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Effect of end of life education program on nurses' knowledge and practice regarding care of terminally ill patients with cancer

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Abstract: **end of life care has received more emphasis in recent years throughout the healthcare system. Terminally ill patients with cancer suffer from several physical and psychological symptoms and multiple organ failures. Nurses who care for dying or terminally ill patients should recognize the dying patients' bill of rights. Aim: the aim of this study was to evaluate the effect of end of life education program on nurses' knowledge and practice regarding care of terminally ill patients with cancer. Methods: The data were gathered from Medical wards, ICU, and Surgical wards at Mansoura Oncology Center. A subjective sampling of 40 nurses were participated in the study. Two tools were used for data collection. A pilot study was conducted and the tools were revised and modified. Four educational sessions were introduced as the nurses were divided into 2 groups; 20 nurses in each. Each group had 2 sessions; one for providing essential knowledge and the other aimed to improve skills and performance regarding providing care for terminally ill patients with cancer. Results: the results revealed that there was highly statistically significant relation ($p<0.001$) as regards to both knowledge and practice scores post educational program.**

Conclusion: There was an improvement of nurses' knowledge and practice after provision of education program on end of life patients care.

Keywords: **end of life care; palliative care; terminally ill; cancer.**

1. INTRODUCTION

End of life refers to the final weeks of life when death is imminent, and this is differ from palliative care as not all palliative care patients are nearing the end of life. Helping terminally ill patients to achieve a good quality of life at the end of life requires attention to the physical, psychological, social and spiritual aspects of wellbeing (Ferrell B, & Coyle N, 2002). It is not easy for nurses involved in end of life care and death to provide care that is appropriate at the time of death for the dying patient as there are many challenges inherent in all of the interpretations of the needs of the dying patients and their families. Likewise, there is a corresponding danger in misunderstanding the needs associated with patient's religion and cultural needs (Komaromy C., et al, 2008).

Moreover, nurses find it difficult and emotionally heavy to deliver end of life care to terminally ill patients and often do not feel competent enough (Ayed A, et al, 2015). In addition, nurses had inadequate education about end of life care at a pre-registration level (Cavage and Walts, 2014).

As nurses are in a central position to improve care for dying patients and their families, they should manipulate current end of life practices in their settings (Kisorio, L., & Langley, G. 2016). King and Thomas (2013) stated that nurses accept the reality of death and express strong commitment to make it as comfortable, peaceful and dignified as possible.

Nurses who care for dying or terminally ill patients should recognize the dying patients' bill of rights; the right to be treated as a living human being, the right to maintain a sense of hopefulness, the right to be cared for by those who can maintain a sense of hopefulness, the right to express patient's feeling and emotions, the right to participate in decisions concerning patient's care, the right not to die alone, the right to be free from pain, the right to have patient's questions answered honestly, the right not to be deceived, the right to have help from his/her family, the right to die in peace and with dignity, the right to discuss his\her religious and spiritual experiences and finally but most importantly the right to be cared by sensitive and knowledgeable people (Ferrell, B, & Coyle, N, 2002).

Many literatures referred to inadequate knowledge level of nurses who cared for terminally ill patients. One of them was Zomorodi and Lynn (2010) who reported that critical care nurses report a lack of preparation in dealing with end of life care in intensive care environment. For this reason education and training opportunities are essential to ensure that nurses who care for terminally ill patients develop the right knowledge, and practice to provide high quality end of life care. Therefore, the current study was established to evaluate the effect of end of life education program on nurses' knowledge and practice regarding care of terminally ill patients with cancer.

2. SUBJECTS AND METHOD

Design: A quasi-experimental research design was utilized to conduct this research.

Setting: The data were obtained from intensive care unit, Medical wards, and Surgical wards at Mansoura Oncology Center.

Sample: A purposive sample consisted of 40 nurses, who work in the previously mentioned settings invited to participate in the study**.**

Inclusion criteria: The inclusion criteria set for sample selection were as follows: nurses who had more than two years of experience in ICU, Medical wards, and Surgical wards at Mansoura Oncology Center with full time employment, and willing to participate in the study.

Tools:

Two tools were used for data collection of the current study:

Tool I: **''Oncology nurses' knowledge questionnaire regarding end of life care**": It was utilized to assess nurses' socio-demographic characteristics as well as their knowledge regarding end of life care. It was composed of two parts:

Part one: Nurses' socio-demographic description such as age, gender, department of work, nursing qualification, and working experience.

