Nursing Students' Perception of Dying and their Contextualizing End of Life and Palliative Care in Nursing Curriculum at Taif University

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Abstract: Our world is rapidly becoming a global community, which creates a need to further understand the universal phenomena of death and professional caring for dying persons. Nursing students are increasingly exposed to dying patients with chronic diseases requiring palliative and End-of-Life (EOL) care in any clinical setting that trigger the importance of integrating that care and considering it an essential component of nursing education and training. Objectives: Assess nursing students’ perception about death and caring for dying patient and Context the palliative and EOL care in nursing curriculum. Methods: A cross sectional descriptive survey study was conducted on Nursing Department; a structured questionnaire was designed by the researcher based up on review of literature and was distributed to female nursing students from February to April 2016. Results: Most of nursing students perceived challenge in communicating and reacted by silent response toward dying patients and their families and their feeling and thoughts were negative, while half of them response that there is an inadequacy of educational program regard Quality of care at End-of-Life and palliative care approach should be a part of practice, the majority agree that it is important to study EOL in undergraduate nursing education and that explain their negative attitude toward caring dying patients. Conclusions: Palliative and EOL care should be a part of practice in basic nursing education. Future research should be done focusing on the students’ perception of caring for dying patients and their families through conducting a qualitative research by using reflective writing method.

Keywords: Contextualizing, Perception, Attitude, Palliative, End of Life care, dying patients.

1. Introduction

As the “Baby Boomer” population ages, so does the increase in aging adults with complex health issues. Nurses today must be more adept than ever at caring for the aging adult while the healthcare environment struggles to accommodate this rapidly increasing population and the current trends in nursing and care are multifactorial including: the increase in the aging population. [1] Our world is rapidly becoming a global community, which creates a need to further understand the universal phenomena of death and professional caring for dying persons. [2] It is estimated by the year 2030, 1 in every 8 of the earth’s inhabitants will be 65-and-older. Significantly, the most rapid increases will be occurring in developing countries, which will see a jump of 140 percent by 2030, and the number of people over the age of 85 will double. These statistics reveal that deficiencies are existing in palliative care education, skills and knowledge of nurses, and there is a need to implement an evidence-based palliative care educational program [3].

Nurses have a key role in caring for patients with a life limiting illness throughout the palliative care trajectory including end-of-life care, especially as they spend more time with patients than any other members of the health professional. Nurses are involved in caring for patients who are dying or have a terminal illness and are faced with the process of dying. Working with these patients and their families can be emotionally demanding and challenging. [4]

Nursing students are increasingly exposed to dying patients with chronic diseases requiring palliative and End-of-Life (EOL) care in any clinical setting that trigger the importance of integrating that care and considering it an essential component of nursing education and training. [5] Nurses should be knowledgeable about end-of-life care but most of studies show that only 0.41% of nurses certified in palliative care medicine and from all deaths that students had experienced, 69.2% of students had been present when a person died. The deaths experienced by students were predominantly grandparents (84.6% of respondents), friends (61.5% of respondents) and patients (61.5% of respondents). [6,7] Adequate clinical preparation and training in Palliative care for undergraduate nursing students will overcome an overwhelming personal and professional challenges, so based on that, making palliative and end of life care education and training as essential components for nursing education. [8,9]

The racial/ethnic demographics are changing along with life expectancy. With this change, students need to understand the healthcare and end-of-life needs of diverse populations. Nurses also need to be aware of their own beliefs and values, and be able to set these aside, and focus on the client’s values and needs. The demographics of the nursing population do not match the population demographics nurses will eventually provide care for.
patients of other cultures, religious backgrounds or who have different values and beliefs than their own. Nursing schools are also increasing efforts to try and have a more diverse nursing workforce through recruitment of minorities into nursing programs. 

When working with end-of-life (EOL) patients, nurses need to be culturally competent. The majority of nurses will need to be able to provide patient and family care consistent with the cultural context. Student nurses as well as hospice nurses are in clinical settings where they may encounter death and dying, so examining their attitudes to death and dying and cultural beliefs is important.  

Major gaps have been identified in the palliative care content of nursing curriculum with several studies showing that facing death can be a stressful experience for nursing students, who experience stress and anxiety related to death and do not feel competent or confident in implementing palliative care. These experiences emphasize a need for strategies to support nursing students during palliative care clinical placements. Palliative care clinical placements can be an overwhelming practice for the nursing student, presenting the individual with both personal and professional challenges. Adequate clinical experience in this area is basic to preparing health professionals for the workforce. Nurses encounter these patients in hospitals, nursing homes, at home or in hospice care settings. They need to be prepared to take an active role in caring for patients who are dying; understanding students’ perceptions of death and dying can help educators prepare students for these situations by using the research available to plan better ways to teach students about the needs of the dying/terminal patient and their families. These needs include physical, spiritual, emotional and social. Part of becoming a good nurse is being able to understand one’s own perceptions about various aspects of nursing including death and dying. One of nursing student response was ‘Somewhere I fear how I will react. What if I become totally paralyzed and just stand there and stare. It is probably not really the same thing, but imagines if I am not able to take action as I want to, like I might totally fail’. Nurses working in different situations with common issues, such as end-of-life care and dying, develop universal meanings about perceptions, options, knowledge, and coping.  

