



Awareness and attitudes of nurses of the Clinical center of the University of Sarajevo (ccus) towards the organization of palliative care

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Summary

Introduction: The health system is one of the most complex systems in any country. According to the definition of the World Health Organization, the health care system includes health infrastructure that provides a spectrum of programs and services and provides health care to individuals, families and the community. A basic human right is the right to health care, which includes health activities such as preventive, curative and palliative treatment. The organization of palliative medicine is necessary at all levels of health care.

Aims: Situational analysis of the organization of palliative care in the Clinical Center of the University of Sarajevo. Examining the knowledge and approach of health-care workers in the process of providing palliative care at the Clinical Center of the University of Sarajevo. To examine the attitude of healthcare workers towards the

way palliative care is organized in the Clinical Center of the University of Sarajevo.

Material and methods: 141 subjects employed at the Clinical Center of the University of Sarajevo (CCUS) participated in the research. The research is descriptive and analytical. The results are presented in tables and graphs, chi-square and Fisher's exact test were used for testing the significance of differences.

Results: It was found that there are different knowledge, attitudes and approaches of the respondents regarding the way palliative care is organized, the provision of services and treatment in the hospital. The majority of respondents (64%) believe that palliative care should be organized in institutions for palliative care that meet the conditions of the prescribed standards and criteria for palliative care.

Conclusion: Significant differences were found in the knowledge, practice and attitudes of health workers about palliative care.

Keywords: management, palliative care, nursing clinical practice, knowledge and attitudes of nurses, dignified dying

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INTRODUCTION

The health care system is one of the most complex systems in any country. According to the definition of the World Health Organization, the health care system includes health infrastructure that provides a range of programs and services and provides health care to individuals, families and the community.¹

In all countries, due to the aging of the population and the introduction of new and expensive technologies, there is a steady increase in the cost of providing health care. The health care system includes, in addition to the public sector, the private health sector.

In order to harmonize the functioning of both sectors as much as possible, based on the above-mentioned principles, it is necessary to improve mutual cooperation and establish greater trust.² According to the World Health Organization (WHO), more than 12 million people in the world get malignant neoplasms every year, and 7.6 million die from this vicious disease.^{3,4,5}

Every man must have freedom in identifying his own needs as well as deciding how his needs will be satisfied. In case of imbalance in the body, development of disease and impossibility of satisfying needs, the need for treatment and health care is created. Different experts in the field of nursing (Henderson, Roper, Orem, etc.) have developed health care through different models, defining health care patient needs, and the role of nurses. Traditionally, palliative care has been applied at a time when death was imminent, but today it can be applied much earlier already after receiving a bad prognosis. Palliative care emphasizes life, and dying is a normal process and it cannot be delayed, but palliative care may alleviate symptoms.⁶

At the Parliamentary Assembly in July 1999, at its 24th session, the Council of Europe adopted Recommendation No. 1418 - Protection of the human rights and dignity of the terminally ill and the dying. The Recommendation clearly states that „the obligation to respect and protect the dignity of the dying or terminally ill patient is a natural consequence of the dignity inherent in the human being at all stages of life“. This respect and protection are brought to life by the creation of an appropriate environment that allows the human being to die with dignity.⁷

A basic human right is the right to health care that includes health activities such as preventive, curative and palliative treatment. So, the organization of palliative medicine is needed at all levels of health care.⁸

The approach to patients is focused on four health challenges faced by every person diagnosed with an incurable disease, and that is that they must continue with disease control therapy as long as possible, alleviate mental and physical symptoms, help in making various decision-making in care planning and preparation for death, and family support including the time before and after the patient's death.⁹

Physical and mental interventions aimed at imminent death must respect the culture, spirituality, faith, ways of mourning, and the loss of the dying patient. For patients who, despite advances in treatment, experience a phase of terminal illness, palliative medicine is becoming the most important form of treatment. Approaches to the palliative care process include physical, psychological, social, and spiritual protection.¹⁰

Palliative care units provide specialist stationary care. The palliative care unit is a department specializing in the treatment and care of incurable patients. It is usually a department within a hospital or next to a hospital, but it can also exist as an independent service.¹¹

In some countries, palliative care units are an integral part of hospitals, providing crisis interventions to patients with complex symptoms and problems. In other countries, palliative care units may also be independent facilities, providing terminal care for patients for whom home care is no longer possible.¹²

