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7 Ethical issues in palliative care and end-of-life care experienced by nursing staff within nursing homes: a cross-sectional study

Abstract

Background: Globally, the proportion of older people is increasing along with life expectancy. A significant proportion of older people spend their terminal phase of life in a nursing home, where palliative care is important. This study aims to determine the type and frequency of ethical issues among the nurses delivering palliative care in nursing homes.

Method: A cross-sectional survey method was used. Data were collected using a survey questionnaire. One hundred and eighteen nurses in two nursing homes in Slovenia completed the questionnaire. The instrument explored the frequency of ethical issues in nursing homes while providing palliative care to older dying people.

Results: The survey showed that the healthcare teams enjoy caring for dying older people; they feel qualified to perform palliative care, which is crucial for ensuring the comfort of the dying person. The survey results show that frequent ethical issues arise in professional, practice, and relational issues.

Conclusion: The comparative surveys showed similar results; we have concluded that palliative care in institutional care is still not well organised or supported by continuous training for nurses.

Keywords: aged, nurses, palliative care, nursing home

7.1 Introduction

Globally, the proportion of older people in the population is increasing rapidly. However, increasing life expectancy increases the chance of developing chronically non-communicable diseases in individuals [1]. A significant proportion of older people, most of whom require complex terminal medical care [2], die in nursing homes. In Europe, between 12% and 38% of older people die in a nursing home, and this is expected to increase in the future [3]. The ageing trend will continue and put increased pressure on resources in care homes due to the increased prevalence of chronic diseases and

complex comorbidities [4]. In doing so, healthcare professionals need to pay attention to older people's physical, psychological, social, and spiritual needs to meet and provide holistic palliative care [5] in the process of caring for a dying older person.

The concept of palliative care is closely related to the terminal phase of life. Its goal is to provide older people in the terminal phase of the disease with a better quality of life and relief from symptoms and the disease's consequences [6]. Palliative care during the dying period is essential to provide older people with all physical, emotional, and spiritual needs. The goal of palliative care is not only focused on quality of life but also on dignified death [7]. Nursing staff in nursing homes are often exposed to the deaths of their residents; with respectful professional and understanding treatment, they contribute daily to the dignity of older people dying in nursing homes [8]. An ethical approach to the care of older people plays an important role in palliative care, which is important in the process of dying, as it preserves dignity. Ethical issues in palliative care often stem from concerns about the adequacy of care and what older people need [2]. Ethical issues or challenges appear more often when there is disagreement, uncertainty, or doubts about making morally good or correct decisions [6]. In palliative care, ethical issues arise more often in advanced care planning, inadequate management of distressing symptoms, involvement or support of the care partners, and at the end of life care [9]. Ethical issues often have harmful consequences for the individual nurse in the form of moral distress, burnout and, as a result, a change of profession [10]. Many studies have found that the problem in nursing homes is a lack of experienced staff and materials, time, knowledge, and an ethical approach to providing quality holistic palliative care to dying older people, in their last days [4, 9]. Abudari and Zahreddine [11] conclude that palliative care should be introduced in nursing school systems worldwide, as they found that nurses do not have sufficient knowledge and experience to be able to provide palliative care independently.

Similarly, Leclerc and Lessard [12] showed significant differences in knowledge, handling, communication, and working with the dying in the nursing home among the staff; none had received specific training in palliative care. Furthermore, Simon, Ramsenthaler [13], and Kmetec and Fekonja [4] found that a person-centred approach is important to people in palliative care. Health professionals, who most often provide nursing care to older people needing palliative care, experience more ethical problems [14], so this chapter aims to determine the type and frequency of ethical issues among the nurses, during the delivery of palliative care in nursing homes.

