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**Death and Dying: Incorporating a Hospice Approach**

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NURS-501-001: Theoretical Foundations of Advanced Nursing

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## Part 1

The Veterans get wheeled through our hospice doors sometimes alert looking like they might have a few days to weeks, and others barely hanging on, like they might just barely make it into their room. The hospice staff know exactly how to greet them, make them feel comfortable and let them know that this final journey they are embarking on will be handled with gratitude for the service of the Veteran, respect, dignified care, and a peaceful death .

Over the next few hours of the Veterans admittance the staff will work diligently to figure out their wishes, their favorite foods, veterans channel preference on the TV, and music. They will understand their personality, their past, and what is most important to the Veteran. They will be called by their preferred name, whether it be by their last name, first name, or nickname. They will be covered in homemade blankets made just for Veterans, and have homemade pillowcases, not the sterile white ones most often used in hospitals. They will be bathed, shaved if need be, combed, moisturized, and polished to feel better. Pictures of family members, teddy bears, and tiny mementos of importance will be placed in their rooms.

The comfort and detail to attention for each, and every veteran is extraordinary and exceptional. Peace and comfort might not come within the first few hours but may take a day or two to regulate symptom, pain, and medication management; but meeting that goal is the driving force. For this is their final place of their journey, the last battle they will face, but the staff have a commitment to also make it their final win...peacefully.

The Hospice unit is a specialized area, that has a “special” way of thinking about death, dying, and ones “final journey”. They have a focused, yet unconventional, and creative way of facing death. They have a unique toolbox and experiences to pull from, that of which others who

have never done hospice care might not be familiar and comfortable with. Hospice caregivers know when medication is needed, when to back off, when to offer presence and reassurance. They know when to acknowledge this journey is hard work and know when to offer silence. They have the ability to know when the time is near, and also recognize a final rally for what it is. They are not facilitating death by administering pain medications, and they are not aiding in assisted suicide when they make patients comfortable. Hospice is about holistic care, pain management, respect of value systems. Key concepts of hospice care include the benefits of: symptom control, total care approach, and meeting physical, emotional, spiritual, and social needs.

The problem is that this care should be offered to all patients entering the dying process, and it is proposed that if it were available throughout the hospital every patient might be given a better ending process. Nurses in units (not hospice) with dying patients try their best to meet the needs of the dying patient but unfortunately there are barriers that might hinder this care from hospice. These include, discomfort with dying and death, discomfort with medication administration, discomfort or unfamiliarity communicating with family during this process, not equipped to deal and recognize the unique signs, symptoms, distress of the dying process. Overall, it is lack of experience and knowledge, or just not being comfortable with these patients. It is much like any nurse in a specific field i.e. hospice nurse going to the OR if they have never had experience, they would not be equipped, and would not offer the best care.

## **Part 2**

After reading various articles on hospice/palliative care and what theories and frameworks have shaped the type of care this specialization provides there has been a general consensus that Dorothea Orem's grand nursing theory, The Self-Care Deficit Nursing Theory,

and Katherine Kolcabas, Theory of Comfort has created a basis for others to create and build additional theories.

Dorothea Orem was an educated nurse who obtained her Bachelor's degree in 1939, and went on to obtain her Master's degree in 1945. She was a nurse that served in many facets that include, private duty nurse, staff nurse, educator and director in nursing (McEwin & Wills, 2019, P. 142). Orem was an accomplished theorist who gained many awards, honorary doctorates, and praised for many achievements from her self-care deficit theory. She worked on her theory from 1959-2001, and it became known as a grand theory because it can be attributed to a broad scope and many areas of nursing (Nursing-Theory.org).