The aim of palliative care units is to alleviate the discomfort caused by illness and therapy and, if possible, to stabilize the functional status of the patient and offer psychological and social assistance to patients and caregivers in a way that allows discharge or transfer to another type of health institution.¹³

Hospital palliative care support teams provide specialist advice on palliative care, support to other clinical staff, patients, and their families and caregivers in the hospital. They offer formal and non-formal education and cooperate with other services inside and outside the hospital.¹⁴

Hospital palliative care support teams are also known as „hospital support care teams“ and „hospital mobile teams“. The central goal of the hospital palliative care support team is to alleviate many symptoms of incurable patients in various hospital departments, through

mentoring staff and supporting patients and their families. Furthermore, this team ensures that expertise in palliative medicine and palliative care is available to all of these departments.^{15,16,17} Volunteers make an irreplaceable contribution to palliative care. The hospice movement, as a civil rights movement, is based on volunteer work. The Council of Europe emphasizes the importance of volunteering to provide quality palliative care in the community.¹⁸

The objectives of this paper include situational analysis of the organization of palliative care at the Clinical Center of the University of Sarajevo, examination of knowledge and approach of nurses in the process of providing palliative care at the Clinical Center of the University of Sarajevo and the examination of the attitude of nurses towards the way palliative care is organized at the Clinical Center of the University of Sarajevo.

MATERIAL AND METHODS

A total of 141 respondents who are employed at the Clinical Center of the University of Sarajevo (CCUS) participated in the study. Criteria for inclusion in the study were: doctors, highly educated nurses with additional education, a multidisciplinary team. Exclusion criteria were: termination of employment at CCUS team of health professionals, health associates and volunteer nurses and caregivers. The study is descriptive and analytical. To collect secondary data in the study, the documentation materials of health records were used, namely hospital protocols, periodic reporting documents, quality documents - strategies, indicators of quality and safety of health services, forms of categorization of patient health care, which are in the possession of the Organizational Unit for Quality and Safety of Health Services of the Clinical Center of the University of Sarajevo.

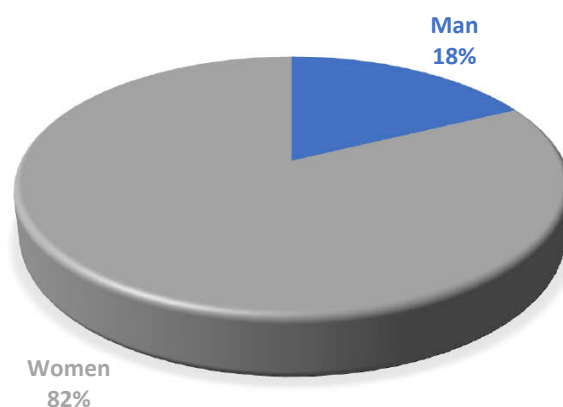
For the descriptive study, a questionnaire was used as an instrument, which was constructed with the help of the use of scientific and professional literature, as well as practical experiences. The questionnaire contains 24 questions, 21 of which refer to the respondent's attitude towards the way palliative care is organized. The questionnaire was created using Google forms and was available to respondents via a link sent to a personal e-mail

or the mail of the organizational unit in which they work. The questionnaire contains questions about knowledge of palliative care, the organization of palliative care, attitudes and opinions of nurses about palliative care in the hospital, expectations of patients and their families, etc. Answers were offered to most questions, however, the questionnaire also contained questions to which respondents could provide their own answers.

The results are presented in tables and graphs by the number of cases and percentages. To test possible differences between the examined groups of institutions, the chi-square test and Fisher's exact test were used. The level of statistical significance was set at 95% or $p < 0.05$. The analysis was conducted using the IBM Statistics SPSS v 23.0 sociological study package.

RESULTS

The study was conducted using a questionnaire and it involved 141 respondents, nurses and employees of the Clinical Center of the University of Sarajevo (CCUS), of which there were 25 men and 116 women working in different medical fields.



Graph 1. Gender structure of respondents

There are significant differences in gender ratios in different fields (Pearson's χ^2 test, $p = 0.028$) as significantly more female respondents participated in the study.

Table 1. Answers to questions about knowledge and attitudes regarding palliative care and their share within a particular medical field of the Clinical Center of the University of Sarajevo (%).

