

Original Article

Knowledge Level of Palliative Care and Perinatal Palliative Care of Midwifery Students

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Abstract

Aim: Lack of training and knowledge about palliative care, especially perinatal palliative care of health professionals, is emphasized in many studies. The aim of this study was to determine the level of knowledge of the midwifery students about palliative care and perinatal palliative care.

Methods: The study sample consists of the midwifery students studying at Giresun University Department of Midwifery in 2017-2018 academic year. The research sample consists of 223 (87%) students who agreed to participate in the study. To collect data, a researcher-developed survey was used. The survey with face-to-face interview assessed socio-demographic characteristics and Palliative Care and Perinatal Palliative Care knowledge and attitudes.

Results: The mean age of students was 20.72 ± 0.12 (18-32) years. 81.6% of participants stated that they had not had education on palliative care (PC), 90.1% have not had education on perinatal palliative care (PPB), 80.3% were wanted education related to PB, and 87.4% on PPB. The topics that should be included in the palliative care education according to the participants following; basic concepts of palliative care (95.5%), communication (74%), roles and responsibilities of team members (73.1%), and PPB-basic concepts and principles (88.8%), loss and mourning process (82.1%) and communication (73.1%). Students stated that the responsibilities related to perinatal palliative care are as follow; adequate information and equipment such as pain management should be provided to increase the quality of life of the baby, giving information about the family situation and being a multi-directional supporter in this process, and treating patients in accordance with ethical rules.

Conclusion: To increase awareness of midwifery students about palliative care and perinatal palliative care, palliative care, and perinatal palliative care should be integrated into in-service training programs before and after graduation.

Keywords: Midwifery Students, Palliative Care, Perinatal Palliative Care, Awareness

Introduction

Palliative care is applied to relieve pain and improve the quality of life in individuals with life-threatening diseases and those living with these

problems (Sujatha & Jayagowri, 2017). The World Health Organization (WHO) defines palliative care as "the determination of pain and other problems with early diagnosis and a perfect assessment in patients and families who encounter

life-threatening diseases; an approach that includes practices for the prevention and palliating of suffering through meeting physical, psychosocial and spiritual needs, and that aims to improve the quality of life” (World Health Organization [WHO], 2014). The basic principle in palliative care is to increase the quality of life of patients and their relatives by early recognition of the symptoms experienced during the disease period and their effective management (WHO, 2014).

The World Health Organization (2016) defines neonatal palliative care as a holistic, multidisciplinary approach to the physical, emotional, spiritual, and social aspects of the neonatal and family at the time of diagnosis (WHO, 2016). Perinatal palliative care is an interdisciplinary care model offered to couples who decided to continue the pregnancy after the diagnosis of life-threatening disease (Limbo et al., 2017). The purpose of perinatal palliative care (PPC) is to increase the quality of life in families with life-limiting fetal diagnosis (Wool, 2013). PPC is specially designed to meet the individual needs of the family during pregnancy, delivery, and the postnatal period (Wool, 2013; Hasegawa & Fry, 2017; Kadioğlu & Oskay, 2016).

Midwives, who are an active team member of the perinatal palliative care team, are expected to plan and implement care to increase the quality of life of the neonatal and their family by being in accordance with the purpose of PPC, sensitive to the culture, values, beliefs, and traditional preferences of the individual (LoGiudice & O'Shea, 2018). Midwives can initiate the referral process to appropriate services, be part of the PPC team, and provide care as part of a specific care team in processes such as the first stage of labor and delivery. Global standards on midwifery education curriculum alignment map competencies of the International Confederation of Midwifery (ICM) include areas that can be met with the PPC model (ICM, 2013). For example, ICM competencies may consist of independent or collaborative management of intrauterine fetal death, care, information and support needed during and after miscarriage or abortion, community resources, the normal evolutionary process, and care during the physical and emotional recovery process after miscarriage or abortion (ICM, 2013). What is expected from midwives in the Basic Competencies for Basic Midwifery Practices includes the encouragement of women and family-centered care, the mutual

