

Full Length Research Paper

Influence of nurses' characteristics and education on their attitudes towards death and dying: A review of literature

Khaled Abdallah Khader¹, Samiha Suhail Jarrah² and Jafar Alasad^{3*}

¹Education coordinator, King Hussein Cancer Center, Amman, Jordan.

²Department of Community Health Nursing, Faculty of Nursing, Applied Science Private University, Jordan. ³College of Nursing, King Saud bin Abdulaziz University for Health Sciences (MC 3105), P. O. Box 22490, Riyadh 11426, Saudi Arabia.

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Nurses working in cancer centers deal frequently with the phenomenon of death and dying during the daily care of patients. Their demographic and experiential characteristics and previous educational background can shape their attitudes toward care for dying patients. To review relevant literature related to nursing care at the end of life and nurses' attitudes towards death and dying, a literature search was conducted utilizing Medline, Elton B Stephens Company, and Cumulative Index to Nursing and Allied Health Literature. The descriptor words were: death, dying, death experience, nursing, palliative care, attitudes, attitudes toward care of the dying, attitude change, and end-of-life. The review showed that certain standardized education programs, like end of life nursing education consortium, can change nurses' attitudes toward death and dying. By using several education methods, including role playing, case studies, reflection and open discussion, such programs help nurses reflect on their emotions and cope with the scene and thoughts of death and dying. Moreover, for change to occur, adequate duration of education is necessary. End of life education is vital for nursing curricula and in-service education to improve nurses' attitude toward death and dying and consequently improve quality of nursing care of dying patients.

Key words: Death, near-death experience, nursing care, palliative care, end-of-life, attitude to death, education.

INTRODUCTION

Oncology nurses play a principal role in the care of individuals and their families in all stages of cancer, from diagnosis to death. Of all health professionals, nurses spend most of their time with patients and their families at the end stages of life (Dickinson et al., 2008). Interacting with the dying patient (a person who is expected to die within a matter of months, weeks or days (Ki, 2003) and providing end of life care evoke some undesirable emotions and attitudes for nurses and caregivers such as anxiety, stress, sadness, and fear. Perhaps no subject in

nursing arouses such an emotional response as care of terminally-ill patients (Tan et al., 2006). These feelings towards death and dying can be reflected positively or negatively on their abilities to provide good quality of care (Iranmanesh et al., 2009; Wu and Volker, 2009).

It is expected that nurses will be exposed to care for more end-of-life cancer patients. This is because advances in health care technology improved treatment and have led to longer life expectancies and increased incidence of chronic diseases like cancer (Caton and Klemm, 2006). Consequently many patients reach terminal phase of disease. On the other hand, cancer is considered one of the leading causes of death in the world (Tarawenh and Nimri, 2005) and in some countries like Jordan, cancer patients seek medical treatment at a late stage (75% of the cancer patients are incurable

*Corresponding author. E-mail: alasadj@nghi.med.sa, jalasad@hotmail.com. Tel: (+9661) 252-0088 ext. 48472.

when diagnosed) (Stjernswärd et al., 2007).

Most nurses lack knowledge and skills to provide effective end-of-life care; this is related to their struggle with negative personal thoughts and anxiety concerning death and dying (Tan et al., 2006; Brajtman et al., 2007; Wu and Volker, 2009) and inadequate preparation to deal with these issues, since nursing curriculum lacked an effective and efficient approach to educate students about EOL care (Beckstrand and Kirchhoff, 2005; Tan et al., 2006). Other studied variables that could contribute to nurses' attitudes towards death and dying were professional experience and experience with death and dying, and nurses' demographics such as age, sex, education (Lange et al., 2008).

The reviewed studies showed that adequate EOL preparation for nursing students and practicing nurses like giving certain educational programs could improve their attitudes and increase control over their emotions (Caton and Klemm, 2006). This review is aimed at exploring relevant literature related to nursing care at the EOL and nurses' attitudes towards death and dying.