Part two: Oncology nurses' knowledge questionnaire. It was adapted from City of Hope Pain & Palliative Care Resource Center (2012) and was assessed as follows: each question had a group of answer points, one point was awarded for each correct answer; and zero point for incorrect answer (out of 14 grades as a total score). The knowledge scores were classified into Poor knowledge (≤50%), Fair knowledge (51- 75%), and (≥76%)considered Good knowledge.

Tool II: ''Oncology nurses' practice checklist regarding end of life care". This tool was developed by the researchers after reviewing the related literature (Hopkinson, Hallett, and Luker, 2005; Skar R. 2010) to assess and evaluate nurses' performance regarding care of terminally ill patients. It was consisted of 12 domains. These domains geared towards items such as discontinuation of unnecessary diagnostic tests, allowing patient and family uninterrupted time together, educating the family on a timely basis regarding the signs and symptoms of imminent death in culturally appropriate manner and so on.

Scoring system: each item scored on the bases of " Done correct" or " Not done" Done correct scored 1 point while not done scored zero. The scores obtained for each practice was summed up to get the total score for nurses' performance. The total performance scores were classified into unsatisfied (≤50%), satisfied (51- 75%), and (≥76%) considered very satisfied.

The questionnaire was revised and validated by panel of 5 experts in academic and health field. A pilot study was conducted with ten nurses to determine the clarity of questions, effectiveness of instructions, completeness of response sets, time required to complete the questionnaire and success of data collection technique.

Ethical considerations: A letter of approval from the director of Mansoura Oncology Center was taken to implement this study. Informed consent was obtained from each nurse before intervention. They have been informed of their rights to refuse to participate or withdraw at any time. Moreover, tools of data collection neither touch moral, religious or cultural issues nor harm the nurses' dignity or their rights.

Study phases:

Assessment phase: Before starting the data collection, the purpose of the study was explained to the nurses. The oncology nurses' knowledge questionnaire was provided as a pre test and the nurses were observed using oncology nurses' practice checklist before starting the educational sessions so that comparison could be done.

Implementation phase: Four educational sessions were introduced as the nurses were divided into 2 groups; 20 nurses in each. Each group had 2 sessions; one for providing essential knowledge and the other aimed to improve skills and performance of nurses regarding providing care for terminally ill patients with cancer.

Each session took about 1.30 to 2 hours using a simple language to track the level of nurses' understanding. Different teaching methods were utilized as lectures, demonstrations and group discussions.

Evaluation and Follow up phase: During this phase, the effect of intervention was evaluated by using the same tools. The immediate post test was conducted.

3. RESULTS

Table 1. Socio-demographic Characteristics of the Studied Oncology Nurses

Items	n	%
Age (years)		
21 -25	26	65.0
26 -30	10	25.0
31 -35	4	10.0
Mean ±SD	25.2 ±3.8	
Gender		
Male	6	15.0
Female	34	85.0
Qualification		
Diploma	21	52.5
Bachelor	17	42.5
Master	2	5.0
Work department		
Intensive care unit	10	25.0
Medical oncology	16	40.0
Surgical oncology ward	5	12.5
Other	9	22.5
Work experience regarding care of terminally ill		
2 – less than 5 years	27	67.5
5 to 10 years	4	10.0
11 to 15 years	5	12.5
Above 15 years	4	10.0
Previous education regarding end of life care		
No	33	82.5
Yes	7	17.5

Table 1: Illustrates socio-demographic characteristics of the studied oncology nurses. It can be noticed that the mean age of the studied group was 25.2 ±3.8. The female gender represented 85% of the studied group. As regards to qualification, 52.5% held diploma degree while 42.5% held bachelor degree. Moreover, 25% of the studied sample worked in intensive care unit while 40% worked in medical oncology ward. It can also be noticed that 67.5% of the studied nurses worked from 2 to 5 years with oncology patients. Lastly, 82.5% of the studied nurses had no previous education regarding end of life care.

Table 2. Comparison of the oncology nurses' knowledge towards care of terminally ill patients pre and post educational program.