Orem's self-care deficit theory describes the idea that when an individual is no longer able to care for self, then the nurse is needed. This care can be given in different ways that Orem's theory directly supports such as:

**Support** for the patient and their needs, and support for other nurses

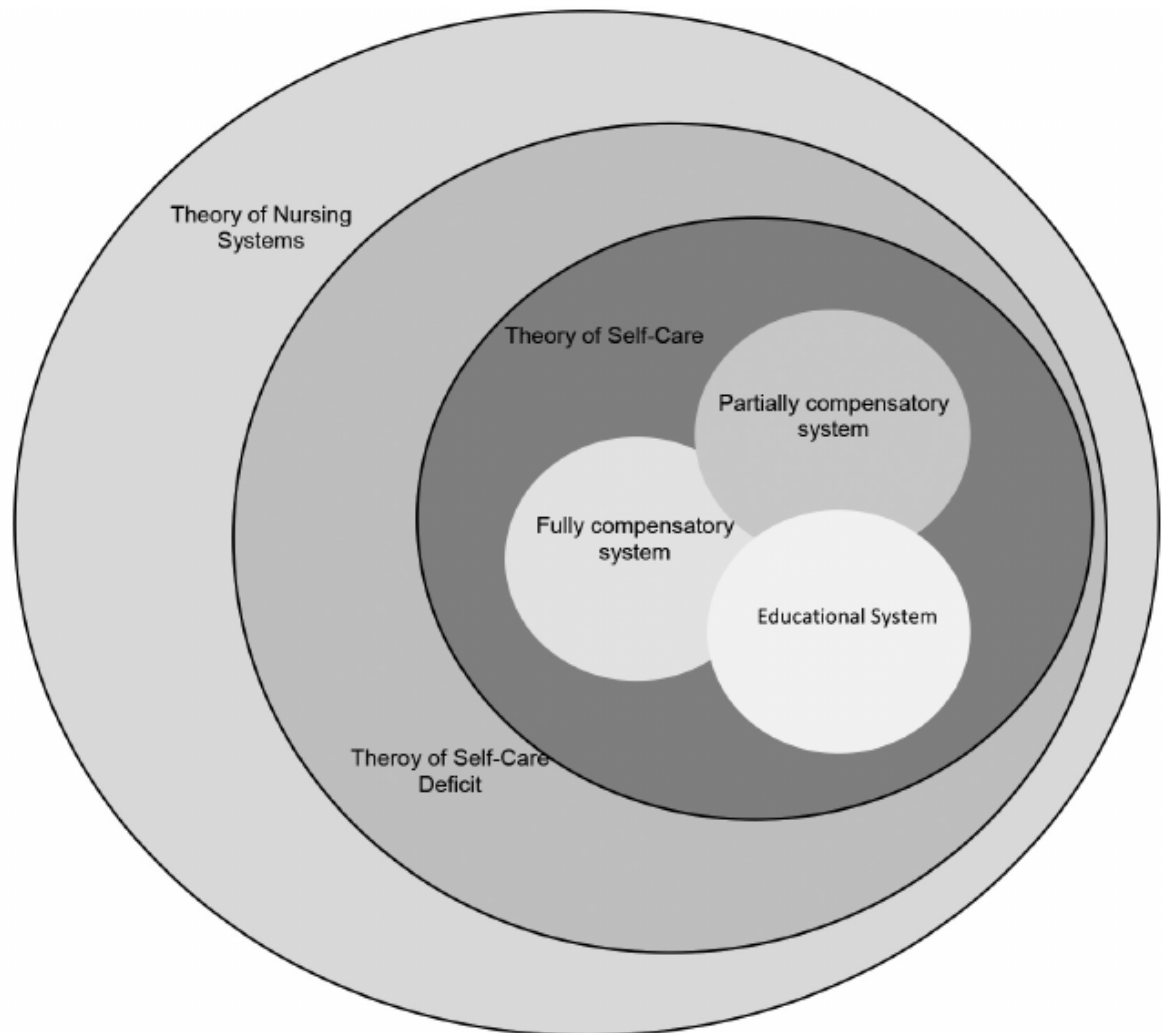
**Teaching** patient and one another of caring and the processes of care