METHOD OF REVIEW

A literature search was conducted utilizing the following databases: Medline, EBSCO, and CINAHL. The key words were: death, dying, death experience, nursing, palliative care, attitudes, attitudes toward care of the dying, attitude change, education, research, longitudinal and end-of-life. The search was limited to full text, peer reviewed studies that were published between January, 2000 and February, 2010. The literature review initially identified 87 papers (methodology, original research, and expert views), of which 39 were considered relevant and included in the review because they were explicitly and solely concerned with EOL care.

FINDINGS

Death and dying are inevitable in human beings and hence have been studied in many disciplines, including nursing (Kim and Lee, 2003). Nurses assist terminally ill patients in hospitals and hospices all of the time, and therefore they are more closely in touch with the anxieties and hopes of both patients and their families (De Araújo et al., 2004). Helping dying patients and their family members to cope is an integral part of professional nursing practice (Ki, 2003), and continue to remain so as the profession has evolved (Cooper and Barnett, 2005). Nurses spend more time with dying patients than do other health care practitioners (Kim and Lee, 2003) and develop valuable relationships with dying persons (Liu et al., 2006).

As knowledge about the dying process developed, nursing skills required for providing end-of-life care becomes increasingly fused (Agrawal and Danis, 2002). Research shows that many nurses and nursing students

have difficulty dealing with death (Mallory, 2003). It requires the maintenance of emotional balance together with scientific skills and an accurate perception (De Araújo et al., 2004), also it requires knowing personal attitude toward death since it will determine his/her way of caring for the terminally ill patient (De-Araújo et al., 2004), as a result, dealing with death and dying issues in general can be a risk factor for professional burnout (Ungureanu and Sandberg, 2008).

The nature and quality of cancer nursing care depends on a number of factors including personal characteristics of nurses, their knowledge and skills, resources, support and clear and relevant policies. One of the most important personal characteristics which can affect nursing care in any setting is the attitude of nurses (McCaughan and Parahoo, 2000).

Nurses' attitudes towards care of the dying

Speaking about dying to those who are near death is challenging for even the most talented and experienced nurse (Gauthier, 2008). Moreover, Working with dying patients often stirs very strong emotions in the nursing staff (Ki, 2003) such as sorrow (Wallerstedt and Andershed, 2007; Ungureanu and Sandberg, 2008; Weigel et al., 2007) , sadness (Brajtman et al., 2007; Weigel et al., 2007), helplessness and anxiety (Weigel et al., 2007), feelings of frustration, and loss (Brajtman et al., 2007; Wallerstedt and Andershed, 2007), depression, and anger (Ungureanu and Sandberg, 2008; Weigel et al., 2007) and guilt after the death of a patient (LeSergenta, 2005; Ungureanu and Sandberg, 2008). The unplanned end of a relationship with a patient could be experienced as extra burdensome (Wallerstedt and Andershed, 2007).

Caring for the dying patient and his/her family is often described by nurses as the most painful and stressful part of the nurse's role (Beckstrand and Kirchhoff, 2005).The care of a dying human being is emotionally taxing, not only for the family but also for the nurses caring for the individual. This stress may be due in part to a nurse's lack of confidence providing appropriate care to the dying (Brajtman et al., 2007).

Variables related to attitudes

Some EOL related studies (Abdel-Khalek and Al-Kandari, 2007; Barrere et al., 2008; Kurz and Hayes, 2006; Wowchuk et al., 2007) have investigated the relationship between nurses' attitudes toward EOL care and certain personal and professional factors. These factors include age, sex, past and present experience with death and dying, taking certain education regarding end of life care

and years of clinical experience.

