

## RESEARCH ARTICLE

# Evaluation of Managerial Needs for Palliative Care Centers: Perspectives of Medical Directors

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### Abstract

**Background:** Palliative therapies have an important role in increasing the quality of healthcare and in dealing with physical and psychosocial problems due to cancer. We here aimed to evaluate the managerial perspectives and opinions of the hospital managers and clinical directors about specialized palliative care centers. **Materials and Methods:** This study was conducted in two large-scale hospitals in which oncology care is given with medical directors (n:70). A questionnaire developed by the researchers asking about demographic characteristics and professional experience, opinions and suggestions of medical directors about providing and integrating palliative care into healthcare was used and responses were analyzed. **Results:** Potential barriers in providing palliative care (PC) and integrating PC into health systems were perceived as institutional by most of the doctors (97%) and nurses (96%). Social barriers were reported by 54% of doctors and 82% of nurses. Barriers due to interest and knowledge of health professionals about PC were reported by 76% of doctors and 75% of nurses. Among encouragement ideas to provide PC were dealing with staff educational needs (72%), improved working conditions (77%) and establishing a special PC unit (49)%. An independent PC unit was suggested by 27.7% of participants and there was no difference between the hospitals. To overcome the barriers for integration of PC into health systems, providing education for health professionals and patient relatives, raising awareness in society, financial arrangements and providing infrastructure were suggested. The necessity for planning and programming were emphasized. **Conclusions:** In our study, the opinions and perspectives of hospital managers and clinical directors were similar to current approaches. Managerial needs for treating cancer in efficient cancer centers, increasing the capacity of health professionals to provide care in every stage of cancer, effective education planning and patient care management were emphasized.

**Keywords:** Palliative care - questionnaire - delivery of healthcare - patient care management

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### Introduction

Various problems occur with the diagnosis of cancer, not just the patients but also the health professionals are confronted with many problems. Both patients and family members and even health professionals enter a different phase that future is perceived obscure. It is stated in a review that patients diagnosed with cancer especially in developing countries are still suffering from the consequences of the disease and that improved palliative care program should be integrated into health-care systems to control this suffering (Komurcu, 2011). Absence of basic principles of PC in medical education and specialty training programmes in palliative care have been reported as the reasons of inadequate awareness about PC among doctors and patients (Gultekin et al., 2010). Palliative care concept has improved in Turkey since a few decades (Komurcu, 2011). The majority of cancer patients are treated in university hospitals that have support units with pain specialists and medical oncologists

(Elcigil 2011) In Turkish culture, PC for patients in need is usually provided in the family, patient is supported and cared by the family (Gultekin et al., 2010). Palliative care has been emphasized in National Cancer Control Programme and since 2010 the Pallia-Turk Project which is community- based and organized at the primary level has been implemented (Ozgul et al., 2012).

Different approaches to PC exist in the world and financial sources define the level and extent of care. Novel approach is that PC for cancer should be provided in comprehensive cancer centers where appropriately trained staff and multidisciplinary teams are present. When compared to conventional care, palliative care provided in a multiprofessional approach by specialist teams improved symptom control, reduced inpatient hospital days and overall cost of care. (Hearn and Higginson, 1998).

Since patients living with cancer exist in every age group and in every clinic in a hospital, we tried to learn the approaches to specialized palliative care centers of health professionals working in different clinics. We aimed

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to evaluate the managerial perspective and opinion of the hospital managers and clinical directors about specialized palliative care centers.

**Materials and Methods**

This cross-sectional descriptive study was carried out in two large-scale general hospitals involved in comprehensive oncology care in 2011. Because oncology patients may have health problems related to every clinic, chief physicians and chief nurses of the adult patients' clinic in both hospitals and in general hospital administration/management who have been working in the same hospital at least for one year were determined to be eligible and 122 medical directors were identified. After an overview of the recent literature on PC, a questionnaire was developed by the researchers asking about demographic characteristics and professional experience, opinions and suggestions of medical directors about providing PC and integrating PC into healthcare. Most of the questions were open-ended in order for the respondent to comment freely. After the aims of the study were explained, the questionnaire with a brief background information about PC were handed out to 100 medical directors whom we could reach and whom volunteered to participate. Each week the completed surveys were collected in a closed envelope, for the not yet completed surveys questionnaires were reminded at three different times and completed surveys were collected. Quantitative and qualitative responses were analyzed by the researchers. The Student t test and chi square tests were used to analyze the variables. p<0.05 was accepted as the significance level. The study was approved by the hospital ethics committee and permission of Provincial Health Directory was also taken.