empowerment of women in health care, and the care of vulnerable populations that can be met with PPC training (American College of Nurse-Midwives, 2012). One of the obstacles to fulfilling these responsibilities expected from midwives is the lack of midwives' training on the philosophy of perinatal palliative care (LoGiudice & O'Shea, 2018). The subject of palliative care and related issues, which has become increasingly important in recent years, is rarely included in the education curriculum of health-related fields (for doctors, nurses, and others). Although the content of the curriculum is revised in line with the current developments in the field of health, the lack of knowledge, skills, and awareness of working clinician healthcare personnel on perinatal palliative care has been emphasized in the studies (Wool, 2013; Hasegawa & Fry, 2017; LoGiudice & O'Shea, 2018; Mills et al. 2016). Although perinatal palliative care is a particular field of specialization, all midwives should have a high level of awareness of PPC philosophy by taking PPC training as part of primary education. It may be difficult for the newly graduated midwife to inform the expectant mother who has a life-limiting child, then manage her care and attend the delivery. Midwifery students need to be prepared in the best way to manage this process effectively and to provide holistic care for the woman and her family. Although there are very few studies examining the knowledge and attitudes of midwifery students on palliative care in Turkey (Ay & Gençtürk, 2013), no studies on perinatal palliative care have been found. Again, studies conducted abroad on the subject are very limited (Price et al., 2019; Martin et al., 2016). In this respect, determining the knowledge and attitudes of midwifery students regarding perinatal palliative care is important in terms of planning both basic midwifery education and continuing education activities to be planned after graduation.

Aim: The aim of this study was to determine the level of knowledge of the midwifery students about palliative care and perinatal palliative care.

Methods

Design: A cross-sectional study.

Sample: The universe of the study consisted of 256 students studying at Giresun University, Faculty of Health Sciences, Midwifery Department in the 2017-2018 academic year. The sample was not selected in the study, it was aimed to reach the whole population and the study was completed with 223 (87%) midwifery students who agreed to

participate in the study. Data were collected between January and March 2018.

Data collection tools: The data were collected by using "Student Information Form" and "Opinions Regarding Palliative Care Form" "Opinions Regarding Perinatal Palliative Care Form." In the Student Information Form, there are 15 questions, including questions regarding the socio-demographic characteristics of the students, as well as their current knowledge on palliative care and perinatal palliative care. "Opinions Regarding Palliative Care Form" was developed by Turgay and Sav (2012) to determine the views of healthcare professionals on palliative care (Turgay & Kav, 2012). This form consists of 16 statements questioning nurses' views on palliative care philosophy and the provision of care services. The researchers developed the "Opinions regarding Perinatal Palliative Care Form" by scanning the relevant literature (15-18) and consists of 14 statements in total.

Data collection: The data were collected separately for each class's students in the students' academic consultation hours. Before the data collection, the students were informed about the purpose of the research, and they were informed that participation in the study was voluntary. Filling out the forms took approximately 20-30 minutes.

Data analysis: The data was analyzed using SPSS 22.0 package software. The findings were shown in terms of numbers and percentages for the categorical variables and as mean \pm standard for the continuous variables.

Results

In Table 1, the distribution of midwifery students' mean ages, grades, and education about palliative/perinatal palliative care is given. The mean age of the students is 20.72 ± 0.12 . Of the students, 28.7% are in the first grade, 22.9% are in the second grade, 20.6% are in the third grade, and 27.8% are in the fourth grade. It was determined that 81.6% of the students did not receive any training on palliative care, and 70.7% of the educational fields regarding PC (18.4%) did not find the scope of the education sufficient. Of the students, 97.3% (n: 184) stated that they wanted to receive education about PC. When their education on perinatal palliative care was questioned, it was determined that 90.1% of the students did not receive any education, and 59.1% of the educational fields regarding PPC (9.9%) did not find the scope of education sufficient. Of the students, 96.5% stated that they want to receive