7.2 Methods

7.2.1 Study design

The study uses quantitative research methodology, a deductive approach within the positivist paradigm characterizing such a methodology [15]. This paradigm provides us with an overview of ethical issues related to dying older people in nursing homes, from the perspective of the nursing team and their perspective on palliative care. A cross-sectional survey using a questionnaire was used. To ensure the reliability and rigour of the study and reporting results, we followed the STROBE guidelines [16].

7.2.2 Settings and participants

The settings were two nursing homes in Slovenia. Convenience sampling was used, and employees who were on the morning shift on a given day were involved [15]. We involved all members of the nursing care team, who work in nursing homes and have experience providing palliative care to dying older people; 118 members of the nursing care team participated in the study by completing the survey anonymously and voluntarily. Individuals were included in the study if they were >18 years of age, provided palliative care to older people, and worked in a nursing care team. Participants were included based on the eligibility criteria; they were working in a nursing home at the time of data collecting and had provided informed consent. We collected the data between December 2019 and May 2020.

7.2.3 Data collection and measures

The questionnaire *Ethical Issues and Palliative Care for Nursing Homes* (EPiCNH) by Preshaw et al. [10] was used and was designed to analyse ethical issues regarding palliative care in a nursing home. Before using the research instrument, permission from the original author was obtained. The questionnaire consists of two parts. In the first part, the questions refer to the demographic characteristics of the respondents. In the second part, in 26 statements, the respondents indicated the occurrence of ethical situations in three areas: professional issues/issues in practice, organisational issues, and relational issues. Participants had to rate each statement from 0 (“did not occur”) to 4 (“high frequency of occurrence”).

Respondents were verbally informed in advance about the survey and were guaranteed anonymity and the freedom to choose to take part in the survey. The content validity of the questionnaire was guided by Polit and Beck’s [15] guidelines. We also checked the appropriateness of the questionnaire structure, appearance, feasibility, readability, consistency of style between questions, formatting, and clarity of

language. Ten experts were purposively chosen for their knowledge of palliative care and heart failure. The expert panel subsequently approved the questionnaire. The questionnaire was pilot-tested with a small sample of the nursing care team ($n = 67$) to assess its reliability using Cronbach's alpha. The Cronbach's alpha of the questionnaire was 0.92.

Of the 118 eligible participants, 36 professional caregivers, 62 nursing assistants, and 20 registered nurses agreed to participate in the study and completed the questionnaires (response rate = 69%). As all the questions required mandatory answers, there were no missing values in any of the variables for data collected.

7.2.4 Data analysis

Data (anonymized) were entered and managed using IBM SPSS version 28 and a database was created for further analysis. Descriptive statistics were displayed as numbers on total (percentage), mean (M), and standard deviation (SD).

7.2.5 Ethical approval

Before the study, approval was obtained from the competent ethics committee in Slovenia (ref. no.: 038/2018/2510-2/504). Study participants were informed about the purpose and objectives of the study, confidentiality, anonymity, and voluntariness. Participation could be terminated at any time before submitting the completed questionnaire. Participants were allowed to see the results of the study, if they wished. The study strictly adhered to the ethical principles of the Declaration of Helsinki [17] and the provisions of the Oviedo Convention [18].

7.3 Results

7.3.1 Participants

Of the 118 respondents, 88.9% ($n = 87$) were women and many participants, 53% ($n = 62$), had a secondary level of education – nursing assistants, 31% ($n = 36$) were carers, and 16% ($n = 20$) were Registered Nurses. The mean age of participants was 39 ($SD = 11.52$) years. The oldest respondent was 60 years old, and the youngest was 19. The mean length of work experience of all participants in the survey was 17 ($SD = 0.78$) years, with the longest being 40 years and the shortest, three months. The mean length of work experience in the current job was 11 ($SD = 9.06$) years, with a minimum of three months and a maximum of 38 years (Tab. 7.1).