**Results**

Through the survey period 70 medical directors (70% of all) returned the filled out questionnaires. 51.4% of the participants were women (n:36) and 48.6% were men (n:34). Physicians(57%) were more than nurses (43%). Participants mostly belonged to the 41-50 age range (42.9%). Average age of the physicians were significantly more than the average age of the nurses (p=0.001). 30% of the nurse chiefs had master degrees. Demographic characteristics of the participants are presented in Table 1.

15.7 % of the respondents were from medical and radiation oncology clinics and 10 % were from surgery clinics. Among the respondents who had a history of a family member in need of PC( 29%), those who reported that care was provided at home were 90%. Opinions of the respondents about the components and implementations of PC are shown in Table 2.

87% of all the respondents thought that a palliative care center should be established in the hospital and there were no differences between the responses of those working in the clinics and the ones working in the hospital administration/management.

76.6% of the respondents would like to be informed about palliative care principles and implementation. There were no differences between health professions (p≥0.05).

Once palliative care center is established in the hospital, whether it should be a separate center or be under supervision of another clinic have been asked and 37.3% responded as oncology clinic must supervise. 27.7% responded as the PC center should be independent. Other responses are shown in Figure-1.

It was also suggested that the PC may be organized by family physicians in the health care system and consultation services from the hospitals may interfere

**Table 1. Demographic Characteristics of the Participants**

	Physician, n=40,%	Nurse, n= 30, %	Both, n=70, %
Gender			
Male	34 85.0	0 0.0	34 48.6
Female	6 15.0	30 100.0	36 51.4
Departments			
Medicine Clinics	16 40.0	9 30.0	25 35.7
Surgery Clinics	21 52.5	10 33.7	31 44.3
General Administration	3 7.5	11 36.7	14 20.0
Mean professional period	24.1±6.1	19.3±7.0	22.1±6.9
Mean chiefery/managerial period	9.2±6.1	8.0±5.9	8.7±5.9

**Table 2. Opinions of Respondents about Components and Implementations of PC**

		Physician (n=40)*	Nurse (n=30)*	Both (n=70)*,(%)	PC experience in the family (n=20)*,%
A special PC training is necessary for	Patient relatives	3	4	7 (10.3)	3 (15.7)
	Nurse/Physician	1	0	1 (1.5)	0 (0.0)
	Both groups	36	24	60 (88.2)	16 (84.2)
A consultant PC team is necessary	Yes	36	27	63 (92.6)	18 (94.7)
	No	3	2	5 (7.4)	1 (5.3)
A special PC unit/center is necessary	Yes	36	25	61 (89.7)	16 (88.9)
	No	5	2	7 (10.3)	2 (11.1)
Would like to learn about PC implementations	Yes	25	24	49 (76.6)	13 (65.0)
	No	13	2	15 (23.4)	7 (35.0)

\*n; changes according to the number of respondents for each question, %; are given for each

when needed.

Opinions about types of support for the patients in need of PC were asked as an open-ended question and responses were divided in four meaningfully together groups. Symptomatic treatment support for symptoms like pain and nausea was suggested by 29.8%, training support by 29.8%, psychological support by 26.9%, and social support by 13.4%. There was no significant difference between the responses about support types suggested by chiefs of the clinics and general hospital managers ( $p \geq 0.05$ ).