training on PPC. Table 2 shows the students' education about palliative and perinatal palliative care. Of the students, 87.0% stated that midwives should be among the team members carrying out palliative care services, 88.8% of them stated that midwives should be in perinatal palliative care services. The first three subjects that should be addressed in the education program on palliative care are the basic concepts and principles of palliative care (95.5%), communication (74.0%), and roles and responsibilities of team members (73.1%). PPC basic concepts and principles (88.8%), pain and symptom management (82.1%), communication (73.1%) were identified as priority issues in education in perinatal palliative care. Midwifery students mostly associated perinatal palliative care with prematurity (65.9%), anencephaly (55.2%), and fetuses less than 23 weeks (54.7%). Table 3 shows the opinions of midwifery students regarding the expressions on palliative care. Students stated that 91.0% of the team members carrying out palliative care services were doctors, 91.0% were nurses, and 87.0% were midwives. They also stated that 72.6% of the team members carrying out perinatal palliative care services were PPC coordinators, 87.4% obstetrics and perinatology specialists, 71.7% neonatal physicians, and 71.3% obstetrics nurses. Of the students, 95.5% stated the basic concept and principles of palliative care as the subject that should be addressed in the palliative care training program. The disease groups associated with perinatal palliative care were mostly stated to be 65.9% premature, 55.2% anencephaly, and 51.6% Trisomy 13, 15, 18. In Table 3, the opinions of the students about the expressions on palliative care are given. Accordingly, it was determined that more than 70% of the students agreed with the following statements: "Palliative care service should be provided by a multidisciplinary team.", "The patient and his/her family are decision-making team members in palliative care.", "The patient and his/her family are decision-making team members in palliative care.", "The physician should lead the palliative care team", "Patients and caregivers should be able to reach palliative care professionals 24/7", "Palliative care requires employees to control their emotions", "The patient should have the right to cardiopulmonary resuscitation and legal regulations should be made", "Palliative care should be a separate field of specialization", "Palliative care should be a compulsory subject in university education programs for healthcare professionals", "Palliative care should be the responsibility of the

state to ensure that this care is provided to everyone when there is a need". In Table 4, the opinions of the students about the statements on perinatal palliative care are given. According to the table, the students most (94.2%) agreed with

the statements that "midwife care should plan the prenatal, during delivery and postnatal period starting from the diagnosis of fetal anomaly" and least agreed with (62.8%) "Perinatal palliative care is family-centered".

Table 1. Socio-demographic Characteristics of Students and Palliative/ erinatal Palliative Care Training Status

	\bar{X}	$\pm SS$
Age	20.72	0.12
	N	%
Class		
First-class	64	28.7
Second class	51	22.9
Third class	46	20.6
Fourth class	62	27.8
Palliative Care (PC) Training Status		
Yes	41	18.4
No	182	81.6
Do you think that the PC training you received was sufficient? (n:41)		
Yes	12	29.3
No	29	70.7
Intend to learn more about PC (n:184)		
Yes	179	97.3
No	5	2.7
Perinatal palliative care (PPC) Training Status		
Yes	22	9.9
No	201	90.1
Do you think that the PPC training you received was sufficient? (n:22)		
Yes	9	40.9
No	13	59.1
Intend to learn more about PPC (n:202)		
Yes	195	96.5
No	7	3.5

Table 2. Students' Knowledge about Palliative \ Perinatal Palliative Care Services

	N	%
Who should be in the palliative care team?		
Physicians	203	91.0
Nurses	203	91.0
Midwives	194	87.0
Social workers	90	40.4
Psychologists	186	83.4
Physical therapists	100	44.8
Dieticians	86	38.6
Pharmacists	58	26.0
Spiritual Advisors	39	17.5
Volunteers	60	26.9
Family members	141	63.2
Who should be in the perinatal palliative care team?		
PPB coordinators	162	72.6
Obstetrician and perinatologists	195	87.4

