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THE IMPACT OF INACCURATE TERMINOLOGY ON THE PROVISION OF NURSING CARE IN CASE OF THE INDICATION OF A PALLIATIVE CARE



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Abstract

Background: The article shows problems that arise due to use of inaccurate terminology during the care for hospitalized patients in the end of life at selected department of long-term intensive care.

Methods: The data were gathered through Ad hoc mixed research (Quan-Qual research design), which was based on a combination of research methods of quantitative and qualitative design.

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Results: The research revealed the fact that a large number of patients in palliative regimen are incorrectly included in the group of inaccurate terminology – when the doctor does not suggest a palliative care and enters unclear terminology in the patient's documentation. Also it represents to the fact that early palliative care is not integrated into the care of incurable patients in this department. This situation is very stressing both for the patient himself and also for the nursing staff, who do not have a clearly defined procedure of treatment and the nursing care for these patients. Last but not least, this phenomenon brings inaccurate information and false hopes to patient's families.

Conclusion: The research points to the need for precise medical terminology in patients with incurable diseases. It further emphasizes the need to accept the views of nurses when deciding on the implementation of early palliative care.

Keywords: Palliative care - Early palliative care - Chronically ill patient - Inaccurate terminology - Dying - Dying patient.

Introduction

Since the end of 1950's when the first anaesthesiology and resuscitation departments and intensive care units were established in the then Czechoslovakia, there has been a significant development in medicine and in nursing as well. We have seen an incredible development of new technologies that radically affects not only the process of diagnosis and treatment, which significantly increases the chances of survival of patients. This fact has changed the health professionals' view of many acute, previously medically unsolvable conditions, and on the other hand, it was the reason why previously unknown problems in the ethical and economic fields have come into existence.²

The new possibilities for medicine begun to appear as unlimited, human lives were prolonged to the maximum possible time, without regard to other aspects such as the quality of patient's life and their wishes. Both of these aspects became the centre of interest of the medical sector of palliative care for terminally ill and the dying patients. This type of care began to develop in the Czech Republic in the 1990's. Although the new branch of medicine is undergoing a process of great development, we can still see many weaknesses, especially in case of patients in the departments of intensive care.³

According to the WHO definition, we can describe the palliative care as "an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual". "In the Czech Republic was palliative care introduced into Act 372/2011 Coll. on health services (§ 5) in 2011. The palliative care is there characterized as a type of health care, the purpose of which is to alleviate suffering and maintain the quality of life in case of patients with diagnosis of the incurable disease."⁵

Palliative care is often related with only cancer patients. It is true that up to 80 % of patients in the palliative care have a certain type of cancer as their primary diagnosis. In these cases, we must into account the fact that directly the tumour or anti-tumour treatment can cause that the patient is in condition requiring intensive care. The remaining 20 % are patients with advanced neurodegenerative diseases, terminal stage of chronic organ diseases, AIDS patients, polymorbid

2 Drábková "Historie a vývoj", 287-289.

3 Drábková and Hájková, *Následná intenzivní péče*, 23.

4 See: "Palliative care," accessed October 8, 2021, <https://www.who.int/health-topics/palliative-care> care (who.int)

5 See: "Zákon pro lidi," accessed October 8, 2021, [https://www.zakonyprolidi.cz/372-2011](https://www.zakonyprolidi.cz/cs/372-2011) Sb. Zákon o zdravotních službách (zakonyprolidi.cz)

geriatric patients, patients with persistent vegetative status and patients with critical irreversible multiorgan failure in intensive care.⁶

The generally accepted objective of intensive care is always to maintain life and health. In situations when it is not possible to achieve this objective, the transition from intensive to palliative treatment / care comes to the forefront with its characteristics that guarantee patients the elimination of pain and other symptoms, for example discomfort and distress, that have negative impact of their quality-of-life, while maintaining human dignity and physical satisfaction, psychological, social and spiritual needs.⁷

In light of the facts above, it is very important for the patient's medical and nursing team to be able to realize that all the possibilities of treatment have been exhausted and that is the reason why further expansion of curative therapy will not improve the patient's health. Properly named and selected palliative care results in reduction of patients suffering. It is necessary to set the treatment of unpleasant symptoms such as pain, shortness of breath, nausea and many others that are connected with specific disease.

