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To Die or Not to Die: This is the Dilemma!

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Abstract

Healthcare professionals are faced with many challenging ethical dilemmas and controversies that are difficult to resolve in today's workforce. Among these issues is the controversial "right to die" debate.

Methods: A review of literature of 10 references, including 3 case studies and 2 qualitative studies published between 2012 through 2016 was performed using the CINAHL database. This research was conducted to gather information on right to die decisions in relation to ethical principles and the role of the nurse.

Results: It was found that up to 60% percent of patients receiving end of life care did not feel they were completely informed of prognosis, possibility of death or alternatives in communications with their health care providers. The number years of experience a nurse had in the said unit was found to be directly correlated with increased comfort levels in these communications with patient and family.

The need for continuing education in end-of-life care and showed the second highest rated core competency needed by nurses is communicating about death and dying.

Conclusion: Nurses should be an integral part of the conversations about end of life care that include values, beliefs, desires and fears of the patient and their families. The better equipping health care professionals with the tools necessary to assist with end of life care in an autonomous way may help to the alleviate the burden that may soon be placed on them regarding the right to die.

Keywords: Euthanasia; Right to die; Ethics; Nursing; End of life; Assisted death

Introduction

Healthcare professionals are faced with many challenging ethical dilemmas and controversies that are difficult to resolve in today's workforce. Among these issues is the controversial "right to die" debate. Patients have many reasons to die but first and foremost are when they lose hope and dignity. For purpose of this paper, a patient's right to die will be examined through the perspective of a nurse Cancer Center Coordinator in relation to individuals with cancer. Ethical principles that must be considered are beneficence and autonomy. As stated by Lalwani et al. [1], the "principle of beneficence focuses on doing good for others and to take action for the best interest of the patient" and "…the principle of autonomy explains that the patient has a right to make decisions for him/herself" [1]. Nurses are at the front lines of these situations since it is nurses who are tending to the medical needs of dying patients on a daily basis. Another important term to define is palliative care. The World Health Organization (WHO) defines palliative care (PC) as caring for a patient with no intent to either hasten or postpone death; furthermore, emphasizes that PC views dying as a normal process of life [2]. Research has shown that cancer patients near end of life are shown to often use forms of palliative care [3].

To further understand the magnitude of this type of ethical dilemma, it is helpful to define a few more terms. In an article by Knowles (4), he defines these important four terms as (Table 1):

- "Life-sustaining treatment: This, in the view of the person, provides healthcare for the person concerned and is necessary to sustain life.
- Mental capacity: the 2005 Act states that a person lacks capacity if an impairment or disturbance in their mind means they cannot make a specific decision at the time they are required to make it. There is a presumption that an individual has capacity.
- Euthanasia: The active and intentional termination of a person's life…The key is that someone other than the individual has control and acts to end the individuals life, with the intention to kill…
- Assisted suicide: Providing someone with the means to end their own life, assisting or encouraging a person to commit or attempt to commit suicide. Assisted suicide may be physician-assisted or amateur-assisted suicide. It differs from euthanasia in that the individual retains control of the process." [4].

There are currently 5 states in the U.S. that have legal physician-assisted suicide laws [5] (Table 2). This highlights the significance of health care professionals familiarizing themselves with the "right to die" concept. The aim of this review of literature was to highlight important considerations for a nurse in end of life scenarios and open the room for new training.

Methods

A review of literature of 10 references, including 3 case studies and 2 qualitative studies published between 2012 through 2016 was performed using the CINAHL database. This research was conducted to gather information on right to die decisions in relation to ethical principles and the role of the nurse. Keywords such as 'end of life', 'ethics', 'palliative care', 'right to die', 'autonomy', 'cancer', 'oncology', 'nurse', 'nurse role' and 'death'

Beneficence	Doing good for others and to take action for the best interest of the patient
Autonomy	Patient has a right to make decisions for him/herself
Palliative care (PC)	Caring for a patient with no intent to neither hasten or postpone death
Life-sustaining treatment	Healthcare for a person that is necessary to sustain life.
Mental capacity	The 2005 Act states that a person lacks capacity if an impairment or disturbance in their mind means they cannot make a specific decision at the time they are required to make it.
Euthanasia	The active and intentional termination of a person's life
Assisted suicide	Providing someone with the means to end their own life, assisting or encouraging a person to commit or attempt to commit suicide