**Guiding** or acting for when the patient/family can no longer do so

**Providing an environment** that meet future needs and development

Orem believed that people are distinct individuals (*Dorothea Orem Self Care Deficit Nursing Theory Explained - HRF, 2017*), and should be treated that way. Figure 1 shows the relationship between these ideas. The outside circle represents the encompassing of nursing theory, within that is the self-care deficit circle, where the nurse is needed in some way. The nurse may be needed in a total capacity in some way, known as fully compensated. Fully

compensated is when the nurse performs all tasks because the patient is unable to for themselves; these patients are dependent on someone else to continue to care for self and well-being. Partially compensated refers to the patient that needs some help to go on living, and meeting demands of ADL's. For example, a patient that knows they need the restroom may need assistance or guidance walking to the toilet. Finally, educational (supportive) system refers to the patient that can-do tasks but needs to be educated on how to carry out those tasks. For example, a patient with dementia, can feed self, but may need to be reminded that a spoon or fork is used to eat. Their environment may be modified to aid in this, utensils with bigger handles, plates with guards so the food doesn't fall off.



*Figure 1 Self-Care Deficit Nursing Theory*

(Source: Mcewen, M., & Wills, E. M. (2019).

This theory illuminates the problem stated in section 1 because it encompasses the nurse's role and calling, when a patient can no longer do for themselves. Sometimes this change does not occur from one extreme to the next (caring on their own, to having total inability to care for self, like a trauma, accident, stroke), but sometimes the change occurs over a spectrum. For example, in hospice care some patients may suffer from a chronic illness that overtime incapacitates them to care for self. They may need help at first just to have cues to remember to

care for self, they may need support to care for self, and instruction and prompting. They may need help ambulating to the restroom so that they don't fall, or on the other spectrum need total care preformed for them. They may need a change of environment to meet the needs of their condition(s), and they may need education on how to navigate that change. Orem's theory covers the spectrum of hospice care and offers a foundation for the nurse's role in caring for patients.

Katherine Kolcaba furthered the intricacies of hospice care. She graduated nursing school in 1987 and went on to obtain her Ph.D. in nursing and specialized in gerontology, end of life and long-term care interventions, comfort studies, instrument development, nursing theory, and research (Nursing-Theory.org). She was an associate professor and won over 5 prestigious awards throughout her career. Since retirement, she has volunteered with the American Nurses Association and the Honor Society of Nursing, Sigma Theta Tau.

Kolcaba's middle range theory published in 1994, Theory of Comfort, where the focus is on patient comfort relates to hospice care. The nurse focuses on managing the patient's comfort and creating care plans that meet their needs and change those plans according to the changing needs of the patient. For example, a hospice patient may need no pain management at the beginning of the process, but as the process proceeds pain may increase, work of breathing may increase, secretions may increase, and so pain medications and comfort measures need to be altered. It is the belief of this theory that if a patient can feel comfortable then they will heal quicker, and in the case of hospice care die comfortably. McEwen & Wills describe, "increasing comfort measures can result in having negative tension reduced and positive tension engaged



(2019, p. 238). Finding comfort for the patient is imperative to have a successful peaceful death; box 1 lists eight propositions of comfort.

Theory of comfort has three forms: relief, ease, and transcendence. Relief, for example from pain can be met by that patient having adequate pain medication, which will give the patient comfort. Ease can be met through dealing with patient agitations and anxieties. For

### **Box 1**

1. Nurses and members of the health care team identify comfort needs of patients and family members.
2. Nurses design and coordinate interventions to address comfort needs.
3. Intervening variables are considered when designing interventions.
4. When interventions are delivered in a caring manner and are effective, the outcome of enhanced comfort is attained.
5. Patient, nurses, and other health care team members agree on desirable and realistic health-seeking behaviors.
6. If enhanced comfort is achieved, patients, family members, and/or nurses are more likely to engage in health-seeking behaviors; these further enhance comfort.
7. When patients and family members are given comfort care and engage in health-seeking behaviors, they are more satisfied with health care and have better health-related outcomes.
8. When patients, families, and nurses are satisfied with health care in an institution, public acknowledgement about that institution's contributions to health care will help the institution remain viable and flourish. Evidence-based practice or policy improvements may be guided by these propositions and the theoretical framework.