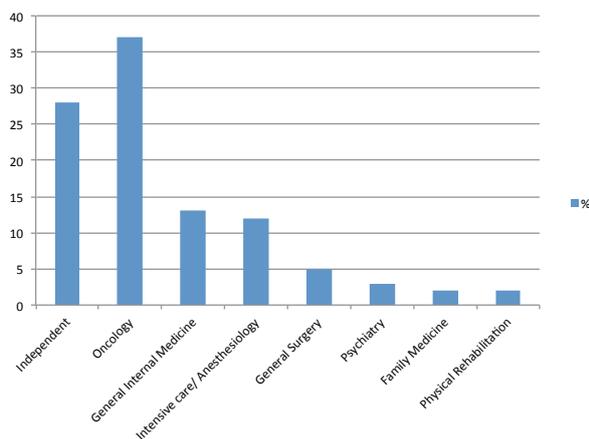
Potential barriers as institutional, social and barriers related to the attitudes of the health professionals in providing palliative care and integrating PC into the health care systems were asked as an open-ended question. Potential barriers were perceived as institutional by most of the doctors (97%) and nurses (96%). Social barriers were reported by 54% of the doctors and 82% of the nurses. Barriers due to the interest and knowledge of health professionals about PC were reported by 76% of the doctors and 75% the of nurses as shown in Table-3.

#### Institutional Barriers

It was reported by the participants that as institutional priorities and points of views change the effectiveness of PC change also. In hospitals and generally in health institutions inadequate information about the components of PC and financial reimbursement are perceived as the main institutional barriers.

Lack of institutional readiness for palliative treatments, procedure and implementations about PC were emphasized.

Participants mentioned the increasing number of patients needing PC, inadequate staffing-physicians and other health professionals- and financial resources being



**Figure 1. Suggested Clinics for Palliative Care Center Supervision**

**Table 3. Participants Opinions about Potential Barriers of Integrating Palliative Care into Health System**

	Physician%	Nurse%	Both%	p
Institutional	97	96	97	$p \geq 0.05$
Social/Public	54	82	66	$p < 0.05$
Attitudes of health professionals	76	75	75	$p \geq 0.05$
All three barriers together	41	64	51	$p \geq 0.05$

not enough and that proper PC is financially challenging even in developed countries with higher income.

#### Social Barriers

Lack of knowledge about some components and implementations of PC in society, inadequate number of centers providing PC and absence of awareness of the family therefore less access to care, besides unacceptance of the terminal period, "perceiving care as complete health", cultural traditions like "spending the last days of the patients' by the family", cultural beliefs, financial problems of the family were mentioned as the social barriers for providing PC.

#### Barriers due to the interest and the knowledge of health professionals about PC

"PC is not perceived as a need, only the symptomatic treatments for physical problems are seen as care, inadequate training about PC, lack of awareness, interest and information about components of PC" were mentioned by most of the participants but the high interest of health professionals was also mentioned by some of the participants.

"There isn't a separate PC unit, the supervisor clinic is not clear, training and specialization in PC does not exist therefore the continuum of PC care is not provided"

"Universities do not have higher education programmes about PC and even in the university education there are not enough lectures." were mentioned as the important problems.

#### Suggestions To Overcome Mentioned Barriers

The participants' suggestions for institutional measures to take to encourage for providing PC were grouped in three as dealing with staff's and families' educational needs (%72), improving working conditions-working hours and financial arrangements-(%77) and establishing a special PC unit with adequate infrastructure(%49). No difference was observed between the participants' responses and professions.

To overcome the barriers for integration of PC into health systems, participants suggested providing training and information for health professionals and patients' relatives, raising awareness in society, using media and web opportunities more effectively, informing the non-governmental organizations about PC components, solving financial problems and providing infrastructure. The necessity for planning and programming were emphasized also.

Providing more information and training by courses and media about standards and latest guidelines for health professionals, caregivers and the family to raise awareness were mentioned as necessities by the respondents.

Terminally ill patients needed PC the most and in order to provide the appropriate care "families should have a role in caregiving and health professionals must remain as the helpers for patients and families to get through this period as good as possible" were the remarks mentioned.

Respondents suggested that if teams consisting of physicians, nurses, social workers and psychologists are well trained for PC; home-based care can be provided

for patients by the interference of the specialist physician consultation teams in the hospitals when needed.