The study aimed to:  
1- Assess nursing students’ perception about death and caring for dying patient.  
2- Context the palliative and end-of-life management in nursing curriculum.  

2. Subjects and Methods:  

2.1. Research design:  
A cross sectional descriptive survey study was conducted from February to April 2016.  

2.2. Settings:  
The study was conducted in Nursing Department - College of Applied Medical Sciences - Taif University - Female Section.  

2.3. Subjects of the study:  

A purposeful sampling approach was used for this study. The sample consisted of 30 female junior level nursing students were included from 3rd, 4th, and internship years in nursing program  

Inclusion criteria:  
- Female nursing students who are successfully finished second year nursing courses in the regular program and working with real patients and their families in the hospital training.  
- Willing to participate in the study.  

Exclusion criteria:  
- Male nursing students that the researcher didn't have direct access to contact with them.  

2.4. Instrumentation:  
Two major self-report questionnaires (self-developed by researchers from relevant literatures and previous similar studies) were prepared to collect data for this study.  

I- A structured questionnaire includes three parts:  
First part; the socio-demographic data, such as: age, level of education, marital state.  
Second part; focused on the experience and feelings of nursing students when dealing with patients who are dying and their families, the physiological and reaction to their feelings (the nursing students) and assessment of the adequacy and importance of current content in the educational program.  
II- The Attitude Rating Sheet; a four-point Likert scale to indicate respondents' attitudes toward caring for dying patients. The scale consists of an equal number of positively and negatively worded statements with response options of strongly disagree, disagree, agree, and strongly agree. Positive items are scored one (strongly disagree) to four (strongly agree). Scores are reversed for negative items. Perceptions are related to attitudes, and the two concepts can be difficult to disentangle. Put simply, perception can be understood as a process of interpretation by which individuals ascribe meaning to things, so the tool was measuring the students’ perception through assessing their attitude.  

2.5. Method of Data collection:  
Approval for conducting the study from Dean of Applied Medical Sciences College was obtained. After that, the subjects were asked to sign the designed consent form, then the researcher gave the questionnaire for filling it out, each participant spend 20-30 minutes to complete the questionnaire. The researcher informed the participants that all information will be gathered, will be used only for the purpose of research, and results of the study will be published in aggregates. All data were installed into computer for data analysis by utilizing SPSS program.  

2.6. Ethics and Human Rights:  
An informed consent was obtained from all the participants before collecting any data. Explanation of the study aim in a simple and clear manner was done to each participant. All data were considered confidential.
Participants were informed about their rights to withdraw from the study at any time without giving any reason.

2.7. Statistical Study:

The statistical Package for (SPSS) version (23) was used to analyze data. Descriptive statistics was used included: Frequencies, and percentages.

3. Results:

Table 1: Socio-Demographic Characteristics of Nursing students were Participated in the Study, N=30

<table>
<thead>
<tr>
<th>Variables</th>
<th>Percent %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age:</td>
<td></td>
</tr>
<tr>
<td>18-&lt;22 years</td>
<td>46.6%</td>
</tr>
<tr>
<td>≥22-25 years</td>
<td>53.4%</td>
</tr>
<tr>
<td>Level of education:</td>
<td></td>
</tr>
<tr>
<td>Third Year</td>
<td>46.6%</td>
</tr>
<tr>
<td>Fourth Year</td>
<td>23.4%</td>
</tr>
<tr>
<td>Internship Year</td>
<td>30%</td>
</tr>
<tr>
<td>Marital Status:</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>3%</td>
</tr>
<tr>
<td>Single</td>
<td>97%</td>
</tr>
</tbody>
</table>

Table 2: Caring for a Dying Patient and their Families during Nursing School, N=30

<table>
<thead>
<tr>
<th>Variables</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you deal with dying patients and their families?</td>
<td>18</td>
<td>12</td>
</tr>
<tr>
<td>Have your experiences with dying patients and families been consistent with your own worldview?</td>
<td>10</td>
<td>20</td>
</tr>
<tr>
<td>Did you face challenges in communicating with dying patients and Their families?</td>
<td>16</td>
<td>14</td>
</tr>
<tr>
<td>Did you have any worries about communicating with dying patients and their families?</td>
<td>21</td>
<td>9</td>
</tr>
<tr>
<td>Do you think your own thoughts and feelings about death and dying influence your work with patients and their families?</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>Did your thoughts and feelings have changed, since working with death and dying patients and their families?</td>
<td>17</td>
<td>13</td>
</tr>
<tr>
<td>Did your coursework has influenced your thoughts about death and dying?</td>
<td>11</td>
<td>19</td>
</tr>
<tr>
<td>Do you think your experience will be different in the future?</td>
<td>19</td>
<td>11</td>
</tr>
</tbody>
</table>