If the palliative regime process is not set right in acute and subsequent hospital departments, early palliative care is not integrated into patient care, this fact is very difficult for the dying patients, their family and the nursing staff too.⁸

The purpose of this article was to draw attention to the problems in practice that occur during the setting up a palliative regime for a selected department of long-term intensive care where the doctors use inaccurate and non-unified terminology in the documentation. The terminology relating to patients in the palliative regimen is not unified and the patient is treated inconsistently and that is the reason why there come about prolongation of the patient's suffering. We can also notice an unclear objective of care in case of the deterioration in the patient's health.

Research objectives are:

1) To evaluate the correctness of the categorization of the type of treatment and care in relation to the definition of palliative care for patients hospitalized in a selected department of subsequent intensive care in 2020.

2) To verify the impact of non-unified terminology not only on nursing staff (practice nurses and general nurses) but on their care for patients as well.

Research issue, characteristic of the research department

Patients in a research department of long-term intensive care are hospitalized there for several months or years. It is very difficult to determine the limit when the medical treatment is still a benefit for the patient and when there is no benefit for them. And for that purpose, the institution has set a procedure for initiating a palliative care. Anyone from the nursing medical team, the patient's family or persons close to family members can initiate it. The initiation of a palliative regimen should begin after record in the medical documentation and informing the patient (if it is possible in view of his or her clinical condition). The senior doctor or the head of the department informs the patient about the palliative care before it starts. The result of the decision to initiate palliative care will be determined by the palliative commission, which meets according to the needs of selected departments and on the basis of the initiative for beginning of the palliative care.

The initiation of palliative care and the decision to initiate or not to continue the ineffectual treatment must always be mentioned in medical documentation as a part of the treatment

6 See: "Co je to paliativní péče", accessed October 8, 2021, <https://www.paliativnicentrum.cz>

7 Bužgová, *Paliativní péče ve zdravotnických zařízeních: potřeby, hodnocení, kvalita života*, 25- 30.

8 Pařízková "Paliativní léčba v intenzivní medicíně", 15-17.

plan. The record should be written before the beginning of palliative care and must include: 1) expert assessment of patient's health status and medical explanation of the decision to start palliative care, 2) formulation of further care and treatment objectives, 3) the priority of the palliative care plan - elimination of signs of pain, discomfort and suffering. The treatment plan must contain sufficient nursing care and analgesia according to the patient's clinical condition. The objectives of care, the benefits and risks of planned and on-going individual diagnostic and treatment procedures should be re-evaluated and considered at regular intervals. Any already taken decision can be modified in the in duly justified cases. A record of the reasons for changes in the treatment plan must be also part of the medical records.

According to the nursing staff's claim, the selected department of subsequent intensive care has long faced the problem of poorly defined palliative care. Doctors do not use the above procedure to apply palliative care but they often choose non-standard qualification that is perceived as an improper synonym for palliative care and that is the reason why it can be often confusing for both doctors and nurses. In the case of inaccurate terminology, there is no unified procedure for medical and nursing care. In consequence of this fact there are many problems from the point of view of nursing staff.

Methodology

In the first part of the research, we took a retrospective data collection from the hospital information system, where we categorized all hospitalized patients according to the type of care that the doctor chose for them. This part of survey was realized in 2020. We divided the patients into 3 groups – curative care, palliative care and other terminology.

In the second part of the research, we focused on determining the differences in care among the 3 groups of patients. With that intention we have chosen case studies as a method of collecting qualitative research data. We randomly selected 5 patients from each group and prepared their case report. Each case report described the selected patient, respectively the aspects of their care. Then there were determined the main aspects in selected areas for each group, and the individual groups were compared with each other.

In view of the fact that the first two parts of the research showed the frequent classification of patients into a group of unclear terminology, where the differences between this type of care and palliative care practically do not exist, we are interested in the nursing health professionals' attitude on this issue. Using a qualitative method to data collection based on the recommendations of the Thematic Analysis we made 9 open interviews with general nurses working in a selected department of subsequent intensive care. The data were analysed in the following order according to individual recommendations – 1. reading and repeated reading, 2. initial notes and comments, 3. development of emerging topics, 4. open coding, 5. searching for connections across the topics, 6. searching for patterns across the topics. The data were processed using Atlas.ti software. We present the main outputs in the article help Smartart.