	Medical field								Total		p-value	
	Surgical field		Internal medicine field		Neuropsychiatry field		Other		n	%		
	n	%	n	%	n	%	n	%				
Knowledge of the position of palliative care within the health system	Primary health care	12	63%	16	57%	10	67%	43	55%	81	58%	0.39098
	Secondary health care	0	0%	5	18%	3	20%	20	26%	29	20%	
	Tertiary health care	7	37%	7	25%	2	13%	15	19%	31	22%	
	Total	19	100%	28	100%	15	100%	78	100%	141	100%	
Attitude towards the justification of palliative care in a hospital	Justified	3	16%	1	3%	1	7%	20	26%	26	18%	0.030035*
	Partially justified	9	47%	22	76%	10	67%	47	61%	88	63%	
	Unjustified	7	37%	6	21%	4	27%	10	13%	27	19%	
	Total	19	100%	29	100%	15	100%	77	100%	141	100%	
Attitude towards the profession that should lead palliative care	Doctors	1	5%	0	0%	0	0%	2	3%	3	2%	0.082959
	Highly educated nurse with additional education	4	21%	5	17%	0	0%	15	19%	24	17%	
	A multidisciplinary team of health professionals, health associates and volunteers	6	32%	22	76%	13	87%	47	60%	88	62%	
	Nurses and caregivers	8	42%	2	7%	2	13%	14	18%	26	18%	
	Total	19	100%	29	100%	15	100%	78	100%	141	100%	
Attitude towards the place of organization of palliative care	At home with the support of a primary health care worker	8	42%	16	55%	5	33%	18	23%	47	34%	0.214471
	In an institution that has adequate conditions for conducting care	11	58%	12	41%	10	67%	56	73%	89	64%	
	In a hospital	0	0%	0	0%	0	0%	3	4%	4	2%	
	Within a nursing home	0	0%	1	3%	0	0%	0	0%	1	1%	
	Total	19	100%	29	100%	15	100%	77	100%	141	100%	
Knowledge of palliative care facilities	Familiar	0	0%	7	24%	0	0%	8	10%	15	11%	0.215671
	Partially familiar	5	26%	3	10%	1	7%	11	14%	20	14%	
	Not familiar	12	63%	19	66%	13	87%	47	60%	91	65%	
	Believes that there is no such center	2	11%	0	0%	1	7%	12	15%	15	11%	
	Total	19	100%	29	100%	15	100%	78	100%	141	100%	

The largest number of respondents was middle-aged, 87 of them (62.6%). The largest number of respondents had a work experience in the range of 21-30 years, 50 (35.7%), and a slightly smaller number of respondents, 45 (32.1%), had 11-20 years of work experience.

The largest number of respondents completed secondary education, 93 (67%). It is expected that the largest number of respondents perform the duties of a ward nurse, 105 (75%).

Table 1 presents the respondents' answers about the knowledge of the scope of palliative care according to the levels of health care. The majority of respondents (58%) believe that palliative care belongs to the domain of primary health care and that it is only partially justifi-

fied in the hospital (63%). Based on this question, there are no differences in any socio-professional group of respondents.

Also, the answers of the respondents regarding the opinion of who should provide palliative care are presented. A significant number of respondents from the internal medicine and neuropsychiatric fields of CCUS stated that they believe that palliative care should be provided by a multidisciplinary team of health professionals, health associates and volunteers, 76% and 87%, respectively (Pearson's χ^2 test, $p=0.006$). On the other hand, in surgical fields, 42% of respondents believe that palliative care should be organized and conducted by nurses. There was no difference in other categories.

Table 2. Attitudes of respondents towards the organization of palliative care in the hospital from the aspect of practice and ethics

Medical field										Total		p-value
Surgical field		Internal medicine field		Neuropsychiatry field		Other						
n	%	n	%	n	%	n	%	n	%			
Attitude on the ethical justification of palliative care in the hospital	Justified	2	11%	4	14%	0	0%	27	35%	33	24%	0.097504
	Partially justified	15	79%	22	76%	14	100%	46	59%	98	69%	
	Unjustified	2	11%	3	10%	0	0%	5	6%	10	7%	
	Total	19	100%	29	100%	14	100%	78	100%	141	100%	
The practice of palliative care in a hospital setting	Well organized	1	5%	5	17%	1	7%	18	23%	25	18%	0.000795***
	Partially well organized	16	84%	11	38%	11	73%	52	67%	90	64%	
	Poorly organized	2	11%	13	45%	3	20%	8	10%	26	18%	
	Total	19	100%	29	100%	15	100%	78	100%	141	100%	

The majority of respondents believe that palliative care in a hospital is ethically partially justified, 97 or 69% of them. Although the result of Pearson's χ^2 test indicated significant differences between medical fields ($p = 0.019$), the number of offered answers „Yes“ or „No“ was too small to give a final conclusion.