Experience

Experience has a significant influence on attitude change (Barrere et al., 2008). Literature revealed that years working as registered nurse (RN) and years employed at a cancer center emerged as the strongest indicators of exhibiting a positive attitude toward caring for dying patients (Lange et al., 2008). Dunn et al. (2005) found that nurses having 17 - 21 years of experience reported more favorable attitudes toward caring for dying patients than nurses with less experience. Also, nurses who cared for a greater percentage of terminally ill patients had more positive attitudes toward caring for dying patients than other nurses (Dunn et al., 2005; Dickinson et al., 2008; Lange et al., 2008; Wowchuk et al., 2007) and feel more comfortable talking about EOL (Kurz and Hayes, 2006). This is because nurses expose briefly to dying patients during their study, but as they care for dying patients, their coping develop and their skills improve (Weigel et al, 2007). The more exposure to death and dying, the more awareness of ones own emotions.

Age

Age has a significant influence on nurses' attitude toward dying (Lange et. al., 2008; Barrere et al., 2008). It was found that younger adults tend to report higher levels of death anxiety than do middle-aged adults (Abdel-Khalek and Al-Kandari, 2007), and older nurses feel more comfortable talking about EOL issues than younger nurses (Deffner and Bell, 2005; Kurz and Hayes, 2006). This is become clear if young healthcare providers have not seen someone die before they became a nurse (Neuberger, 2003). This will reflect on their attitudes toward caring for dying patients; as revealed by the previous studies findings (Dunn et. al., 2005). Also it is found that younger age was more conducive to attitude change after an educational intervention (Barrere et al., 2008).

Gender

Sex-related differences in death anxiety are real rather than artifactual, and it is most probable that these differences are the product of differential socialization of men and women as supported by studies conducting on Arab samples (Abdel-Khalek and Al-Kandari, 2007). Women are more open to death-related thoughts and feelings, and men are somewhat more concerned about keeping these thoughts and feelings in check. The relatively higher level of reported death anxiety among women perhaps contributes to empathy with dying and grieving people and the desire to help them cope with their ordeals (Abdel-Khalek and Al-Kandari, 2007). This is explained by the close relationship of personality

characteristics of femininity with anxiety, and thus fears of death (Hegedus et al., 2008). It is argued that the higher levels of empathy were associated with higher levels of death anxiety (Abdel-Khalek and Al-Kandari, 2007). In contrast, according to Barrere et al. (2008), gender was not a significant factor.

Previous death education

Mallory (2003) found that previous death education did not have an affect on attitudes toward care of the dying in spite of very high score on the Frommelt Attitudes Toward Care of the Dying (FATCOD). But this result may be due to the small number of participants who had previous death education. Similarly, Barrere et al. (2008) studied 73 student nurses and found no significance effect of previous death education on dying attitudes.

These results agree with studies that recommend continuity of EOL education on regular intervals to keep the positive effects on nurses' attitudes towards dying patients (Kurz and Hayes, 2006).

Previous death experience

Previous studies found a relationship between recalling first death experience and death anxiety and death attitude (Knight et al., 2000) and found that experience with individuals who were dying have an influence on attitude change (Barrere et al., 2008). In a study of 110 student nurses, it is found that previous death experience was correlated negatively with a positive attitude towards caring for people at the end of life ($r = -0.178$) (Iranmanesh et al., 2009).

Education of end of life care

Attitudes can be changed through education and experiences and exploration of feelings, attitudes, and beliefs of self and others (Wessel and Rutledge, 2005). Care for the most seriously ill patients requires special knowledge and training for all health care professionals (Hegedus et al., 2008). Many research findings support the importance of education in changing attitude toward caring for death and dying patients. This was clearly evident in a research study with a larger sample size (Iranmanesh et al., 2009).

Although, nurses play a pivotal role in palliative and end of life care, nurses either don't received end of life care topics in their nursing school curricula (Dickinson et al., 2008) , or the curricula don't contain enough topics related to care for dying (Mallory, 2003). It seems therefore logical that nursing school curricula should include these topics in their course provisions (Dickinson et al., 2008).

Several studies evaluated change in attitude towards death and dying after implementing certain educational

Program (Table 1). The studies focus on the content and duration of programs and how they reflect on nurses' attitudes. There is large variation in outcomes of study in relation to the duration of program and there is no definite study of continuity of program effect and period needed for repetition of the EOL programs.