Almost half of the respondents, 48% ($n = 57$), see a dying person at work often, which means at least once a month, and 35% ($n = 30$) very often, at least twice a month. Only 0.8% ($n = 1$) of the respondents had never met a dying older person, and 21.2% ($n = 25$) had rarely met them. We wanted to know how the nursing care team felt about working with dying older people: 62.7% ($n = 74$) are empathetic and think about it at home; 27.1% ($n = 32$) consider nursing as their job and have no special feelings; and 10.2% ($n = 12$) are more sympathetic to the dying person compared to other employees. The care of the dying is very important, with 113% ($n = 95.7$) of respondents agreeing and 4.2% ($n = 5$) disagreeing (Tab. 7.1).

Tab. 7.1: Demographic characteristics of included nurses.

Variables (<i>n</i> = 118)	%(<i>n</i>)		
Gender			
Male	11.1(13)		
Female	88.9(105)		
Education			
Professional caregivers	31(36)		
Nursing assistants	53(62)		
Registered nurse	16(20)		
Frequency of encounters with the dying:			
I have never met before	0.8(1)		
Rare (up to twice a year)	21.2(25)		
Often (at least once a month)	48(57)		
Very common (more than twice a month)	30(35)		
Feelings when working with the dying:			
I have no special emotions	27.1(32)		
I feel empathetic, and I think about it at home too	62.7(74)		
I am more in favour of the person than others	10.2(12)		
The importance of caring for the elderly in the process of dying:			
Yes	95.7(113)		
No	4.2(5)		
	<i>M(SD)</i>	<i>Min</i>	<i>Max</i>
Age	39(11.52)	19	60
Total years of work experience	17(0.78)	0	40
Work experience in a nursing home	11(9.06)	0	38

M, mean; min, minimum; max, maximum; *n*, sample size; SD, standard deviation; %, per cent of participants.

7.3.2 Ethical issues

The survey showed that ethical issues often occur in different areas of providing palliative care in nursing homes. In professional issues/problems in practice and relationships, difficulties often arise concerning making decisions in the older person's best interests, to avoid unnecessary harm ($M = 3.09$; $SD = 0.99$) (Tab. 7.2). The fear of death is not a particular problem for the respondents, as 62.7% ($n = 74$) do not avoid the dying person due to fear of death. Very often, in 14% ($n = 11.9$), the subject of the death of older people is deliberately avoided. Fifty-six per cent ($n = 56$) of respondents strongly agreed that the nursing care team is key to ensuring the comfort of the dying older person. When a person is dying, the time of treatment is crucial. This is confirmed by the analysis of the statement, where 46% ($n = 46$) of the respondents strongly agree with this statement, 41% ($n = 41$) agree, and 9% ($n = 9$) cannot decide. Only 4% ($n = 4$) disagreed or strongly disagreed with the statement, meaning that the time of dealing with the dying person is unimportant to them.

Considering the family's wishes for care as opposed to their own opinion was the second most chosen statement ($M = 2.77$; $SD = 0.85$) related to attention to residents' care needs. The older people's rejection of food and liquids was the third most commonly endorsed statement ($M = 2.72$; $SD = 1.08$), and the fourth most widely reported statement was witnessing distress by family members or care partners ($M = 2, 60$; $SD = 1.20$). The fifth most frequently reported point was poor communication with staff, resulting in more inferior quality of care ($M = 2.05$; $SD = 1.06$). These survey ratings highlight ethical issues in relationships as the most common of these topics.

Organisational ethical issues, particularly lack of resources, were reported to occur frequently in practice by respondents, such as lack of time for providing older people with needed nursing care ($M = 2.48$; $SD = 0.98$), lack of physician support for older people nursing care ($M = 2.20$; $SD = 1.21$) and involvement in non-care activities, which reduce the time spent with the older people ($M = 2.14$; $SD = 1.21$). These items were scored infrequently on the frequency score, with mean scores ranging from 0.81 to 2.48. We noticed that the nursing team's lack of resources within the nursing home does not pose a major problem in providing sufficient palliative nursing care for the dying person, as 48.3% ($n = 57$) never or rarely have problems with this. Of the participants, 27% ($n = 32$) said they often experience a lack of resources, while 24.6% ($n = 29$) said it happens.