Graph 1: Nursing Students' Thoughts and Feeling Response to Dying Patients and their Families in the future , N=30

<table>
<thead>
<tr>
<th></th>
<th>Positive</th>
<th>Negative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent</td>
<td>16.7</td>
<td>83.3</td>
</tr>
</tbody>
</table>
Table 3: Nursing Students' Physiological Response and Reactions when Facing Dying Patients and their Families, N=30:

<table>
<thead>
<tr>
<th>Variables</th>
<th>No.</th>
<th>%</th>
<th>No.</th>
<th>%</th>
<th>No.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing Students' Physiological Response when caring the Dying Patients and their Families for the first time.</td>
<td>Headache</td>
<td>6</td>
<td>20%</td>
<td>Fainting</td>
<td>15</td>
<td>50%</td>
</tr>
<tr>
<td>Nursing Students' reactions to their Feeling.</td>
<td>Crying</td>
<td>2</td>
<td>6.7%</td>
<td>Silent</td>
<td>24</td>
<td>80%</td>
</tr>
<tr>
<td>How They Deal with these feeling if recurrent?</td>
<td>Positively</td>
<td>11</td>
<td>36.7%</td>
<td>Negatively</td>
<td>6</td>
<td>20%</td>
</tr>
</tbody>
</table>

Table 4: Assess the Adequacy of the following Aspects for Palliative and EOL Care from Students' Perspective, N=30:

<table>
<thead>
<tr>
<th>Variables</th>
<th>Adequate</th>
<th></th>
<th>Inadequate</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>NO.</td>
<td>%</td>
<td>NO.</td>
<td>%</td>
<td></td>
</tr>
<tr>
<td>Goals of palliative care</td>
<td>7</td>
<td>23.3%</td>
<td>23</td>
<td>76.7%</td>
</tr>
<tr>
<td>Quality of life at EOL</td>
<td>8</td>
<td>26.7%</td>
<td>22</td>
<td>73.3%</td>
</tr>
<tr>
<td>Pain management</td>
<td>11</td>
<td>36.7%</td>
<td>19</td>
<td>63.3%</td>
</tr>
<tr>
<td>Other symptom management</td>
<td>9</td>
<td>30%</td>
<td>21</td>
<td>70%</td>
</tr>
<tr>
<td>Communication with patients/families at EOL</td>
<td>12</td>
<td>40%</td>
<td>18</td>
<td>60%</td>
</tr>
<tr>
<td>Role/needs of family caregivers in EOL care</td>
<td>12</td>
<td>40%</td>
<td>18</td>
<td>60%</td>
</tr>
<tr>
<td>Death and dying</td>
<td>4</td>
<td>13.3%</td>
<td>26</td>
<td>86.7%</td>
</tr>
<tr>
<td>Ethical issues in EOL care</td>
<td>6</td>
<td>20%</td>
<td>24</td>
<td>80%</td>
</tr>
</tbody>
</table>

Figure 1: Assess the Importance of Palliative and EOL Care in Basic Nursing Education from Students’ Perspective, N=30:

Graph 2: Context of Palliative and EOL Care in nursing curriculum from Students’ Perspective, N=30:

Graph 3: Nursing students' Perception Toward Dying Patienta and thier Families, N = 30

| Negative | | Positive | |
| % | | % |
| 64% | | 36% |
Table 1: Showed that the demographic characteristics of the nursing students who participated in the study, 53.4% of them were above 22 years of age and almost half of them in the 3rd year of the bachelor nursing degree, while the majority was single.

Table 2 & Graph 1: Described that the experience of participants in dealing with dying patients and their families, (60%) of students dealt with dying patients and their families. They reported that their experiences in dealing with dying patients and families has been inconsistent with their own worldview and they facing challenges and worries in communicating with dying patients, that will make them feel that their experience will be different in the future (68.7%, 53.3%, 70% & 63.3%). The coursework influenced only 36.7% of them and that affect negatively most of them (83.3%) in their thoughts and feeling response to dying patients and their families in the future.

Table 3: Illustrated that 50% of the students were fainted in the first time dealing with dying patients, where 80% of them reacted in silent toward this and 43.3% were uncertain about their reaction if this situation was recurrent.