Results

The following text presents the results of all 3 consecutive studies. Table 1 shows the results of the first part of the research – the categorization of patients from the monitored group that were hospitalized at the research department in 2020.

Table 1: Categorization of hospitalized patients

Group	Gender	Number of patients	The average age of patients	The youngest patient's age	The oldest patient's age
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Curative care	men	40	65	27	83
	women	23	64	23	88
Palliative care	men	23	65	41	87
	women	5	70	46	93
Other terminology	men	27	72	21	83
	women	17	71	26	91

The interpretation of the Table 1

During 2020, there were 135 patients admitted to the long-term intensive care department. 63 patients (40 men and 23 women) were in the curative care group in which the patients are fully treated. The second group includes patients in the palliative regimen, when all treatment procedures are exhausted and patients can no longer receive treatment that would improve their health. There were 28 patients in this group (23 men and 5 women). The last group consists of patients characterized with inaccurately used terminology (in their case doctors often use terms such as adverse prognosis or rationalization of treatment) and without clarification of the further medical treatment. There were 44 patients in this group (27 men and 17 women).

Table 2 describes the practice situation of particular types of care at research departments and it also shows the data obtained from the analysis of the patients' case reports.

Table 2: The most common characteristics of patient care during long-term intensive care

Curative care	Palliative care	Other terminology
<ul style="list-style-type: none"> • Continuous monitoring of physiological functions and ventilation parameters • Fluid balance • Monitoring signs of infection • Hygienic care • Curative care and rehabilitation • Pulmonary rehabilitation concerning breathing techniques, airways clearance techniques • Collection of blood and urine samples • Samples for cultivation and sensitivity • Antibiotic treatment according to the results • Aseptic changing of all invasive inputs • Inhalation therapy • Ward round • Preventive and therapeutic positioning • Pain monitoring and pain treatment • Cardiopulmonary resuscitation during cardiac arrest 	<ul style="list-style-type: none"> • Monitoring of physiological functions and ventilation parameters according to patient's condition • Monitoring of pain symptoms, analgesic therapy • Hydration and nutrition care • Hygienic care • Analgesic rehabilitation • Care of airways / respiratory care • Aseptic changing of all invasive inputs • Ward round • Patient and relatives are information about prognosis and care • Cardiopulmonary resuscitation during cardiac arrest is not initiated 	<ul style="list-style-type: none"> • Monitoring of physiological functions and ventilation parameters according to patient's condition • Monitoring of pain symptoms, analgesic therapy • Hydration and nutrition care • Hygienic care • Analgesic rehabilitation • Care of airways / respiratory care • Aseptic changing of all invasive • Ward round • Patient and relatives are not information about prognosis and care • Cardiopulmonary resuscitation during cardiac arrest is not specified

The interpretation of the Table 2

The first described group is **curative care** which is characterized by the fact that the patients are fully treated with the objective of complete healing. This includes continuous monitoring of blood circulation, respiration (physiological functions are recorded to the nursing documentation every hour), repeated blood collection (twice a week), appraisal of their results, antibiotic therapy according to cultivation and sensitivity, support of blood circulation with catecholamines (Noradrenaline, Dobutamine, Empressin), control of fluid intake and output. CPR is initiated in case of cardiac arrest. Doctors visit the patient during the ward round twice a day. Nursing care is provided nonstop. During the duty the medical staff care for patient's complete hygiene, aseptic changing of all invasive inputs and defects (decubits, surgical wounds, venous accesses) and carrying out the treatment recommended by a doctor. The patients are positioned every 2 hours. The nursing staff takes care of a quality airways clearance. The patients are regularly monitored for pain and analgesics are provided according to the regular medication. In case of the pain aggravation the medical staff reacts according to the doctor's prescription. Medical rehabilitation is carried out on patients twice a day depending on their current condition.