(Source: Mcewen, M., & Wills, E. M. (2019).

hospice sometimes anxieties are managed through medication like lorazepam. Other non-pharmacological methods include, listening to music, quiet environment, minimizing noise and visitors. We also speak to the patient letting them know that what they are doing is hard work, they are doing a great job, do not have to worry and can let go whenever they are ready. We reassure them that affairs are in order, their family will deal, cope, and find solace. All these can ease the agitations and anxieties and welcome comfort and the ability to let go. "Transcendence

is described as a state of comfort in which patients are able to rise above their challenges” (Nursing-Theory.org). In hospice transcendence can manifest in a patient finding acceptance they are dying, finding acceptance that they will not be able to do all things they have planned, or that the dominant male Veteran will no longer be able to lead, and head of the family.

Kolbaca’s theory covers the importance of comfort for a patient, what benefits finding that comfort can do for the patient, families, and nurse. “Understanding comfort can promote nursing that is holistic and inclusive of physical, psychospiritual, social, and environmental interventions” (McEwin & Wills, 2019. p. 238-239).

### Part 3

For these models to work directly for hospice and end of life care incorporation of key concepts and main points of the theories need to be taught. In a perfect world, to do this, I would propose that there be training sessions among hospitals in hospice type training. If this could not be hospital wide, I would at least propose that the training be incorporated among floors that continually have the most amount of death and dying on the unit. Also, most hospitals have yearly competencies/trainings that need to be completed and so I would include a special death and dying module along with these other competencies.

To really relay the main points and theories I would include story telling or short videos that are detailed to truly demonstrate situations that may occur with someone dying. I feel like trainees would be more inclined to connect with the situation and gather a foundation of the feelings that go through the nurse through heartfelt, possibly tragic, sad scenarios which leads the trainee the ability to connect to the situation. A scenario type situation would offer the nurse insight on how they would treat the patient to offer Kolbaca’s relief, ease, and transcendence.

Training would also demonstrate how a hospice nurse might handle the situation, and show the techniques, communication style, so there is an example of what that looks like for the trainee.

Furthermore, to teach Orem's theory I would focus first on the different levels of need, how death can progress and how significant the nurse's role to care for a patient throughout those changes; partially compensated and fully compensated. Incorporation of managing not only the patient, but how the family comes in to play with all aspects, but the educational aspect from Orem's theory. Family's need education, and an environment to learn hospice processes, and what hospice care really entails. They also need support and information on the death process and some amount of preparation on what can occur. In my experience families always have a major concern with the patient eating and drinking. This would be an educational opportunity on the process and how not eating is not starvation of the patient, but the patient at this point no longer *wants* nourishment.

To meet symptom control for patients and help manage pain I would implement a symptoms/pain assessment that nurses need to complete per shift. It would be placed into the nurses daily nursing note/charting. There would be standardized questions assessing pain, symptoms of pain, things being done currently, and a space for any recommendations. This would allow staff and providers to track patients pain and what is being done for symptom control. By doing this it would incorporate Kolcaba's relief and ease aspects. Additionally, incorporating Orem's theory by offering support, teaching on pain management, advocating and acting for others when they may not be able to do so entirely themselves.

During intake the patient will be visited by social work and the provider to determine and help navigate the important aspects of care, and end of life expectations the Veteran may have. They will address wants, wishes, and worries pertaining to emotional, spiritual, and social

aspects. They will be asked if they want a clergy man to offer visits if there are spiritual concerns. Visitation from family and friends will be addressed; some Veterans have family visit up until a certain point, and then ask for them not visit towards the end for various reasons. Social work can address any other concerns like property management, pets they may be worried about, final arrangements. Some Veterans carry these concerns with them that delay or hinder the patients ease and comfort. The information gathered will be placed in the Veteran's care plan, so that they can receive a total care approach in their treatment. Also, staff will be able to see this part of their care plan and meet each veterans' specific needs. Addressing these issues early on gives the patient ease, which Kolcaba believes offers comfort to the patient. Social work in this phase can be supportive and aiming to create the hospice environment, which correlates with Orem's theory.