Items	Pre				Post				Chi square test	
	Incorrect		Correct		Incorrect		Correct			
	n	%	n	%	n	%	n	%	X^2	p
1. What are the goals of end of life care?	37	92.5	3	7.5	17	42.5	23	57.5	22.792	<0.001
2. Which approach to addressing cultural beliefs in end of life?	40	100.0	0	0.0	20	50.0	20	50.0	26.667	<0.001
3. The most accurate judge of the intensity of the patient pain is?	18	45.0	22	55.0	11	27.5	29	72.5	2.650	0.104
4. Which explanation should be given to a patient who has terminal pancreatic cancer regarding addiction to pain medication?	34	85.0	6	15.0	14	35.0	26	65.0	20.833	<0.001
5. When analgesia for chronic pain should be given?	17	42.5	23	57.5	10	25.0	30	75.0	2.739	0.098
6. What is the recommended route of administration of opioid?	34	85.0	6	15.0	11	27.5	29	72.5	26.870	<0.001
7. Why a patient with pain requested increase doses of pain medication?	10	25.0	30	75.0	3	7.5	37	92.5	4.501	0.034
8. Which of the following are intervention to relieve dyspnea?	7	17.5	33	82.5	2	5.0	38	90.0	3.130	0.077
9. Fatigue at the end of life can be a result of what?	4	10.0	36	90.0	0	0.0	40	100.0	4.211	0.040
10. All of the following interventions help to relieve nausea except?	36	90.0	4	10.0	18	42.0	22	55.0	18.462	<0.001
11. What is the most critical step in communication ?	27	67.5	13	32.5	10	25.0	30	75.0	14.532	<0.001
12. What are the barriers to communication with oncology patient?	4	10.0	36	90.0	1	2.5	39	37.5	1.920	0.166
13. What is the key component of improving care at the time of death?	29	72.5	11	27.5	19	47.5	21	52.5	5.208	0.022
14. Signs and symptoms of impending death include all except?	28	70.0	12	30.0	2	5.0	38	95.0	36.053	<0.001

Table 2: Illustrates comparison of the oncology nurses' knowledge towards care of terminally ill patients pre and post educational program. It can be seen that 7.5 % of oncology nurses answered correctly the question investigating the goals of end of life care compared to 57.5% post educational program which was statistically significant. Moreover, 50%, 65% and 72.5% of them answered correctly regarding cultural beliefs in end of life care, addiction to pain medication and recommended route of administering opioids respectively, post educational program compared to 0% and 15% pre-

education which was highly statistically significant (P<0.001). As regards to question investigating interventions that help to relieve nausea, 55% of the studied oncology nurses answered it correctly post education compared to 10% pre-education. Moreover, 75% answered correctly regarding the most critical step in communication compared to 32.5% pre-education. Lastly, 95% of the studied oncology nurses answered correctly regarding signs and symptoms of impending death compared to 30% pre-education which was highly statistically significant (P<0.001).

Table 3. Comparison of the oncology nurses' practice towards care of terminally ill patients pre and post educational program

Items	Done correct					
	Pre		Post		Chi square	
	n	%	n	%	X^2	p
1. Discontinue unnecessary diagnostic test and interventions	10	25.0	30	75.0	20.000	<0.001
2. Allow patient and family uninterrupted time together	12	30.0	28	70.0	12.800	<0.001
3. Educate the family on a timely basis regarding s & s of imminent death	15	37.5	25	62.5	5.000	0.025
4. Documentation in the medical record that patient is actively dying	10	25.0	25	62.5	11.429	<0.001
5. Provide adequate dosage of analgesics and sedatives	40	100.0	40	100.0	0	1.000
6. Provide adequate dosage of analgesics and sedatives	40	100.0	40	100.0	0	1.000
7. Provide options for out of hospital care	0	0.0	0	0.0	0	1.000
8. Psychologically support the family members	25	62.5	40	100.0	18.462	<0.001
9. Educate terminally ill patients about the process of their disease	17	42.5	30	75.0	8.717	0.003
10. Meet patients and family needs	40	100.0	40	100.0	0	1.000
11. Provide family with information about patients progress	18	45.0	40	100.0	30.345	<0.001
12. Include family and patient in decision making	0	0.0	25	62.5	36.364	<0.001

Table 3. Illustrates comparison of the oncology nurses' practice towards care of terminally ill patients pre and post educational program. It can be noticed that there was a statistically significant difference among nurses in the pre and post educational program in that, following the program, 75% of oncology nurses discontinue unnecessary diagnostic test and interventions compared to 25% pre-education (P<0.001). 70% of oncology nurses allow patient and family uninterrupted time together compared to 30% pre-education (P<0.001). Documentation is performed in 62.5% post education compared to 25% pre education (P<0.001). Moreover, all nurses psychologically support the family members and provide family with information about patient progress post educational program (P<0.001) . Finally, 62.5% of oncology nurses include family and patient in decision making post educational program however no one performs this task in the pre-education period (P<0.001).