On the other hand, there are evident differences between fields at CCUS in the question of whether palliative care is well organized in a hospital setting (Pearson's

χ^2 test, $p = 0.001$). The staff from the internal medicine field more often answered this question negatively, in 45% of cases.

However, as with the previous question, the majority of respondents (64%) offered the answer „Partially“. Most respondents state that palliative care in the hospital is not well organized due to a lack of resources.

There were no significant differences in the offered answers between different socio-professional groups.

DISCUSSION

The research conducted at the Clinical Center of the University of Sarajevo, that is, the results of the respondents' attitudes, showed that the organizational units in which patients with incurable diseases are most often hospitalized do not have adequate material and personnel conditions for their treatment.

Hospitalization of patients in the terminal phase also increases the mortality rate at certain clinics. This was recorded at the clinics, where it was stated that patients with a poor prognosis due to an incurable disease, and with comorbidities present, are most often admitted. These are most often internal medicine clinics, namely the Clinic for Lung Diseases and Tuberculosis, the Clinic for Nephrology, the Clinic for Anesthesia and Resuscitation, the Clinic for Cardiovascular Diseases and Rheumatism and the Department of Endocrinology. So, in 2018, the number of deaths at the Clinic for Cardiovascular Diseases and Rheumatism was 210 (7%), the Clinic for Lung Diseases and Tuberculosis was 142 (4.5%), the Clinic for Nephrology 115 (14%), and the Department of Endocrinology 52 (8%). A similar situation was recorded in 2019, where the number of deaths at the Clinic for Anesthesia and Resuscitation was 210 (31.3%).

As expected, mostly middle-aged female respondents (35–54 years) participated in our study. Regarding the level of education, two-thirds of the respondents have a secondary education. There are no significant differences between men and women.

The questions related to the respondents' position on the organization of palliative care showed that slightly more than half of the respondents believe that this type of care belongs to the domain of primary health care and that it is only partially justified in the hospital.

About two-thirds of the respondents believe that palliative care should be organized by a multidisciplinary team in any institution that has adequate health conditions for providing care. Interestingly, the surgical staff significantly believe that nurses and caregivers should organize and implement palliative care. This opinion is not shared by colleagues from the Department of Internal Medicine and Neuropsychiatry. The reason for this can be the fact that in surgical disciplines the nurse takes on a more active role while caring for the patient, which they confirmed with a positive answer

to the question of whether they give suggestion to the doctor when performing palliative procedures. The research by Swagata et al. which was conducted in India combine with our research. It included 138 nurses who, on average, worked in the Intensive Care Unit for more than a year. It was found that the majority of nurses believe that nurses should be involved or start discussions about palliative care, while more than 50% of nurses indicated that palliative care patients should not be 'allowed' a peaceful death or unlimited visits.¹⁹

Elderly respondents did not show a positive attitude towards the institutional way of organizing palliative care in their answers, a larger number of respondents expressed a positive attitude towards the organization of palliative care at home. A possible reason may lie in the fact that, as elderly people with a family, they expect the help of their closest ones. About two-thirds of respondents do not know if there are palliative care centers in their domain.

The answer that palliative care in the hospital is only partly rhetorically justified is clear, bearing in mind the personal experiences of the respondents. The vast majority of respondents believe that the clinics where they work do not have enough nurses to provide services in the field of palliative care, and somewhat fewer in neuropsychiatric areas. Also, the respondents do not think that the clinics where they work meet the conditions for palliative care following the standards that include improving the quality of life of patients and their families faced with problems related to a fatal disease. The situation is somewhat better in the surgical field, where there is an organized mourning room. A negative response is more common among staff with a university degree, probably because more educated staff have a clearer knowledge of what services clinics should provide to incurable patients.

Respondents stated that they were partially educated to work with patients in need of palliative care. The staff is occasionally in a situation to treat incurable patients with therapeutic procedures.