Impact of EOL education

The effect of education on nurses' attitudes toward death and care for dying patients start from the time of study in nursing college. It is found that early and ongoing involvement in end-of-life educational experiences may allow students to acquire the attitudes, skills and knowledge essential to implement supportive end-of-life care interventions (Mallory, 2003).

Education of issues related to death and dying have an effect on medical students and health care workers' attitude towards death (Hegedus et al., 2008) and caring for the dying (Kurz and Hayes, 2006; Hegedus et al., 2008; Barrere et al., 2008; Wessel and Rutledge, 2005; Mallory, 2003; Brajtman et al., 2007), and may benefit nurses who have had little experience (Dunn et al, 2005). It also improves therapeutic communication behaviors (Mitchell et al., 2006). Additionally, EOL education prevents maladaptive coping strategies (Jenull and Brunner, 2008) and alleviates nurses' anxiety (Kurz and Hayes, 2006; Dunn et al., 2005; Hegedus et al., 2008). These outcomes of education were supported by other nursing studies (Mallory, 2003; Wessel and Rutledge, 2005; Brajtman et al., 2007).

Most studies conducted on nurses to measure the effect of palliative and EOL education on nurses' attitudes reported positive effects of education on attitudes toward care of the dying (Frommelt, 2003; Mallory, 2003; Delvaux et al., 2004). Only few studies had contradicting results or no effect of education (Wessel and Rutledge, 2005) which may be due to sampling method or length of education program. The majority of attitudes studies were conducted on students through integrating EOL courses in nursing curricula or just studying impact of the current nursing curricula on death and dying attitudes. On the other hand, few studies were performed to measure the impact of EOL education on clinical nurses' attitudes towards death and dying (Ferrell et al., 2006; Barrere et al., 2008; Kurz and Hayes, 2006).

Content and duration of EOL education

Education in palliative and end of life care is complex (Hughes et al., 2006). It not only requires special knowledge and training (Hegedus et al., 2008), but also developing attitudes, approaches to care, and the ability to work with emotionally difficult situations. It is difficult to cover all aspects of palliative care in a short period of time (Ferrell et al., 2006).

There are different studies about EOL education with different durations of program and different number of nurses. Some programs take hours, and some take weeks or even longer; Mallory (2003) studied 104 nurses, and found that a 6 week palliative care education component using ELNEC had made a significant difference in the attitudes of nursing students toward care of the dying. Other nursing studies found that a period of one year (Caton and Klemm, 2006) or five months (Caton and Klemm, 2006) are needed to develop a positive effect. Adriaansen and van Achterberg (2008) reviewed seven articles about attitudes from 1993 - 2005, with different duration (6 h - 6 months), using pretest-posttest design, and found that attitudes were changed positively except for one study that used six hours training held on three sessions. This review along with reviews of other articles revealed the need to determine the minimum duration of educational program that is required for undergraduate nurses and nurses working in health care settings. However, given the nursing shortage and costs to institutions to release nurses for continuing education, time limitations must be considered (Ferrell et al., 2006). Based on this study, 12 h training program can be effective in changing death attitudes.

Many recommendations have been made for adding certain end-of-life contents in any educational program; Table 2 below illustrates such contents.

Standardized projects are available that includes all necessary contents of EOL care. An example of these projects is the ELNEC (funded mainly by the Robert Wood Johnson Foundation and additional funding from the National Cancer Institute) and the TNEEL (Toolkit for Nursing Excellence at End of Life Transition) developed by University of Washington School of Nursing (Wilkie et al., 2004). ELNEC is recommended by many researchers to be integrated in nursing baccalaureate program (Barrere et al., 2008) and in continuing education. ELNEC is a comprehensive educational program to help nurses improve end-of life care in all areas of nursing (Denham et al., 2006). ELNEC initially was focused on improved EOL care within the United States but has since expanded its international outreach activities (Wu and Volker, 2009). One study conducted in 2002 evaluated the effects of the ELNEC program on nurses' attitudes, anxiety, and knowledge, and found that the ELNEC program was effective in increasing nurses' knowledge on end-of-life care as well as decreasing death anxiety (Kurz and Hayes, 2006).