Neonatal physicians	160	71.7
Obstetrician nurses	159	71.3
Neonatal intensive care nurses	149	66.8
Midwives	198	88.8
Social workers	55	24.7
Psychologists	164	73.5
Physical therapists	65	29.1
Dieticians	63	28.3
Pharmacists	46	20.6
Spiritual Advisors	32	14.3
Volunteers	38	17.0
Genetic counselor	65	29.1
Breastfeeding consultants	74	33.2
Anesthetist	46	20.6
Psychiatrist	113	50.7
Family members	112	50.2
Which topics should be included in the palliative care courses?		
Fundamental principles and concept of palliative care	213	95.5
Symptom management	154	69.1
Legal and ethical issues in palliative care	152	68.2
Loss and grief	161	72.2
Communication	165	74.0
The roles and responsibilities of the team members	163	73.1
Economic dimension of palliative care	115	51.6
Which topics should be included in the perinatal palliative care courses?		
Fundamental principles and concept of perinatal palliative care	198	88.8
Perinatal and neonatal palliative care	137	61.4
Pain and Symptom Management	183	82.1
Legal and ethical issues	151	67.7
The loss and mourning process	162	72.6
Communication	163	73.1
Genetic counseling	118	52.9
Discharge training	137	61.4
What are the disease groups associated with perinatal palliative care?		
Trisomy 13, 15, 18	115	51.6
Anencephaly	123	55.2
Complex congenital heart diseases	119	53.4
Renal agenesis	98	43.9
Nanism	71	31.8
Hydranencephaly	116	52.0
Prematurity	147	65.9
Fetus younger than 23 weeks	122	54.7
Prolonged premature rupture of membranes involving oligohydramnios	93	41.7
Hypoplastic left heart syndrome	101	45.3
Multiple anomaly	96	43.0
Severe diaphragmatic hernia	95	42.6

Table 3. Students' Views regarding Palliative Care

Statements about Palliative Care	Agree	Neutral	Disagree
	n (%)	n (%)	n (%)
Palliative care comprises health services for terminal cancer patients.	148 (66.4)	54 (24.2)	21 (9.4)
Palliative care should start when curative treatment is not possible or at the terminal stage of the disease.	93 (41.7)	82 (36.8)	48 (21.5)
A multidisciplinary team should provide palliative care.	168 (75.3)	52 (23.3)	3 (1.3)
In palliative care, the patient and her family are decision-making team members.	180 (80.7)	34 (15.2)	9 (4.0)
Physicians should lead palliative care teams.	160 (71.7)	51 (22.9)	12 (5.4)
Patients and caregivers should be able to reach out to palliative care professionals 24/7.	198 (88.8)	24 (10.8)	1 (0.4)
It is inevitable for individuals working in palliative care to experience burnout as they face constant loss.	109 (48.9)	82 (36.8)	32 (14.3)
Individuals working in palliative care need to control their emotions.	190 (85.2)	27 (12.1)	6 (2.7)
Emotionally empowering programs should be provided only for patients and their families	51 (22.9)	60 (26.9)	112 (50.2)
Palliative care focuses on symptom management without concentrating on the causes of symptoms.	75 (33.6)	52 (23.3)	96 (43.0)
Palliative care consists only of pain management.	25 (11.2)	50 (22.4)	148 (66.4)
Palliative care centers should be hospital-centered.	99 (44.4)	72 (32.3)	52 (23.3)
Patients should have the right not to be resuscitated, and legal regulations should be done.	159 (71.3)	61 (27.4)	3 (1.3)
Palliative care should be a separate specialization.	186 (83.4)	34 (15.2)	3 (1.3)
Palliative care courses should be mandatory in all baccalaureate programs in health science.	174 (78.0)	45 (20.2)	4 (1.8)
Being able to reach palliative care when needed should be guaranteed by the government.	192 (86.1)	29 (13.0)	2 (0.9)