From this assessment to offer further support to the Veteran who may be dealing with certain issues additional sessions with a therapist can be arranged. If there are emotional issues the Veteran is struggling with, extra therapy sessions to work through these issues, or stages of grief can help aid in the transition to acceptance. Sometimes Veterans are consumed and stuck in one stage of the grieving process and need additional resources to work through those feelings. By allowing the Veteran to express their feelings it will offer support, education, and an environment shifting towards ease and transcendence, so that the Veteran can work towards comfort and the letting go process.

I understand there are several limitations with my proposition of having hospice type care provided to every patient, especially due to the recent times with so much attention towards COVID, the shortage of nursing staff, and the availability of this program to everyone. For this

reason, I believe that initial attention should be paid to the units with the most occurrence of death; ICU, oncology's, trauma ER, etc..

Another limitation is that this knowledge really would stem from experience and setting aside time for nurses to train in a hospice unit would be very difficult. Just like nurses' transition to different units frequently, and many need training, time, and cost might not be manageable. Having modules depicting real life scenarios as close to the situations that present themselves would be a second option to gather, experience and see hospice like care.

Limitations within the theories include the broad scope and the idea that these theories guide for health promotion, rather than dying. Focus about the theories would need to be modified so that it met the needs of the dying, rather than the idea of getting better.

Orem's part of her theory about providing an environment for promoting development for the future backs and strengthens the ideas proposed for hospice care. Providing therapist, providing environments to work through feelings, educating on symptom management and continually assessing Veterans for pain or issues they are fearful of are all working toward creating a peaceful death. Promoting for the future helps patients deal with unfinished business so that they can find peace.

#### Part 4

In hospice care, at whatever point in an illness a patient may become unable to care for self (in any capacity), and need the help of someone else (nurse) to provide care; a patient may also need ranges in comfort measures throughout their dying process. Nurses possess the abilities to deal with these patients, however, hospice nurses obtain extra on the job experience and opportunities that nurses on other floors may not get. From this experience they can gather tools,

tactics, communications skills, and knowledge that prepare them to deal with death and dying from a unique perspective, and all patients can be offered a good death.

From learning session, modules and experience throughout a hospital, nurses can obtain information and skill sets that help patients die peacefully. They can incorporate aspects of Orem's self-care deficit model and help facilitate the patient through the stages by acknowledging when patients need help, educate patients on what the help looks like and means. They can work with the patient through communication practices to assess a plan for the patient on what they feel that help looks like, and what help measures the patient is open to, and step in to the nurses role to meet those needs.

They can work through Kolcaba's theory understanding comfort for the patient and what the significance of finding that does for patients. Nurses would also understand that when you make a patient comfortable, it crosses over to other aspects of care, and makes a positive impact. Kolcaba explains, "the understanding of comfort directly guides nursing care that is inclusive of physical, psychospiritual, social and environmental interventions" (Kolcaba, 1994).

For future work Orem's model could be applied very specifically to the world of hospice. As it stands it's a broad topic that can be used and shifted to fit many issues within nursing, but if there could be some additional studies related to hospice it would connect it better. For example, when you get to the center circles of Figure 1 partially compensated and wholly compensated really pertain to the process of hospice. I would include subcategories within these that aid in hospice care.

Kolcaba's model does a really great job as it relates to hospice, this model focuses on comfort meeting not only the patient, but the family as well. However, comfort is hard to

measure consistently among patients. The measurement of comfort is measured by reports from the patient, and/or observations of the nurse, also the level of comfort could change rapidly. Continued documentation of what is working and what does work for the patient is needed. For this to relate to the dying process maybe a standardized list of interventions could be used, and if it is something not on the list a box marked “other” could be added.

Overall, both these two theories can be used as foundations and nursing models to guide nurses familiar, and even more so unfamiliar with the dying process. With education and use of these model’s novice nurses with the dying process or those that find it uncomfortable can gather tools and a model to reference to make the process better on everyone involved. The dying process although can be a sad, hard at times road can be managed through caring for the patient and finding comfort for the patient. The ability for a nurse to offer that final piece of care to a patient is rewarding for the nurse and the patient.

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