Method of EOL training

Knowledge alone do not contribute significantly to attitudes of nurses, inversely, cognitive and affective information significantly and independently do (Wowchuk et al., 2007). Self-awareness of nurses' own beliefs towards their own death and dying is especially important

Table 1. Effect of EOL education on nurses' attitudes towards care of dying patients.

Impact on attitudes	Measurement	Method of education	Duration of education	Design	Sample and sampling method	Author and year of study
Significant positive change in experimental group	Questionnaire (FATCOD)	Theoretical information and role play	45 h over 15 weeks	Pretest -posttest with control group	N = 115 junior Undergraduate nursing students Convenience sample	Frommelt (2003)
Significant difference in the intervention group; no change in the control group	Questionnaire (FATCOD)	Theoretical information using (ELNEC), role play , group process , patient interaction along with Experiences in a Hospice .	6 weeks	Pretest- posttest with control group	N= 104 junior undergraduate nursing students Randomized at group level	Mallory (2003)
Positive changes on stress level, attitudes towards cancer and death	Interviews The Semantic Differential Attitude Questionnaire (SDAQ)	Theoretical information, role playing exercises and experiential exchanges	105 h	Pretest- posttest with control group	N=115 oncology nurses Random sample	Delvaux et al. (2004)
No significant changes in attitudes toward care for dying patients, decrease in death anxiety	Questionnaires: FATCOD and DAP-R	Theoretical information, Video, clinical practice, narrative reflection writing	6 months	Pretest- posttest with no control group	N= 33 home care and hospice nurses Convenience sample	Wessel and Rutledge (2005)
Positive change	End-of-Life Attitudes Survey	Classroom educational presentations	2 session per week over 3 weeks	A repeated measures pretest- post test design (quantitative component) with no control group and Qualitative components.	N = 9 RN and LPN A Purposive sampling	Easom et al. (2006)

Table 1. Contd.

Positive change	Questionnaire (FATCOD)	Theoretical Information and clinical experience	Integrated through nursing curriculum	A quasi-experimental, longitudinal repeated measures design with no control group	103 senior baccalaureate nursing Students. A Purposive sampling	Barrere et al. (2008)
Positive attitude toward care of cancer pt and psychological care	A revised version of the Intervention With Psychosocial Needs: Perceived Importance and Skill Level Scale	Clinical visits, as well as interactive and didactic learning sessions with clinical experts.	5 days	A quasi-experimental, longitudinal, pretest/post-test design, with control group and with a follow-up assessment six weeks after completion of the nursing education course	53 RNs A Purposive sampling	Steginga et al. (2005)
The intervention group's RDAS (death anxiety) scores increased at the first posttest immediately post education, decreased significantly at 6 month post-education, and then returned to pre-test levels at 12-month post education. No change in control group	The Revised Death Anxiety Scale (RDAS)	Conference	3-day program	Quasi-experimental, longitudinal study's with control group	60 nurses A Purposive sampling	Kurz and Hayes, (2006)

Table 2. Recommended contents for EOL educational programs.