Regarding competence to provide palliative care, 71% ($n = 84$) of the respondents felt sufficiently competent, and 12.7% ($n = 15$) felt that they are not sufficiently competent to provide palliative care. However, they must do it, and 16% ($n = 19$) answered "rarely", which suggests that their competence depends on the individual case. The participants were not, or were least involved in the inadequate provision of palliative care ($M = 0.8$; $SD = 1.00$). About 82% ($n = 82$) of the participants feel that the nursing home lacks the staff to provide quality care for the dying older person. Although nursing care is focused on the dying person, 73% ($n = 73$) of respondents

felt that they did not have enough time to devote to the older person and their relatives, in the terminal phase.

Tab. 7.2: Frequency items for ethical issues during palliative care provision.

Frequency items (scale 0–5)	Never <i>n</i> (%)	Rarely <i>n</i> (%)	Often <i>n</i> (%)	Very often <i>n</i> (%)	<i>M</i> (<i>SD</i>)	EI
6. I have decided in the resident's best interest to prevent them from coming to harm or unnecessary risk.	0(0)	11(9.3)	20(16.9)	87(73.8)	3.09(0.99)	PI/IP
15. I have to follow the family's or care partner's wishes for the resident's care when I do not agree with them.	1(.8)	7(5.9)	32(27.1)	78(66.2)	2.77(0.85)	RI
5. I have to care for residents that only accept small amounts or refuse food and fluids near the end of life.	3(2.5)	15(12.7)	27(22.9)	73(61.9)	2.72(1.08)	RI
14. I witness distress from family or care partners.	7(5.9)	19(16.1)	19(16.1)	31(61.9)	2.60(1.20)	RI
20. I do not have enough time to provide the resident with the care she/he needs.	2(1.7)	17(14.4)	40(33.9)	59(50)	2.48(0.98)	OI
22. I find physician support lacking for resident care.	14(11.9)	20(16.9)	27(22.9)	57(48.3)	2.20(1.21)	OI
9. I have to initiate extensive life-saving actions when I think they only prolong death (e.g. PEG feeding, sub-cut fluids).	17(14.4)	22(18.6)	24(20.3)	55(46.7)	2.16(1.31)	PI/IP
24. I am involved in non-direct care activities, which reduce time spent with the residents.	14(11.9)	23(19.5)	29(24.6)	52(44)	2.14(1.21)	OI
1. I find it difficult to protect a resident's rights and dignity.	12(10.2)	28(23.7)	34(28.8)	44(37.3)	2.08(1.20)	PI/IP
7. I witness how poor staff communication diminishes the quality of care to residents.	11(9.3)	22(18.6)	44(37.3)	41(34.8)	2.05(1.06)	RI
4. I struggle to provide care to a resident due to their verbal or physical resistance.	13(11)	31(26.3)	32(27.1)	42(35.6)	2.03(1.23)	RI

Tab. 7.2 (continued)