The second group describes a **palliative regimen**, where all treatment options have been exhausted. The patient is monitored continuously for blood circulation and respiration, and blood sampling. Antibiotic therapy and collection of the blood samples are reduced. Emphasis is put on treatment of the pain – it usually includes providing of continuous analgesics, as well as on patient's adequate nutrition and hydration. In case of cardiac arrest, cardiopulmonary resuscitation is not initiated. Doctors visit the patient during the ward round once a day. Nursing care is provided nonstop. During the duty the medical staff cares for patient's complete hygiene, changing of all invasive entrances and skin defects. Nurses proceed according to the doctor's prescription. The patients are positioned depending on their current condition. The nursing staff takes care of an airways cleanness. Rehabilitation is carried out on patients only if it is not painful for them and if it does not aggravate their condition. Patient and relatives are completely full information about prognosis and care.

The third group is a group of **inaccurate terminology**, where the doctor enters an inaccurate term to the documentation (non-extension of therapy, rationalization of treatment or adverse prognosis). This inaccurate terminology causes that it is not evident how the patient's treatment will continue. That is the reason why there are confusion about the subsequent care for patient and question if their treatment will be continued or not. Patient's blood circulation and respiration are monitored continuously. Antibiotic therapy and collection of the blood samples are reduced. Emphasis is put on treatment of the pain – it usually includes providing of continuous analgesics, as well as on patient's adequate nutrition. The initiation of cardiopulmonary resuscitation is not clear in case of these patients. Patient and relatives are not completely full information about prognosis and care.

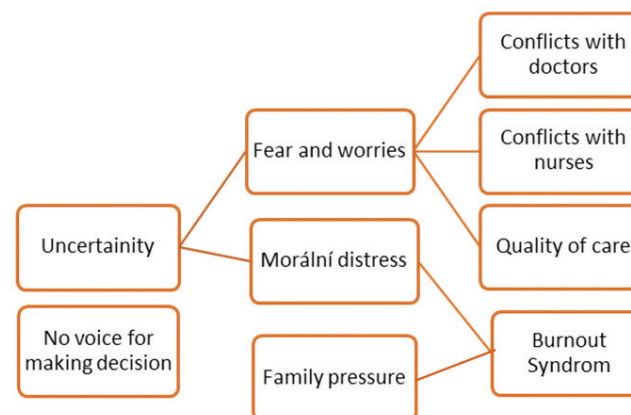
Doctors visit the patient during the ward round twice a day. Nursing care is provided nonstop. During the duty the medical staff cares for patient's complete hygiene, changing of all invasive entrances and skin defects. Nurses proceed according to the doctor's prescription. The patients are positioned depending on their current condition. The nursing staff takes care of a quality airways cleanness. Rehabilitation is carried out on patients only if it is not painful for them and if it does not aggravate their condition.

Full nursing care is provided in all three groups of patients, regardless of the reducing of the medication in case of palliative care and inaccurate terminology.

To achieve the set research objective nr. 2, qualitative field research was apply using the approach of thematic analysis. The thematic analysis was obtained from transcripts of interviews.

This research sample includes full-time Long-Term Intensive Care nurses who were willing to answer the question: "What do they think about the inaccurate terminology of the SIC patients that they care for?" Nine nurses have answered this question. Summary of the main topics is illustrated in Picture 1.

Picture 1: The main topics of interviews



The interpretation of the Picture 1

The most often topic that predominated in informants' answers was uncertainty. When the patients have in their documentation the inaccurate terminology instead of the palliative care and although the fact that this type of care is basically the synonymous with the palliative care it is not the official term in the legal terminology meaning, the nursing staff have no certainty, mainly in case of the cardiac arrest. The initiation or non-initiation of cardiopulmonary resuscitation is not clear.

"During the rationalisation of treatment, I don't know what we should include to the care for patient and what we should not."

"For example, the term rationalization does not determine the exact procedure in the case of CPR, and this makes the work of nurses very difficult. They don't know how to decide in that situation to the result of this decision is correct."

"If there is entered in the documentation: 'Due to the exhaustion of possibilities and the effect of treatment, the therapy will be aimed at a symptomatic palliative way', the palliative care is not clearly assigned to me. The used word 'will' evokes a feeling of indecision and unclear assignment."

"In the case of changes in the patient's condition, I am undecided if I should inform the doctor or not. After consulting with the team, we always call the doctor, but it still isn't clear how to proceed. Should we call a doctor? How will he or she react? In my opinion it is useful to clearly determine the procedure of care in the documentation."

The second main topic was the fact that nurses have no advisory voice during making decision on the implementation of palliative care. They lack the medical authority for discussion.