Table 4 & Figure 1: Revealed that there is an inadequacy of the following Aspects for Palliative and EOL Care especially in the following aspects, Death and dying, Ethical issues in EOL care and Goals of palliative care (86.7%, 80% & 76.7% respectively). From all of these uncertain feelings the majority (93%) agree that there is an importance of Palliative and EOL Care in Basic Nursing Education

Graph 2: Regarding to Context of Palliative and EOL Care in nursing curriculum from Students’ Perspective, 36.7% of them reported to thread the PC&EOL care in practical part of all nursing courses.

Graph 3: reflected that above half of the students has a negative attitude toward caring for dying and their families.

4. Discussion

The current study showed that the first experience for undergraduate nursing student in facing death of a patient has a considerable experience. Indeed, this is an event of enormous emotional significance that is never forgotten and which may have lasting effects, both personally and professionally and clear that the death of another person confronts us with our own fragility and mortality, as well as that of our loved ones, and it also serves as a reminder of the certainty and universality of death. This study aimed to Assess nursing students’ perception about death and caring for dying patient and Context the palliative and EOL care in nursing curriculum.

The gap between theory and practice, a disparity between educational emphasis and the reality of clinical practice remains a source of stress for students that clearly reflected in the present study, above half of students who dealt with dying patients and their families reported that their experiences has been inconsistent with their own worldview and they facing challenges and worries in communicating with dying patients, that will make them feel that their experience will be different in the future and this is supported by the findings of Timmins and Kalisher (2002) who reported that one aspect that causing stress to the students due gap between theory and practice in. Only third of the students’ participating in the study were influenced by coursework and results of the present study showed that they have negative attitudes toward taking care of dying patients. Regarding physiological response to facing dying patients, 50% of the students were fainted in the first time, where most of them reacted in silent toward this and they were uncertain about their reaction if this situation was recurrent and these could explained that the students were not prepared enough for facing such situation and as mentioned by Kristina et al., (2014), also emotional reactions limit the professional ability to care for dying patients and make it difficult for students to comprehend the emotional responses of the patients and their families.

Results of current study also showed that education affects nursing students’ attitude to care for dying patients negatively congruence with Jafari et al., (2015) who reported that education affects nursing students’ attitude to care for dying patients positively their students. Also the result of study documented that there is a close relation between adequate knowledge and attitude of care giver toward dying patients and their families, more than half of the sample their answers was in negative side which is in contrast with the results of Youssef, H. A. M., et al. (2015) study who reported that despite of the poor knowledge among nurse participants in this study, most of the participants (83%) showed more positive attitude regarding end-of-life care, and this was evident with most of previous studies.

There is a limitation in the research about death and caring for dying patients in Saudi context, but similar to the current study in another countries, Iranmanesh et al. (2010), conducted a study among nursing students in Bam and Kerman to measure their attitudes toward death and caring for dying patients and their findings were similar to our findings, they reported that Iranian nursing students did not have positive attitudes toward caring for dying patients. One factor could explain that is lack of experiences, our nursing students are junior and have no experience in dealing with those patients so they classified according to Benner (1984) a novice nurses. It is clear that mentioned factors affect negatively most of them in their thoughts and feeling response to dying patients and their families in the future similar to the findings that reported by Mok et al., (2002) who Providing the end of life care with high quality is only possible if nurses are educationally prepared.

According to Robinson (2004), “nurses are the healthcare providers that are most often with individuals at the end of their lives” so palliative and EOL care provision is acknowledged to be a priority in the development of
comprehensive health care services, particularly where there a high rates of mortality from complex conditions and cancer with increasing the demand for skilled supportive care, pain management, and symptom control at the end of life and should starting preparation of nursing caliber from the beginning to have the needed knowledge and skills with positive perceptions toward such vulnerable group of patients and their families. [23]

5. Conclusion:
Palliative and EOL care should be a part of practice in basic nursing education. The results are beneficial to clinical instructors and nursing personnel in providing guidance to understand students’ pressures and difficulties in facing patient death, as well as developing a relevant curriculum.

6. Recommendations:
Recommendations could be concluded as follow:
- From administrative point:
  Attention should be given towards care for dying patients and their families in the undergraduate nursing training plan.
- From educational point:
  Revising the undergraduate nursing curriculum for integrating the palliative and EOL care in practical part of all nursing courses and in communication skills course also.
  Developing and implementing educational program for training the graduate nurses about EOL.
  Developing evaluating tool for the effectiveness of educational program for palliative and EOL nursing care.
- Future Researches:
  Through conducting a qualitative research by using reflective writing method, more focusing on the students' perception of caring for dying patients and their families should be done.
  Further research also recommended to exam nursing students’ knowledge about caring for dying patients and the effect of education on their knowledge.

7. Acknowledgements:
The authors wish to express appreciation for all female students in nursing department who actively approved to participate in this work especially 4th year students. Special gratitude is directed Prof. Dr. Magda Mansour for her contribution and cooperation.

8. References
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