Table 1: Key terms for euthanasia

State	Date passed	How passed (Yes votes)	Residency required	Minimum age	# of months until expected death	# Requests to physicians
California	Oct 5th, 2015	End of life option Act(AB)(2-15)	Yes	18	Six or less	Two or all (or least 15days sort or) and one written
Montana	Dec 31st, 2009	Montana Supreme court Baxter V. Montana	Yes	-	-	-
Oregon	Nov 8th, 1994	Ballot Measure 16 (51%)	Yes	18	Six or less	Two or all (or least 15days sort or) and one written
Vermont	May 20th, 2013	Act 39 (Bill S.77) End of life choices	Yes	18	Six or less	Two or all (or least 15days sort or) and one written
Washington	Nov 4th, 2008	Initiative 1000 (58%)	Yes	18	Six or less	Two or all (or least 15days sort or) and one written

Table 2: States with right to die

were used to search the literature. As for the actual studies conducted, information was gathered using 2 methods: survey and personal interview. In one study, 8 nurses working in a chemotherapy center of a teaching hospital were interviewed. In the other study, data was collected using a survey, over a 1-month time frame in a 378-bed hospital in Idaho. 37% of 215 oncology, telemetry and critical care nurses participated in the survey.

Results

Results of the interviews helped uncover 4 categories in which nurses of a chemotherapy center experience the pathway necessary to deal with patient death (Table 3). These four categories are: experiencing death as a natural cycle of life; experiencing impotence before the death of the other; experiencing death with the help of faith; and experiencing empathy facing the possibility of death of the patient [6]. Results of Moir et.al [7], found that in regards to end of life and right to die communication, oncology nurses reported a significantly higher comfort level in these family-centered communications. The number years of experience a nurse had in the said unit was found to be directly correlated with increased comfort levels in these communications with patient and family [7]. Communicating with family during this process is of outmost importance. In a review of literature conducted by Materstvedt et al. [2], he found that two main reasons patients request assisted dying include loss of dignity and loss of autonomy in their daily life functions at the end of life. A case-study reviewed found nothing controversial in a cancer patient's right to die decision since it offered a dignified death with relief from suffering [8]. In the state of Oregon, where there are currently right to die laws enacted, less than 3% of all deaths were those that were assisted to die [9]. A study that was referenced in Nevidjon et al. [10] "reinforces the need for continuing education in end-of-life care and showed the second highest rated core competency needed by nurses is communicating about death and dying. It was found that up to 60% percent of patients receiving end of life care did not feel they were completely informed of prognosis, possibility of death or alternatives in communications with their health care providers [3].

Discussion

When one begins to think about a patient's right to die, research revealed that there is a gap in literature on how nurses handle and feel about this topic. This was interesting to find, since the nurse many times is the one closest to the patient and family during these difficult times. In the instance of oncology nurses, it is important for each individual nurse to understand and learn to deal with feelings that arise during the disease process of cancer. Not only those feelings of the patient and family, more importantly, their own feelings. As the study by Comasetto et al. [6] pointed out, understanding how one perceives death assists with one's own emotions. Whether one views death as a part of life, as a sense of powerlessness, empathetically, or seeks understanding of death through faith; the nurse must be prepared emotionally to face the death of the patient. This is an important concept for nursing administrators that work in settings such as oncology. Ensuring that your staff is adequately prepared and trained for this is just as important as ensuring that their skill level is up to par. Evaluation and understanding of ethical principles are equally important when discussing a patient's right to die. As a health care professional, a highly asked question is: Is it right to respect a patient's autonomy and let the patient die? The principle of autonomy should assist in understanding that a patient's wish should be respected regardless of the positive or negative outcomes. Considering that state laws govern the acts of euthanasia and assisted suicide, right to die decisions in Texas (since euthanasia and assisted suicide is illegal in this state), currently deal with instances as refusing treatment or choosing palliative care as opposed to aggressive curative care. Health care professionals work towards the best interest of the patient; however, this is why this topic is so controversial. Lalwani et al. [1] reminds us that "Best interest of patients resides in alleviating suffering and preserving life". Take for instance a terminal cancer patient who is receiving palliative care that is not able to relieve suffering due to extreme pain. In this scenario, how can one preserve life, yet not alleviate suffering and still be keeping the patients best interest in mind. This illustrates the blurred line in regards to right to die. Research has shown that many people would rather die by choice, instead of prolonged treatments or going through an undignified illness. Interestingly, a recurring theme in the majority of these articles; was in support of individuals having the right to factual information from their health care provider on end of life choices and should be able to make the informed decision about their right to die.