"We are with them all time during work service with patients, we know everything about them and no one asks us anything, no one even cares. If the patient does not fit into the relevant rows of the scientific tables, he will be treated, even if he does not want to."

From uncertainty also arises often mentioned theme of fear. Fear of the situation that the nurse would harm the patient's health if she did not inform the doctor or if the doctor would be indecisive in the subsequent procedure of patient care. That is the reason why nurses often call a doctor for any deterioration in the patient's condition, which heads towards another related topic and the fact that some doctors are irritated and think that the nurses are incompetent and call them due to every banality.

"When I don't inform the doctor of it, the patient's death causes the feeling of guilt connected with doubts that I was supposed to choose different procedure."

A frequently mentioned topic was also moral distress, when the nurse proceeds according to the doctor's prescription, which is not in accordance with her moral values and beliefs of what is and what is not correct. She abides the doctor's prescription for fear that she will be prosecuted.

"In case of patient's cardiac arrest, I will inform the doctor about the current condition of the patient and I will proceed according to his decision, although I do not always agree with resuscitation. I often wish those people rest in peace. They have experienced so much horror. Unfortunately, I properly record everything to the documentation according to the doctor's decision, with which I don't completely identify. Every decision and responsibility is up to the senior doctor."

"It's a terrible feeling to resuscitate a patient and actually wish them the end and peace."

Unfortunately, not all families are able to understand the patient's serious condition. They want full care even in situation when all medical procedures have been exhausted. If the exact procedure of care is not clarified, the families are not given a comprehensive picture of the patient's condition. That is the reason why misunderstandings and subsequent conflicts with the patient's family can arise. This situation very often prolongs the patient's suffering.

"At any costs to save the patient, at any costs to look for other treatment alternatives. – Unfortunately, it doesn't bring any benefit to the patient; on the contrary, it prolongs their suffering."

Inaccurate terminology does not provide a specific procedure in case of deterioration of patient's condition. If the doctor on duty has a different view of the procedure than the doctor who recorded inaccurate terminology in the documentation, there may be a delay in therapy in subsequent care – for example, a delay in initiating cardiopulmonary resuscitation.

"The patient's condition is often serious and these delays can harm him. If doctors no longer want to extend the patient's therapy, they should accurately describe the procedure in case of cardiac arrest."

The last topic was burnout syndrome. The nurses described themselves as burnt out or spoke openly about its symptoms.

"Then I'm tired of it all, exhausted, I don't want to be at work. I'm pretty irritated. The kids tell me it's not me."

"Sometimes I dreamed about it, I'm standing over the bed, heart arrest in the monitor and I don't know what to do."

Discussion

The research was emerged from problem defined by general and practical nurses working in a selected long-term intensive care in a region town hospital. The problem was focused on wrong defined palliative care for end-of-life patients in research ward. Doctors here often do not use the recommended procedure for the deployment of palliative care and often use non-standard qualifications, which is rather perceived as an inappropriate synonym for palliative care. When inaccurate terminology is used, there is no uniformity of medical and nursing case.

The research aimed to assess the accuracy of the categorization of the type of treatment and care in relation to the definition of palliative care for patients hospitalized in a selected department

of long-term intensive care in 2020. The second aim of the research was to examine to impact of inconsistent terminology on nursing staff (general and practise nurse) and their care of patients.

In 2020, a total of 135 patients were admitted to the research side, were divided into three pre-defined groups, namely curative care, palliative care and groups of inaccurate terminology. In the first group, 63 patients were hospitalized in the year, in the second group, 28 patients were hospitalized, and in the third group, 44 patients were hospitalized. The number in the third group reflects the number of patients for whom the palliative care terminology is inaccurately determined and for whom the procedure of care in case of deterioration of the patient's condition is not determined in advance.

The prognosis for these patients is also not established, so the goal of care, how follow-up treatment will proceed, and the exact course of action when the patient's condition deteriorates are not predetermined. Both the patient and his family are in uncertain information about the prognosis. However, pain therapy, nutrition and other therapies are set in advance according to the current condition, as it is in the case with the palliative care group. However, the procedure for circulatory arrest, whether to initiate cardiopulmonary resuscitation or not, is not specified. This activity then applies to the service of the doctors and their surgeries, which makes the work of the attending staff difficult.