*“Caregivers should receive advice and support from the PC team” .*

*“Training in special issues in communicating to cancer patients and relatives should be provided also.”*  
*“Patients’ family and caregivers should be informed about how to take care of decubitus ulcers, when to call the home based teams.”*

*“In nursing, a specialization, a master’s programme is necessary. Care must be kept up to date, continuous medical education on PC components, knowing how to deal with terminally ill patients and their families are important.”*

#### **Working Conditions**

*“Curing more than disease is curing the patient so especially during these uneasy times the problems and the role of the health professionals should be defined clearly, so education and economic support should be provided for the hospital and the staff.”*

*“Staff working in the palliative unit should be supported, working hours should be defined. Staff working in the PC unit should feel that their efforts are noticeable, what they do is valuable and respected”*  
*“Rotations among staff are needed, non-physician staff of the PC center should be adequate, even 2-3 times more than the other clinic staff.”*

*“Feedback should be taken from staff.”*

*“There must be psychological support for staff providing PC to avoid the burn-out syndrome.”*

#### **A Special Unit With Infrastructure**

In hospitals inadequate infrastructure and equipment, *“a specific separate PC unit with an encouraging atmosphere”* is needed.

The respondents also mentioned that patient relatives should be trained for very basic care, medical equipment may be lended to patients’ home to be used in care. *“Home based care may be provided for basic needs, collaborate work may be organized and when needed care may be provided in the hospital for some procedures, this may be more cost effective”.*

*“A pilot hospital with a separate comfortable palliative unit would be encouraging.”*

*“PC center should be accredited according to quality standarts.”*

In terms of easy access to healthcare service, the establishment of many PC centers was also suggested.

## **Discussion**

This study focuses on the opinions of the director of the hospitals both nurses and doctors. In our study, 83 % of the target group received the questionnaire and 70 % this group responded, the response rates were similar when compared to other studies (Brazil et al., 2006). Most of the respondents worked in the radiation oncology, medical oncology and general surgery departments who may have higher awareness about PC because of their professional experiences with cancer patients during the treatment.

In a study in Turkey, it was observed that most of the non-small cell lung cancer patients’ health-related quality of life was poor and that those patients could not benefit from different disciplines; so comprehensive care with multidisciplinary team is needed (Gultekin et al., 2008). Patients receiving early integration of PC into oncologic care had an improved quality of life (Temel et al., 2010).

The respondents of our study emphasized that a medical consulting team of physicians from various departments such as oncology, internal medicine, anesthesia and psychiatry should be provided for patients in need of PC. It was reported that almost half of the inpatient PC consultations were for patients with cancer who may have complex needs and that opportunities to provide improved multidisciplinary care and earlier PC intervention even in the outpatient clinics (Kamal et al., 2011) should be considered.

Our respondents emphasized that institutional considerations, lack of awareness in the hospitals and in health care system, not knowing the components of PC and not believing the necessity of PC have an effect on PC implementations. In literature more or less the same potential barriers were reported by the medical directors (Brazil et al., 2006)

In a survey conducted with the directors of care in long-term care facilities the importance of the adequacy of institutional resources was emphasized as a barrier in providing continuing education to both staff and families in end-of-life care (Brazil and Vohra, 2005)

Specific medicare reimbursement does not exist for palliative care in hospitals and programs without reimbursement generally are not supported by hospital administrators (Edens et al., 2008).

In our study, nurses reported the presence of social barriers significantly more than physicians, this may be explained as nurses are more involved in patient care and spend more time with patients and caregivers in the family and perhaps more aware of the perspectives of the community. Family perceptions about PC, unpreparedness of families for deterioration of patients’ conditions and insufficient communication with physicians were reasons found for late-referrals to specialized PC services (Morita et al., 2005).

In our study, to overcome the barriers for integration of PC into health care systems; organizing continuous medical education for health professionals, educational courses on PC for caregivers, raising awareness in society, utilizing media and web to inform society about PC, bringing up solutions to financial problems to provide infrastructure with adequate equipment and staffing were suggested. Necessity for developing programmes and plans considering patient needs and legal arrangements-precautions were emphasized as priorities and providing PC should be a component of healthcare policy and therefore financial sources should be provided. The suggestions of the respondents were similar to other studies (Brazil et al., 2006).

General oncologist’s knowledge about the benefits and the right time of referral to specialized palliative or hospice care teams is important in cancer management (Wiebe and Von Roehn, 2010). Integrating skills of the

palliative care physicians and oncologists may improve PC (Schenker et al., 2013).

In our study, it was also suggested that the PC may be organized by family physicians in the health care system and consultation services from the hospitals may interfere when needed.

PC is needed to be integrated in comprehensive cancer care and for effective palliative cancer care it should be provided in all patient settings including outpatient clinics, acute and long term care facilities and at homes by special teams (Ferris et al., 2009).