Table 4. Students' Views About Perinatal Palliative Care

Statements regarding Perinatal Palliative Care	Agree	Neutral	Disagree
	n (%)	n (%)	n (%)
Perinatal palliative care is the management of supportive and end-of-life care with a holistic approach to the fetus or newborn diagnosed with life-limiting anomalies in the perinatal period and the family.	202 (90.6)	18 (8.1)	3 (1.3)

Perinatal palliative care begins when the baby is diagnosed with an anomaly.	145 (65.0)	59 (26.5)	19 (8.5)
After the fetal anomaly is diagnosed, the midwife should be planned for prenatal, perinatal and postnatal period care.	210 (94.2)	13 (5.8)	-
The midwife plans with the family about where and how the birth will take place.	206 (92.4)	12 (5.4)	5 (2.2)
In perinatal palliative care, the midwife talks about the issues such as taking pictures with the family, creating memories about the baby, seeing / not wanting to see the baby and supports the family in realizing their requests.	193 (86.5)	27 (12.1)	3 (1.3)
It is the midwife's responsibility to provide care to the family's wishes for resuscitation and medical treatments for the newborn baby.	141 (63.2)	70 (31.4)	12 (5.4)
After the baby's death, the midwife plans the discharge of the family and follows the family.	188 (84.3)	32 (14.3)	3 (1.3)
The perinatal palliative care team is a multidisciplinary team consisting of a midwife, perinatology nurse, obstetrician, genetic counselor, neonatal intensive care nurse, psychologist, and religious officer.	191 (85.7)	29 (13.0)	3 (1.3)
Perinatal palliative care is family-centered.	140 (62.8)	68 (30.5)	15 (6.7)
The midwife should provide genetic counseling to the family within the scope of perinatal palliative care.	188 (84.3)	28 (12.6)	7 (3.1)
Perinatal palliative care should be a separate specialty.	192 (86.1)	27 (12.1)	4 (1.8)
Counseling the family in the decision-making process regarding the continuation of pregnancy and informing the family about the current situation and possible consequences are critical perinatal palliative care interventions.	201 (90.1)	19 (8.5)	3 (1.3)
After the loss, she visits the family at the time intervals the PPC team has planned for the family.	179 (80.3)	41 (18.4)	3 (1.3)
It enables families to be brought together with other families who have similar experiences.	163 (73.1)	51 (22.9)	9 (4.0)

Discussion

In this study, the attitudes of midwifery students towards palliative care and perinatal palliative care were examined. Midwives, in the prenatal, delivery, and postpartum periods, are the healthcare professionals who have the closest contact with pregnant women. Therefore, in addition to many responsibilities, they are responsible for providing perinatal palliative care to pregnant women with fetuses with chromosomal or genetic disorders (Kadioglu & Oskay, 2016). Perinatal palliative care creates stress for both the caregivers and the care-receiving group. For this reason, midwives who will do the first intervention during the follow-up and delivery of this sensitive group should be equipped related to perinatal palliative care. Therefore, midwives should be given basic training on the subject during their undergraduate education (LoGiudice & O'Shea, 2018; O'Shea et al. 2015).

In some countries, palliative care is a separate field of specialization (Luyben et al., 2018). In our country, on the other hand, palliative care nursing is a special branch, and certified training is given by the Ministry of Health. In addition, with postgraduate training programs, palliative care training is provided. Training on perinatal palliative care is included in the neonatal intensive care nursing certificate program, but there is no special branch for perinatal palliative care. In our country, although palliative care and perinatal palliative care are mentioned within the scope of some courses in the midwifery curriculum, there is no standard course or subject in both subjects (Ay & Gencturk, 2013; Sahan & Terzioglu, 2015). In our study, it was determined that most of the midwifery students did not receive training in palliative care and perinatal palliative care and that the students wanted to receive training on these subjects. Similarly, in a study examining intern nurse students' views on palliative care, 94% of the students have stated that they did not receive palliative care training during their undergraduate education (Bahcecioglu et al., 2017). In a qualitative study conducted to evaluate the care experiences of senior midwifery students for families with perinatal loss, midwifery students have stated that they felt inadequate and unprepared on this subject (Alghamdi & Jarrett, 2016).

