limited time and personnel resources, this approach was waived at this time. However, further studies on the status of the implementation will be carried out with a mixed method design.

Conclusion

All in all, excellent implementation of the recommendations has already been reached in many fields. The recommendations can be implemented beyond the CCCs [9]. Further development is of course necessary in certain areas, such as the integration of a quality concept for managing dying patients and death situations, the improvement of further training in palliative medicine, and the early integration of palliative medicine even at diagnosis of an incurable disease. An important milestone is the availability of a palliative unit, a specialized inpatient palliative care service, a day-care hospital, and an ambulance for palliative care, as well as regional networking, in almost all CCCs.

So far, the best practice recommendations have achieved a very good effect across the CCCs because of their easy availability via the homepage of the CCC network hosted by the German Cancer Aid. The CCCs were able to expand their function as role models by agreeing on and setting out the criteria in writing [9]. After 15 of the 15 CCCs took part in the survey, it was possible to collect clear results from the survey that represent all CCCs in Germany and can also be extended to unfunded CCCs as well other cancer centers.

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Disclosures

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