Content recommendation	Recommending study
Needs assessment	Ciccarello, 2003
Overview of hospice ideals	Wessel and Rutledge, 2005
Quality management in end-of-life care	Jenull and Brunner, 2008; Wessel and Rutledge, 2005
Pain management	Jenull and Brunner, 2008; Wessel and Rutledge, 2005
Symptom management	Jenull and Brunner, 2008; Wessel and Rutledge, 2005
Handling of grief and bereavement	Jenull and Brunner, 2008; Wessel and Rutledge, 2005
Communication with all persons concerned	Jenull and Brunner, 2008; Wessel and Rutledge, 2005; Ciccarello, 2003
Grief and loss	Ciccarello, 2003
Managing prognostic uncertainty	Ciccarello, 2003
Goals of end-of-life care	Wessel and Rutledge, 2005
Nutrition at end of life	Wessel and Rutledge, 2005
Ethics resource	Wessel and Rutledge, 2005
Issues of spirituality	Wessel and Rutledge, 2005; Ciccarello, 2003
Complementary therapies	Ciccarello, 2003

for nurses because awareness of the similarities and differences between their belief system and those of their patients enables them to take care of terminally ill patients as whole persons in a more empathic way (Kim and Lee, 2003); this can be achieved by choosing the appropriate teaching methods. According to Frommelt (2003), end-of-life education can be accomplished via videos, lectures, readings, discussions, and clinical exposure to dying patients.

Within nursing literature, there is extensive support for the use both didactic and clinical components to teach issues related to death and dying (Mallory, 2003; Caton and Klemm, 2006; Birkholz et al., 2004; Wessel and Rutledge, 2005; Brajtman et al., 2007; Adriaansen and van Achterberg, 2008); A research study conducted by Mallory (2003) shows that a well-organized systematic exposure to dying patients and their families while learning about how to care for dying patients enhances a student's positive attitude toward care of the dying.

In addition to didactic and clinical components, narrative reflection (Wessel and Rutledge, 2005; Brajtman et al., 2007; Iranmanesh et al., 2008) and concurrent exposure to dying patients (Brajtman et al., 2007; Wessel and Rutledge, 2005), written materials, videos, individual and group teaching, sharing of experiences (Wessel and Rutledge, 2005) increase the effect of program. A study of 33 nurses found that a video-, reading-, and writing-based intervention positively affected attitudes (Wessel and Rutledge, 2005). Reflection method was supported by study on students at the University of Iowa's College of Medicine (USA); it was found that a lecture-based course on end of life care, integrated with reflective exercises may prove to be useful (Dickinson et al., 2008).

Positive effects can be attained if EOL education not only teach knowledge and skills, but also foster an

attitude of caring and compassion (Torke et al., 2004) and take into account the beliefs and emotions of nurses, and include explorations of self-care, self-healing, the resolution of issues of loss and grief, and mutual support (Wowchuk et al., 2007).

Current nursing curricula

The curricula of many nursing schools do not routinely include EOL education, and many nursing texts cover a limited number of EOL topics (Caton and Klemm, 2006). In addition, during traditional clinical rotations, nursing students are not often involved in the care of patients who are dying (Leighton and Dubas, 2009). It seems therefore, it is logical that nursing school curricula should include these topics in their course provisions (Dickinson et al., 2008).

Despite some increase in curricular inclusion regarding care of dying patients, it appears that relevant instruction, clinical experience, and assessments of students' attitudes, knowledge, and skills are still limited, even as they pertain to patients who die in hospitals (Birkholz et al., 2004). Previous studies found that more than 60% of nurses rated their basic nursing school education on end-of-life care as inadequate (Dunn et al., 2005; Ferrell et al., 2000).

CONCLUSION AND IMPLICATIONS

Nurses are not well prepared to care for the dying. Consequently, they have negative attitudes towards caring of dying patients and this in turn affect quality of EOL care. Applying a standardized module like ELNEC, using interactive and different teaching techniques in

timely fashion can give remarkable outcomes in nurses' knowledge, skills and attitudes towards dying patients.

It is evident that addition of certain educational courses to nursing curricula at nursing faculties and continuing training programs at hospitals and cancer care units along with experiences with terminal patients enhances nurses' positive attitudes of caring for dying patients. Moreover, integrating concepts of death, dying and end of life care in all nursing theoretical and practical areas will reflect on quality of care. The purpose of this review is to clarify a critical missed issue in nursing education and add the results of review to nursing knowledge.

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