It is evident that a patient's right to die decision directly effects nurses involved in their care. The majority of nurses that care for patients with terminally ill conditions watch people suffer at the end of their lives.

A recurring theme in this review of literature was how nurses need to be educated on communication regarding end-of-life and right to die decisions. This brings up that education in cultural beliefs is just as important. Many times health care professionals lack knowledge of their patient's cultural and religious beliefs that pertain to life and death situations [1]. Nurses that provide care to the terminally ill must be able to differentiate a decision made by a patient made in fear or misconception of the prognosis as opposed to a clear autonomous choice they make to die. The health care professional needs to be able to assist the patient to weigh out the risks and benefits associated with their decision, while keeping in mind enhancing quality of life and still being able to justify the actions of the health care professional. This takes us back to a fundamental role of a nurse, patient advocate. The future implications for nurses are summarized in Table 4. The fact that patients feel that they were not given complete information during their end of life discussions; highlights the importance of preparing nurses to deal with these types of encounters. Cases scenario can also be helpful for discussion for future nurses involved in these issues (Table 5).

To live or to die it is not an easy task and assisting as a nurse providing loving care and support to the patient and to the family it is even more difficult. There are no tools that nurses used during this process except their own experience and learning from other. Neither the school training nor most of the hospital wards are places for learning these important tools.

We strongly suggested to introduce this training in the nursing school since the population is growing older and issue about death will be more common everywhere.

In the meantime many hospitals have been developed services to assist in this transition where physician, nurses, social service working together to assist during this process, and those service could be extremely important in the training of health care professionals.

By those experiences and training we might be able to prepare a young nurse to have the capabilities to handle the choice of death or the actual death of a patient appropriately.

S.No	Categories
1	Experiencing death as a natural cycle of life
2	Experiencing impotence before the death of the other
3	Experiencing death with the help of faith
4	Experiencing empathy facing the possibility of death of the patient

Table 3: Experiences by oncological nurses

S.No	Future implications
1	Curriculum needed for both new and current nurses in communication strategies to better prepare nurses for end of life care
2	Cost implications
3	Better equipping health care professionals with the tools necessary to assist with end of life care in an autonomous way may help to the alleviate the burden that may soon be placed on them regarding the right to die.

Table 4: Future implications

S.No	Case scenario
1	Mr. W is a 68 year old terminal cancer patient who is receiving palliative care. He is in extreme pain, has lost ability to independently perform activities of daily living. The palliative care he is receiving is not able to relieve suffering due to extreme pain. He has voiced his choice to die a dignified death. He is of sound mental capacity. The amount of sedation he needs to minimize pain will keep him unconscious; therefore, will be requiring a feeding tube to meet his nutritional needs. He prefers to with hold treatment and allows himself to die.
2	Is it right to respect his autonomy and let him die?
3	What is in the best interest of the patient: • Preserving life? • Alleviating pain and suffering? • Keeping dignity intact?

Table 5: Case scenario

Conclusion

Nurses are at a unique position in the health care setting. Nurses have the opportunity to build trusting therapeutic relationships with their patients, different than other health care professionals. Nurses should be an integral part of the conversations about end of life care that include values, beliefs, desires and fears of the patient and their families. It is suggested through the research, that there is ethical justification for respecting autonomy and being beneficent in regards to end of life care for the health care professional. "Seriously ill people need end of life options. It is a basic human right to live and die with one's dignity intact".

Future implications for nursing include developing curriculum in the nursing school and at work for both new and current nurses in communication strategies to better prepare nurses for end of life care. The economic health crisis brings to light the fact that this same economic pressure may lead to the perspective that euthanasia is much less costly than palliative care. Therefore, better equipping health care professionals with the tools necessary to assist with end of life care in an autonomous way may help to the alleviate the burden that may soon be placed on them regarding the right to die.

As health care professionals, it is important to always consider: each individual case is different and our duty should be to help each make the best decision for them, and ultimately give them their own say in a quality of life that is bearable for them in their terminal state.

With the new services dedicated to this issue the importance of faith, comfort and experience of the team is making the bases for the end life support and treatment.

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