Table 4. Comparison of the total knowledge and practice scores at pre and post educational program

	Pre	Post	Student's t test	
Score	Mean ±SD	Mean ±SD	t	p
Knowledge score (Total score=14)	5.9 ±1.3	10.6 ±1.4	15.590	<0.001
Practice score (Total score =12)	6.7 ±1.3	9.1 ±1.3	11.708	<0.001

Table 4 illustrates comparison of the total knowledge and practice scores at pre and post educational program. It can be noticed that there was highly statistically significant relation (p<0.001) as regards to both knowledge and practice scores with pre mean ±SD =5.9 ±1.3, 6.7 ±1.3 and post mean ±SD =10.6 ±1.4, 9.1 ±1.3 respectively.

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Table 5. Comparison of the oncology nurses' knowledge and practice grades among oncology nurses pre and post educational program

Score	Pre		Post		Chi square test	
	n	%	n	%	X^2	p
Knowledge						
Poor	36	90.0	0	0.0		
Fair	4	10.0	20	50.0		
Good	0	0.0	20	50.0	66.667	<0.001
Practice						
Unsatisfied	30	75.0	0	0.0		
Satisfied	10	25.0	25	62.5		
Very satisfied	0	0.0	15	37.5	51.429	<0.001

Table 5 illustrates comparison of the oncology nurses' knowledge and practice towards care of terminally ill patients' pre and post educational program. It can be seen that there was a statistically significant relation regarding knowledge and practice pre and post educational program. It can be noticed that 100% of the nurses had good and fair knowledge post educational program compared to 90 % had poor knowledge pre-educational program. As regards to practice, 62.5% had satisfied practice post-educational program compared to 25% pre-educational program (p<0.001).

Table 6. Association between socio-demographic data and oncology nurses' knowledge post educational program

Items	Knowledge					
	Fair (n=20)		Good (n=20)		Chi square test	
	n	%	n	%	X^2	p
Age (years)						
21 -25	11	55.0	15	75.0		
26 -30	6	30.0	4	20.0		
31 -35	3	15.0	1	5.0	2.015	0.365
Gender						
Male	2	10.0	4	20.0		
Female	18	90.0	16	80.0	0.784	0.376
Qualification						
Diploma	8	40.0	5	25.0		
Bachelor	12	60.0	13	65.0		
Master	0	0.0	2	10.0	6.073	0.048
Department						
Intensive care unit	3	15.0	7	35.0		
Medical oncology	8	40.0	8	40.0		
Surgical oncology ward	5	25.0	0	0.0		
Other	4	20.0	5	25.0	6.711	0.082
Experience						
Less than 5 years	12	60.0	15	75.0		
5 to 10 years	2	10.0	2	10.0		
11 to 15 years	3	15.0	2	10.0		
Above 15 years	3	15.0	1	5.0	1.533	0.675
Previous training						
No	17	85.0	16	80.0		
Yes	3	15.0	4	20.0	0.173	0.677

Table 6. Illustrates association between socio-demographic data and oncology nurses' knowledge post educational program. It can be seen that no significant difference was found as regards to association between socio-demographic data namely; age, gender, department of work, experience, previous training towards end of life care and oncology nurses' knowledge pre educational program except for qualification as it was noticed that 25% of diploma nurses had good knowledge compared to 65% of bachelor degree nurses which appears to be statistically significant (P=0.048).

Table 7. Association between socio-demographic data and oncology nurses' practice post educational program

Items	Practice Satisfied (n=25)		Very satisfied (n=15)		Chi square test	
	n	%	n	%	X^2	p
Age (years)						
21 -25	17	68.0	9	60.0		
26 -30	5	20.0	5	33.3		
31 -35	3	12.0	1	6.7	1.026	0.599
Gender						
Male	4	16.0	2	13.3		
Female	21	84.0	13	86.7	0.052	0.819
Qualification						
Diploma	13	52.0	8	53.3		
Bachelor	11	44.0	6	40.0		
Master	1	4.0	1	6.7	0.172	0.918
Department						
Intensive care unit	7	28.0	3	20.0		
Medical oncology	8	32.0	8	53.3		
Surgical oncology ward	4	16.0	1	6.7		
Other	6	24.0	3	20.0	2.027	0.567
Experience						
Less than 5 years	17	68.0	10	66.7		
5 to 10 years	3	12.0	1	6.7		
11 to 15 years	2	8.0	3	20.0		
Above 15 years	3	12.0	1	6.7	1.616	0.656
Previous education						
No	21	84.0	12	80.0		
Yes	4	16.0	3	20.0	0.104	0.747

Table 7. Illustrates association between socio-demographic data and oncology nurses' practice post educational program. It can be noticed that no significant difference was found as regards to association between socio-demographic data namely; age, gender, qualification, department of work, experience, previous education towards end of life care and oncology nurses' practice post educational program.