The need for proper identification of patients for palliative care and the necessity to start early palliative care is highlighted by experts from the medical field and other disciplines such as nursing, social work, psychology and others. Greer et al. (2018) highlight the fact that early palliative care provides an opportunity for the patient and their loved ones to be well oriented in the trajectory of the disease, to receive support for coping with the diagnosis, to improve the quality of decision-making among alternatives of management to match the patient's values and preferences, as well as to have realistic expectations of treatment outcomes, anticipating further developments in time so that the patient and the family can be well prepared.⁹

Many studies also demonstrate the benefit of palliative interventions in the intensive care setting. Research shows that palliative care is beneficial for two groups of patients in particular. The first group is patients in the intensive care setting, where the main focus tends to be intensity of care appropriate to the patient's values. Through the use of invited specialist doctor in palliative care (consultative model) or palliative interventions by intensivist physicians themselves (integrative model), studies have shown that reductions in ICU and hospital stays are most often achieved, satisfaction with care is increased in some studies, and mortality is unchanged or reduced. The second group is patients with chronic advanced disease resulting in acute decompensation, e.g. requiring repeated acute hospital admissions (e.g. for breathlessness in COPD or heart failure) or for pain in generalised malignancy).¹⁰

Hospitalization after the crisis allows anticipating the further development of the disease and, in collaboration between the patient, the primary care team, the palliative care team and the patient's family, developing a plan for deterioration that matches the patient's values and preferences.¹¹

We can only guess at the reasons why the number of patients included in the inaccurate terminology group is so high. According to Kopecký (2018), the most common barriers to the indication of supportive and palliative care are concerns about the communication of prognostic information related to the belief that this information can "take away hope" from patients.¹² According to

9 Greer, "Early integration", 349- 363.

10 Nelson, "Models for structuring", 1065-1072.

11 Kopecký, "Úloha paliativní medicíny", 449-452.

12 Kopecký, "Úloha paliativní medicíny", 450-453.

researchers the most common barrier is the need for the patient's condition to be assessed as terminal. Further research would be useful to verify this.¹³

The second aim of the research was to examine the impact of inconsistent terminology on nursing staff (general and practice nurses) and their care of patients. In response to the question regarding inaccurate terminology, "What do you think about inaccurate terminology for the patients you care for." nine nurses working in the long-term intensive care unit responded. According to the nurses, caring for patients who have inaccurate terminology in their documentation is very challenging and they feel a great deal of uncertainty in caring for these patients.

With imprecise terminology, nurses do not know whether to rescue a patient when basic vital signs fail. The concept of rationalisation, which is often used, is an incomprehensible term for them and they cannot imagine how they are supposed to care for the patient. This term does not tell them whether cardiopulmonary resuscitation is initiated in the event of circulatory arrest. Nurses feel a great deal of uncertainty about the next course of care when caring for these patients. They would feel guilt if they did not inform the doctors of the patient's deteriorating condition and the patient's subsequent death occurred. In addition to this, they very often experience moral distress, where the nurse acts according to the doctor's orders, which are not in line with their moral values and beliefs about what is right and wrong. She will only perform the requested surgery for fear of being legally prosecuted.

According to Altaker et al. (2018), increased moral distress among nurses caring for terminally ill patients is associated with poor workplace ethical climate, non-integrated palliative care teams, and little or no nurse voice in decision-making about palliative care implementation. The research also highlights the need to promote palliative care education and palliative care teams that are well integrated into intensive care units.¹⁴

According to Wolf et al. (2019), many critical care nurses do not feel prepared to provide palliative care. If the approach to palliative care is perceived as inadequate, nurses may experience moral distress. Again, this research highlights the need to prepare nurses for potential pitfalls and educate them in palliative care.¹⁵

Nurses in our research report that they want patients in the post-acute care unit not to suffer for long periods of time and to be able to leave with dignity without prolonging their suffering, which is not the norm when terminology is inaccurate. There is frequent changing of therapy according to the serving physician, thus prolonging patient suffering, which causes futility and misunderstanding of treatment procedures by nurses. Drtinová states in her work that up to 74% of nurses providing palliative care are at risk of burnout syndrome.¹⁶ Burnout syndrome is an issue that also emerged as a theme in our research, so it is very important to listen to the issues and perceptions of care by nurses who spend a lot of time with patients.¹⁷

The role of the nurse has changed in recent years and the nurse has become an equal partner of the doctor. High demands are placed on nurses, as they are the closest to the patient and form a bridge in communication between the patient and their family members and the doctor. In long-term intensive care units, these demands are higher because of the long-term hospitalisation of patients, often with an unfavourable prognosis.