In patients with advanced non-small cell lung cancer and colorectal cancer early palliative intervention and outpatient service experience led to improvement in patients' outcomes. (Otsuka et al., 2013).

In our study, hospital administrators and clinic directors mentioned the same types of support that should be provided to the patients needing PC and that both groups were aware of the needs.

Respondents who had experience concerning cancer had a higher awareness compared to general population was found in a survey conducted in Japan (Hirai et al., 2011).

In our study, most of the respondents who had experience with a family member in need of palliative care, have reported that PC education should be provided both for health professionals and families. Caregivers should be prepared to deal with the medical and psychological problems of the patients. Providing specialized PC services has been found to be associated with improvements in short and long term outcomes defined by the caregivers of the patients such as needs during the care period and adaptation after the care process is over (Abernethy et al., 2008).

Approaches to PC infrastructure may differ institutionally. When patient outcomes are considered, it was concluded that presence of both PC unit and palliative care consultation services in one hospital contributes to optimal PC (Gaertner et al., 2012).

In our study, the need for establishment of a PC center in the hospital was mentioned by both hospitals' staff and both professions reflect that the experience about oncology patients were similar.

In literature, many studies investigated the effectiveness of PC and specialized centers for and also cost-effectiveness and it is reported in a review that when compared to usual care PC is generally cost-effective (Smith et al. 2014) but there is no data on cost-effectiveness of different models of PC (Lockett et al. 2014).

The impact of PC on costs of cancer care and appropriate standardized care given for the terminal patients in a specialized unit has been found to reduce costs (Smith et al., 2003)

In Canada, it was concluded that palliative care teams providing home-based care in a shared care model can be sustained by integration and collaboration of local, regional and provincial organizations. Outcomes of a health system in which hospices, hospitals, long term care facilities and home based care are integrated would be better. (Demiglio and Williams., 2013).

To provide an efficient PC, respondents emphasized the

educational needs about guidelines and implementation of PC and raising awareness about PC components in society as well as organizing the appropriate working conditions for staff and establishing a special PC unit with the infrastructure. There were no differences between the answers of nurses and physicians. Respondents were aware that PC is a special care and an additional training is needed even for the health professionals.

Certain studies have been carried out about different health professionals' perspectives about palliative care both in Turkey and in other countries. (Turgay and Kav, 2012; Budkaew and Chumworathayi, 2013)

The lack of training programs and a standardized education with guidelines inadequate staffing in hospitals have been mentioned as the problems to be solved for efficient palliative care in Turkey (Turgay and Kav, 2012) In Thailand, the need for formal education in palliative care and development of palliative care services for terminal cancer patients have been emphasized (Budkaew and Chumworathayi, 2013). One of the main causes of terminally ill cancer patients' emergency visits were found as the lack of sufficient trained caregivers, it is claimed that an effective palliation of end-stage cancer patients causes to improve their quality of life (Yildirim and Tanriverdi, 2014). Similar studies were carried on in other countries and some interventions have been made and staff benefitted from the educational program on PC (Nagamatsu 2014).

In a study about schools of public health, it was concluded that future public health professionals are not prepared with a basic knowledge about components of PC and hospice and that development of curricular material about PC is needed (Lupu et al., 2013).

Adequate staffing, capacity building among staff providing PC, programming PC through illness, finding financial resources, planning research and training in PC have been emphasized in recent literature. In our study, opinions and approaches of medical directors about PC were similar to current approaches. Palliative care should be provided in comprehensive professional PC centers by staff trained according to contemporary standards and guidelines. It is concluded that medical directors pointed out the managerial need for implementation of palliative care in the hospitals.

In conclusion, Palliative care centers should also be evaluated in the context of delivery of healthcare. Comprehensive cancer care given in specialized centers with adequate infrastructure for every stage of cancer with specialized palliative care teams trained for every aspect of cancer is needed. We think raising awareness among health professionals, society and policy makers about the need for implementing PC and that PC completes the oncologic care by these surveys is needed. We think our study will be helpful for plans made for health institutions especially for patients needing PC and direct new researches which will make new analyses. This study has some limitations, it is limited to the time that it has been conducted and to the tools that have been used. It is more appropriate to repeat and compare this kind of studies at different times with larger groups..

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