The respondents stated that pain therapy is the most common way of treating incurable patients, and physical therapy, which is typical for the neuropsychiatric field, is somewhat less common. On the other hand, visits by a religious official in that field are not common. In Ruk's final paper on the attitudes and knowledge of nurses of the Bjelovar General Hospital about palliative care, the attitudes, and knowledge of terms related to palliative care, such as pain control, opioid use,

etc., were examined, and 37 respondents participated. As many as 43.24% of those surveyed do not agree at all with the view that palliative care is only needed for terminally ill patients, while only 8.11% fully agree that palliative care is only needed for terminally ill patients, while for example in the same survey from Palestine, 29% of nurses do not agree with this statement at all.²⁰

The respondents believe that incurable patients would have more adequate palliative care outside the hospital because in this way the dignity and wishes of the patient would be preserved, and this opinion is more pronounced among the respondents from the field of internal medicine, which does not coincide with the research conducted by Labaš at Varaždin General Hospital. This study aimed to examine prolonged treatment and palliative care from the perspective of the patient's family and to examine whether there is a connection between information, the gender of the family member of the palliative patient, the length of the illness and satisfaction with the quality of the palliative care provided. 74 respondents participated in the research. The results of the research showed that family members of incurable patients are satisfied with the health care.²¹

CONCLUSIONS

The research confirmed that very often patients in the terminal phase of life are hospitalized in the hospital, even though there are no adequate conditions for treatment and health care. It was established that there are different knowledge, attitudes, and practices of the respondents regarding the way palliative care is organized, the provision of services, and treatment in the hospital. The majority of respondents (64%) believe that palliative care should be organized in institutions for palliative care that meet the required conditions. Older respondents are mostly committed to the organization of palliative care at home in comparison to respondents of younger age and a shorter working experience. 78% of the respondents with a university or higher professional degree believe that palliative care cannot be adequately organized and carried out in the hospital because there are not enough nurses.

Respondents who are younger and have a shorter working experience in the hospital, mostly have the opinion that patients should be provided with treatment for the rest of their lives, including invasive medical procedures in the hospital.

Based on relevant hospital reports and survey research, it has been proven that patients with incurable diseases are hospitalized at standard wards,

by inspecting the institution's internal acts (organizational structure) and based on the questionnaire survey, it was determined that the conditions for hospitalization in the Clinical Center were not met in care for palliative patients,

based on the conducted survey, we received different answers which relate to knowledge, attitude, and practice in the process of providing palliative care in the Clinical Center of the University of Sarajevo.

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Informiranost i stavovi medicinskih sestara Kliničkog centra univerziteta u Sarajevu organizaciji palijativne skrbi

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Materijal i metode: U istraživanju je sudjelovao 141 ispitanik zaposlen u Kliničkom centru Univerziteta u Sarajevu (CCUS). Istraživanje je deskriptivno i analitičko. Rezultati su prikazani tablično i grafički putem broja slučajeva i postotka. Testiranje signifikantnosti razlika provedeno je primjenom hi-kvadrat testa i Fisherova egzaktnog testa.

Rezultati: Utvrđeno je da postoje različita znanja, stavovi i pristupi ispitanika povezani s načinom organizacije palijativne njege, pružanjem usluga i tretmana u bolnici. Većina ispitanika (64%) smatra da palijativnu njegu treba organizirati u institucijama za palijativnu njegu koja ima zadovoljene uvjete u skladu s propisanim standardima i kriterijima za palijativnu njegu.

Zaključak: Utvrđene su znatne razlike u znanju, praksi i stavovima zdravstvenih radnika o palijativnoj njezi.

Sažetak

Uvod: Zdravstveni sustav predstavlja jedan od najsloženijih sustava u bilo kojoj državi. Prema definiciji Svjetske zdravstvene organizacije, sustav zdravstvene zaštite obuhvaća zdravstvenu infrastrukturu koja osigurava spektar programa i usluga i pruža zdravstvenu zaštitu pojedincima, obiteljima i zajednici. Osnovno ljudsko pravo jest pravo na zdravstvenu zaštitu koja uključuje zdravstvene aktivnosti kao što je preventivno, kurativno i palijativno liječenje. Organizacija palijativne medicine potrebna je na svim nivoima zdravstvene zaštite. Ciljevi ovog rada obuhvaćaju situacijsku analizu organizacije palijativne njege u Kliničkom centru Univerziteta u Sarajevu, ispitivanje poznavanje i pristupa zdravstvenih radnika u procesu pružanja palijativne njege u Kliničkom centru Univerziteta u Sarajevu te ispitivanje stava kod zdravstvenih radnika o načinu organizacije palijativne njege u Kliničkom centru Univerziteta u Sarajevu.

Ključne riječi: menadžment, palijativna njega, sestrinska klinička praksa, znanja i stavovi medicinskih sestara/tehničara, dostojanstveno umiranje