Each member of the nursing team has an irreplaceable role in providing care to patients admitted to the ICU. Teamwork is very essential to patient care, therefore, if there is no interplay

between all team members and the goal of care is not clarified in advance, they cannot provide quality nursing care and there could be harm to patients and major discrepancies within the entire team. Therefore, the opinions and experiences of nurses should also be given more consideration by physicians. Their experience is a great asset in the care of long-term patients and their opinion on the care provided is often a great benefit to the patient.

Conclusion

The article is evidence that palliative care is an absolutely necessary part of intensive care, especially in long-term intensive units. The patient's indication for this regimen has to be clear, accurate, comprehensible to all members of the nursing team and other doctors. Uncertainties in the terminology of setting / not setting up of palliative care are the cause of a wide range of problems, especially among nurses. The severity of the problems can be also result in the onset or development of burnout syndrome. Therefore, it is very important to remove the barriers that cause this condition. In addition to the integration of early palliative care, it is also necessary to educate both nurses and doctors in this issue. In nursing teams, it is necessary to increase the position of the nurse and her voice in the decision-making process when implementing palliative care.

Author Contributions

All the mentioned authors significantly, directly, and intellectually contributed to the work and approved its publication.

Conflict of interest

All the authors declare that the research involved in the article and the publication of the article were carried out without having any business, financial or other relations and/or circumstances that could be considered as a potential conflict of interest. At the same time, all the authors declare that there is no conflict of interest related to this article or its review.

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ASPECTS OF THE COMMUNICATION AND ACCOMPANYING PEOPLE IN END-STAGE OF DEMENTIA AND THEIR INFORMAL CARERS IN RELATION TO OPTIMAL PALLIATIVE CARE: A SYSTEMATIC REVIEW



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Abstract

Background: Dementia, as by now untreatable geriatric syndrome, presents an important life-limiting group of diagnoses. The prognosis survival period of people with dementia in the terminal stage ranges from 3 to 10 years. Part of the dementia trajectory is physical and cognitive problems accompanied by neuropsychiatric symptoms that limit the patient as well as his informal caregiver. In systematic review of papers published from January 2017 to July 2021 out of the total number of 24 studies 10 relevant studies were selected for further analysis.

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Conclusions: The aim of this paper was to search for and present good practice examples of interventions related to the domains of optimal palliative care. Seven out of 11 domains were identified as covered by found intervention: Applicability of palliative care, Person-centred care, communication, shared decision making, Setting care goals and advance planning, Optimal treatment of symptoms and providing comfort, Psychosocial and spiritual support, Family care and involvement, and Education of the health-care team. All found interventions are related to communication and may be the inspirations for social workers and other specialists who are active in palliative care for people living with dementia.

Keywords: Dementia – Palliative care – Communication – Validation therapy.

Introduction

Dementia, as by now untreatable geriatric syndrome, is considered as a terminal health condition.² The umbrella term dementia covers more than a hundred forms. According to Alzheimer's Disease International,³ from 50 to 60 % of all dementia cases occurring in Alzheimer's disease (AD). Currently, AD and other dementias are the seventh foremost cause of death in the world.⁴ It is alarming that one third of people in older age die with dementia.⁵ In dementia widespread of neurons' death consequences in numerous deficits of memory, behaviour, language, movement and executive function and ability to recognize relatives or common items.⁶ Failure to treat these symptoms leads to increased disability, premature institutionalization, increased financial costs of care and burden of caregivers.⁷

Progression of dementia is heterogeneous and results from types of condition and characteristics of person living with dementia.⁸ Studies show that people over the age of 65 live an average of 4 to 8 years after clinical diagnosing AD, some for more than 20 years.⁹ It is clear that one third to half of dementia course presents late stage dementia.¹⁰ In literature, the "late stage dementia" is also named as "advanced dementia", "severe dementia" or "end-stage dementia"¹¹ and it is characterised with memory deficit, minimal

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