4. DISCUSSION

The aim of this study was to evaluate the effect of end of life education program on nurses' knowledge and practice regarding care of terminally ill patients with cancer. In the present study, the mean age of the studied group was 25.2 ±3.8. this finding come in agree with Ayad A, et al, 2015 whose study demonstrated that, the majority of respondents were within the age between 20 and 30 years. The present study also showed that the majority of the sample was female. This finding contrasted with Ayad A. et al, 2015 who stated that, the majority of respondents were male. Moreover, the present study revealed that more than half of the studied nurses held diploma degree which contrary with Huijer et al, 2009 who mentioned that the highly percent of nurses were prepared to BSN level of education.

Furthermore, the current study noticed that the quarter of the studied sample worked in the intensive care unit while more than one third of them worked in the medical oncology ward. This come at the same line with Ayad A. et al, 2015 who found that 30.2% were from medical wards, 28.1% from emergency department, 26% from ICU, and 15.6% from surgical wards.

The present study showed that, about two thirds of the studied nurses worked from more than 2 years to less than 5 years with oncology patients and the majority of them had no previous education regarding end of life care. A study that conducted at Palestine hospital agreed with our study related to years of experience which mentioned that the majority of nurses had less than 5 years of experience regarding end of life care but disagree related to previous education regarding

end of life care which reported that more than half of the sample had get training course on palliative care (Ayad A. et al, 2015).

In relation to nurses' knowledge level scores toward care of terminally ill patients pre and post education program, the findings found that there was highly statistically significant relation as regards to nurses' knowledge level in which half of the nurses had good knowledge and half of them had fair knowledge post educational program compared to 90 % had poor knowledge pre-educational program. This improvement is related to initiation of relevant education program which is essential to develop nurses' basic knowledge and beliefs. Another study assess nurses' knowledge and attitudes towards the palliative care found that, the knowledge scores had shown that 20.8 % had good knowledge about palliative care (Ayad A. et al, 2015). Another study findings showed that about one third of nurses had good knowledge (Kassa et al, 2014). The variation might be due to lack of updating knowledge regarding end of life and palliative care, and this may be due to the fact that end of life and palliative care education was not integrated into diploma and bachelor degree curriculum.

As regards to practice of nurses on terminally ill patients, the results showed that more than two thirds of nurses had satisfied practice post-educational program compared to only quarter of them in the pre-educational period. This mirror the findings of Karkada et al, 2011 who indicated the majority of participants had favorable practice towards terminally ill patients. On the other hand, the findings come in contrast with Huijer and Dimassi, 2007 who reported unsatisfied practice level regarding palliative care patients, and this was related to overworked nurses because of shortage in the nursing staff.

As regards to association between socio-demographic data and oncology nurses' knowledge post educational program, the present study showed that there was no significant difference found between socio-demographic data and nurses knowledge except for nurses' qualification in which quarter of diploma nurses had good knowledge compared to nearly two third of bachelor degree nurses which appears to be statistically significant. This can be explained as when the nurses' experience and qualification increase their knowledge also improves. This findings was in agreement with Huijer et al., 2009; Abudari et al, 2014 who reported that there was no significant association among nurses' work place and knowledge of palliative care and that there was a positive relationship between nurses' qualification and their level of knowledge.

In relation to association between socio-demographic data and oncology nurses' practice post educational program, the present study revealed that no significant difference was found which contrasted with Huijer, Dimassi, and Abboud, 2009, who reported that significant differences were found between medical and surgical nurses.

5. CONCLUSION

Improvement of nurses' knowledge and practice after provision of education program on end of life patients care..

6. RECOMMENDATION

- Highlight the need for developing 'End of life' services.
- The introducing of quality 'End of life' services needs education and training of nurses in this area.
- 'End of life' requires to be a fundamental part of all nursing curriculum as well as continuing nursing and medical education program contributions.

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