Most of the students defined the team members who carried out palliative and perinatal care

services as doctors, nurses and midwives; however, very few of the students identified dietitians, pharmacists, religious officials, social workers and physiotherapists as team members. Also, very few of the students mentioned breastfeeding counselors, genetic counselors, and anesthesiologists as team members who carried out perinatal palliative care services. It was determined that midwifery students need information about defining the team members who carry out palliative and perinatal care services.

The students stated that the basic concepts and principles, communication, roles and responsibilities of team members, pain and symptom management, and the process of loss and grief are the main topics that should be addressed in the palliative and perinatal palliative care training program. Most of the students knew the subjects that should be included in the palliative and perinatal palliative care training program. According to these results, it can be said that the awareness about palliative and perinatal palliative care training of the midwifery students who participated in our study is high. In other studies conducted with nursing students, it was determined that students who stated that they received training on palliative care were mostly trained in ethical issues, symptom management, reporting bad news and communication skills (Bahcecioglu et al., 2017; Ozveren et al., 2018). In a study conducted abroad, the opinions of health professionals and about fetuses and newborns with severe chromosomal or genetic disorders have been examined, and the majority of the participants have preferred to provide palliative care. Those who chose palliative care have often stated that they aimed to reduce suffering and preserve the sanctity of life; however, it has been concluded that they did not have sufficient information about the laws regulating the practices related to the life of the fetus/neonatal (Grether et al., 2015).

In our study, midwifery students mostly associated perinatal palliative care with prematurity and anencephaly. It was determined that about half of the students were familiar with the disease groups related to perinatal palliative care. In this respect, it is thought that students need information about the disease groups associated with perinatal palliative.

When the opinions of the students regarding the expressions on palliative care were evaluated, it was determined that they had insufficient

knowledge about the time to start palliative care, the head of the palliative care team, experiencing burnout, emotional strengthening programs, symptom management, places where palliative care can be provided. On the other hand, when the opinions of the students about the expressions on perinatal palliative care were evaluated, it was determined that the knowledge of the majority of the students was sufficient. Based on these data, it was determined that midwifery students had training needs on palliative care. In line with the data obtained from our study and studies conducted in our country (Ay & Gencturk, 2013; Bahcecioglu et al., 2017; Sahan & Terzioglu, 2015) it was concluded that midwifery students had insufficient knowledge, especially on palliative care.

Conclusion: It was determined in our study that midwifery students did not receive sufficient training on palliative care and perinatal palliative care and did not find their knowledge level sufficient. The student's level of knowledge about perinatal palliative care is high; however, their level of knowledge about palliative care is lower. Students need training on the time to start palliative care, the head of the palliative care team, experiencing burnout, emotional strengthening programs, symptom management, and places where palliative care can be provided. In order to provide palliative care, midwives must have advanced knowledge and communication skills. Therefore, these subjects should be included in the undergraduate education curriculum so that midwives can provide palliative and perinatal palliative care services. It is necessary to improve the skills of midwives with the trainings to be given to them after graduation on palliative care and to meet their advanced knowledge needs.

Ethical aspects and conflict of interest : The study was commenced after the required permissions were received from Giresun University Faculty of Health Sciences (Date: 2017, Decision No: 384/044). The study adhered to the ethical guidelines set out in the Declaration of Helsinki. All students participating in the study were informed about the study, their written/verbal consents were obtained, and they were also informed that they could leave the study at any time. The authors declare that they have no conflict of interests.

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