Frequency items (scale 0–5)	Never <i>n</i> (%)	Rarely <i>n</i> (%)	Often <i>n</i> (%)	Very often <i>n</i> (%)	<i>M</i> (<i>SD</i>)	EI
3. I have to follow a request by a senior clinician not to discuss the resident's diagnosis with them when he/she asks for it.	27(22.9)	28(23.7)	21(17.8)	42(35.6)	1.85(1.45)	PI/IP
25. I feel the pain management is not satisfactory.	12(10.2)	35(29.7)	38(32.2)	33(27.9)	1.84(1.07)	OI
13. I feel powerless in decision-making during resident care.	17(14.4)	31(26.3)	34(28.8)	36(30.5)	1.82(1.15)	PI/IP
19. I cannot provide the care I want due to a lack of resources within the care home.	19(16.1)	38(32.2)	29(24.6)	32(27.1)	1.73(1.21)	OI
21. I cannot provide the quality of care I want due to conflicting care directions by external health and social care services.	17(14.4)	41(34.7)	31(26.3)	29(24.6)	1.72(1.19)	OI
8. I have observed professional incompetence due to insufficient staff training for providing nursing care.	19(16.1)	43(36.4)	27(22.9)	29(24.6)	1.62(1.13)	OI
2. At times, I have not been honest with a resident because I thought it was in their best interest.	19(16.1)	37(31.4)	38(32.2)	24(20.3)	1.61(1.07)	PI/IP
23. I have been involved in what felt like an unnecessary hospital admission.	24(20.3)	43(36.4)	24(20.4)	27(22.9)	1.57(1.25)	OI
12. I do not feel confident voicing my opinion regarding palliative care decisions.	25(21.2)	37(31.4)	32(27.1)	24(20.3)	1.54(1.18)	PI/IP
16. I am asked to provide care to the resident according to a senior clinician, specialist palliative care nurse, or charge nurse against my personal or professional opinion.	32(27.1)	42(35.6)	24(20.3)	20(17)	1.32(1.14)	RI
10. I do not know what care to provide, when no advance care plan has been agreed upon.	28(23.7)	45(38.1)	32(27.2)	13(11)	1.27(0.98)	PI/IP

Tab. 7.2 (continued)

Frequency items (scale 0–5)	Never <i>n</i> (%)	Rarely <i>n</i> (%)	Often <i>n</i> (%)	Very often <i>n</i> (%)	<i>M</i> (<i>SD</i>)	EI
18. I witness staff avoiding residents at the end of life due to their fears about dying.	29(24.6)	45(38.1)	30(25.4)	14(11.9)	1.27(1.01)	PI/IP
11. I do not know what to do when a senior clinician has provided unclear resident care instructions.	34(28.8)	43(36.4)	28(23.8)	13(11)	1.20(1.05)	PI/IP
17. I must provide palliative care for residents I do not feel trained to care for.	51(43.2)	33(28)	19(16.1)	15(12.7)	1.05(1.20)	OI
26. I have witnessed end-of-life care, which I felt was not satisfactory.	59(50)	35(29.7)	14(11.8)	10(8.5)	0.81(1)	OI

EI, ethical issues; *n*, sample size; OI, organizational issues; PI/IP, professional issues/issues in practice; RI, relational issues; SD, standard deviation.

7.4 Discussion

This study aims to determine the type and frequency of ethical issues among the nurses during the delivery of palliative care in nursing homes. Caring for older people needing palliative care brings on an emotional and psychological burden on the career; ethical issues appear, and it is difficult to manage them during such care [10]. The results showed that the most common ethical issues appear from the decision-making on behalf of the older people, in the areas of nutrition and hydration, family distress, and staff facing lack of time and poor communication between them.

Similarly, on the scale of frequency of occurrence, lack of time and too many non-patient-related activities are rated high (item 24). The ethical issue of reducing time to perform care is supported by Juthberg and Eriksson [19], who also found out that lack of time is associated with consciousness and causes stress, as the reduced time allocation to older people leads to the inability to perform person-centred care [4]. Older people's care in a nursing home must be comprehensive and person-centred, aiming to support older people's physical, social, spiritual, and psychological needs [2].

Many participants felt that the nursing home where they were employed provides person-centred care for the dying older person, but does not have enough time for the dying person to give full attention to them and their family. Research

[20] has shown that health professionals emphasise the safety of older people and do not allow them to make independent decisions about their health and themselves [20]. Our research agrees with the emphasis on care ethics, where the most common and difficult issues are related to ethical issues in practice and relational issues, including family distress, harm prevention, and respecting the family's wishes. To offer quality and comprehensive care, it is important to involve older people and their family members, early in the decision-making process [20].

It is also important that healthcare professionals trust each other and share decision-making power. Such an approach contributes to greater trust, reduction of ethical issues, and greater autonomy of older people. Not involving relatives in the medical treatment of older people causes stress, distress, and lack of strength and often leads to unhealthy hope. However, this unhealthy hope contributes to forcing unnecessary treatments and invasive procedures on older people needing palliative care. In this study and also Enes and de Vries [21], Schaffer [22], and Gjerberga et al. [23] found that interaction with family members is a concern for the nursing care team. Communication difficulties have led to challenges in decision-making and ethical issues in relationships, such as involving the patient and family in decision-making about care choices [9].

Communication problems cause feelings of not being heard, anger, helplessness, and bad conscience in older people, which has a fatal effect on individual healthcare professionals [2]. Results of our research showed how the family members' lack of support and involvement in the palliative care of their loved ones could contribute to unrealistic expectations in palliative care. The patient and family must be at the centre of the palliative care treatment, which can reduce unnecessary ethical issues.

Lopez [24] found that nurses feel they are between the physician and the family members in decision-making and are often doubtful about their role in providing care that will be acceptable to older people. In our study, we find out that older people, often, are not involved in the decision-making process of their own treatment when their ability to make decisions is questionable. Hence, the nurse plays an important role as an advocate of the wishes of the older people and, consequently, has an even greater role in making decisions in favour of the most vulnerable group of older people [2].

Among the organisational ethical issues, staff shortages and problems of inclusion of physicians in palliative care emerged as the biggest problems. Therefore, it is necessary to increase resources and improve the physicians' management of the care coordination in the palliative care of older people in nursing homes. Several problems involving the doctor have been reported in the literature.

Gágyor et al. [25] found that care coordination is limited even in homes with only one physician visit per week, and Enes and de Vries [21] found that the biggest ethical issue in nursing homes is the physician's lack of knowledge about symptom management. In contrast, Gágyor et al. [25] found that where there were more

employed physicians, advanced guidelines were more often discussed at admission, and medical records were audited. Based on this, the older people made decisions in their treatment, and each healthcare professional was aware of their role and responsibility.

The health care team is crucial in ensuring the comfort of the dying person, as evidenced by the fact that very few nurses feel uncomfortable in performing nursing care, and there is little fear of death among them. They are trying to provide good care, even though they feel they do not have enough staff to provide effective nursing care. Although there are occasional shortages of resources within the institution, the dying person's care is adequately taken care. There is a definite shortage of staff in nursing homes, which is explained by the survey data of our research. As a result, nursing staff are more physically and mentally exhausted. Although care in care homes is centred on the dying older person, there is lack of time to devote fully to the dying older people and their relatives. Finally, poor staff communication and observation of professional incompetence reflect on staffing deficiencies, including a lack of knowledge, education and training on the extent of responsibility previously identified in the ethical literature in nursing homes [9, 25]. They may contribute to a reduction in the quality of care.

7.4.1 Limitations

Limitations of this research have been acknowledged. There may have been a non-response bias at the level of nursing homes, as those facing many ethical issues may not want to participate. Data was collected using a questionnaire, which means that there is a possibility that they gave socially desirable answers. Also, a relatively small sample was included in this study. All limitations need to be considered when interpreting the results.

7.5 Conclusion

The key ethical issues during the provision of palliative care in a nursing home include the autonomy of older people, family distress, lack of communication, lack of time, and staff incompetence. These findings have implications on nursing care practice in nursing homes, including how care is organized and the ability of nursing staff to care of older people needing palliative care. Many ethical issues can be solved by training staff to consider patient and family values, when making decisions consistent with global policy recommendations. Future research should explore these findings in more detail and use them to develop interventions that address these fundamental ethical issues. Nursing care homes should recognize

and be attentive in order to identify ethical issues and educate their staff on how to resolve them.

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