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ARTÍCULOS DE INVESTIGACIÓN ORIGINALES

Transformation in the Nurse-Patient Dyad or the Caregiver-Patient Dyad

Lee Susan M¹

INFORMACIÓN DEL ARTÍCULO	ABSTRACT
<i>Historia del artículo:</i> Recibido el 12 de noviembre de 2018 Aceptado el 29 de noviembre de 2018	Dependent nursing practice is following the doctor's orders for medications, treatments, diet, activity, tests, etc. We ensure that the medical treatment is given. Shared practice is when the doctor is giving us parameters but leaves us to make
<i>Keywords:</i> End of life care Interdisciplinary Education Nursing Palliative Care	– judgments, as well. One example is giving medications "as needed" or titrating vasoactive medications in the intensive care unit according to blood pressure. Independent practice is what we do in our own scope of practice. What do we do with and for patients for which we do not need an order?
	Transformación en la díada enfermera-paciente o la díada cuidador-paciente
	RESUMEN
Palabras claves: Cuidado al final de la vida Educación interdisciplinaria Enfermería Cuidado paliativo	La práctica de enfermería dependiente es seguir las órdenes del médico para medicamentos, tratamientos, dieta, actividad, pruebas, etc. Nos aseguramos de que se brinde el tratamiento médico. La práctica compartida es cuando el médico nos da parámetros, pero también nos deja hacer juicios. Un ejemplo es administrar medicamentos "según sea necesario" o valorar medicamentos vasoactivos en la unidad de cuidados intensivos de acuerdo con la presión arterial. La práctica independiente es lo que hacemos en nuestro propio ámbito de práctica. ¿Qué hacemos con y para los pacientes para los que no necesitamos un pedido?

Dependent nursing practice is following the doctor's orders for medications, treatments, diet, activity, tests, etc. We ensure that the medical treatment is given.

Shared practice is when the doctor is giving us parameters but leaves us to make judgments, as well. One example is giving medications "as needed" or titrating vasoactive medications in the intensive care unit according to blood pressure. Independent practice is what we do in our own scope of practice. What do we do with and for patients for which we do not need an order?

Today, specifically, I want to talk about ways of being with patients. Dr. Jean Watson wrote that we spend all of our time in nursing school learning "what to do," rather than "how to be" (Watson, 2008). These are people skills or ontological

¹ PhD, RN, CNP, ACHPN, FAAN. Senior Nurse Scientist, Brigham and Women's Hospital. Clinical Professor Graduate Program Director. Post Master's Certificate Track Coordinator. Caring Science Scholar. College of Nursing and Health Sciences. University of Massachusetts, Boston, EE.UU. Email: susan.lee@umb.edu ORCID: https://orcid.org/0000-0003-4288-7394

skills. Dr. Jean Watson's middle range theory, "Caritas Processes" are essentially ways of being. By following these processes in our practice, we are giving and receiving all that we are supposed to give and receive this day.

Practicing at this deeper level of practice feeds our soul. Knowing we are helping others in ways that are meaningful to them is a marvelous feeling. Philosopher, Nell Noddings, says that when Other receives our care, we know we have done the right thing. How do patients let us know that we delivered care that is personal, meaningful? They smile. The say thank you. Or, fall asleep because they are finally comfortable.

Dr. Watson teaches that being aware and alert and "reading the field" helps us to be fully present to Other. The nurse creates this moment through intentionality and, in essence, becomes the field, a source of healing energy.

- Nurses who thrive in relationship with clients in hospice and other situations of terminal care reveal the sacredness of the ordinary and the timeliness of the present in their work (Lamendola, 1998).
- "The sacredness of the ordinary," is a beautiful thought. A smile. A touch. A kind word, An expression of hope. Providing physical comfort.
- Caritas Process #9 states, "Reverentially assisting with basic needs as sacred acts, touching mind-bodyspirit of other; sustaining human dignity." That is beautiful language to describe our work. Washing a human being is not like washing a car or a floor. It is sacred, gentle, and requires that we protect the dignity of others. When we think about our work as sacred, the work takes on a new meaning and importance.
- Rather than being "burned out" by the strenuous demands of this work, these nurses related how they were nourished and rewarded by their relationships with the patients (Newman, 2008).

Where are our graduate nursing students? Please raise your hands. You are likely very smart and very good nurses already. However, there is always something more to learn and there are always new ways of being. Palliative care calls upon each of us to be our best selves and to learn new ways of being.

I often tell my graduate nursing students that they should not be the same nurse/person at the end of their programs as they were in the beginning of their programs. We should be trying to new ways of knowing/being/doing/becoming (Watson, 2008). We should be trying new ways of relating to patients and families. That is my story. As a graduate student, I tried being different with patients. I became less task-oriented and more patient- and family-focused. I tried to provide care that was meaningful to patients.

In order to do that, I had to ask, "What can I do for you today that would be most meaningful?" Some of the answers were:

• "I really need to sleep. Can you let me sleep for 2 hours?"

- "It would mean so much to me if I could take a shower."
- "I need to understand from the doctor what he was saying yesterday about a possible surgery."
- "I've been so worried about how I'm going to manage when I go home. Can I talk to the social worker again?"

When we are new to nursing, an Advanced Beginner, according to Dr. Patricia Benner who wrote Novice to Expert, we work in the "task world." We make lists of things we need to do for each patient and the list organizes our day.

As we become more expert, we can deepen our practice and go beyond the task world. As we engage patients in their care, we stop doing to and start doing with, always watching the face of our patients to see how our care is received.

I would like to talk about praxis today. I will use the term praxis as described by North American nursing theorist, Dr. Margaret Newman. She states, "In nursing praxis, research takes the form of practice" (Newman, 2008, p, 21). It is a "dynamic partnership between the patient and nurse, transforming both the client and the nurse."

Jean Watson describes this as a "transpersonal moment," one of the five core elements of her theory of human caring. Dr. Watson says, "Transpersonal caring moments can be existential turning points; these moments are reverential in honoring the unity of the whole person; mind-bodyspirit...Developing a caring relationship requires skill and ontological human caring competencies."

"Authentic caring relationship building is concerned with deepening out humanity; it is about processes of beingbecoming more humane, compassionate, aware, and awake to our own and others' human dilemma. It is about human presence, authentic listening and hearing, being present for another in the moment. It is about "reading the field." It is about being reflective, mindful, and skillful mid-step, midsentence, mid-action when connecting with another person...It is a life-giving, life-receiving, human-to-human, spirit-to-spirit connection that goes beyond the physical-ego level...This process, this consciousness, this skill of being-inrelation is fundamental and essential to any caring-healing relationship, as it is often the relationship itself that is healing rather than the external interventions alone." (Watson, 2008; Kindle location 1240).

I want to share with you today three examples of transformation in the nurse-patient relationship that changed me forever. I do not tell you these stories to brag or to say that I am special. I share them in humility as personal examples of how theory-guided practice made me open to others in new ways. Practicing this way for years has yielded a great return. I have had the privilege of being part of this life-giving/life-receiving profession. Furthermore, Watson promises and I confirm that when we practice in this way, we will never burn out or tire of the work.

Christine was a 41-year-old woman who was in the intensive care unit with chest pain. She had Type 1 diabetes since a

child and was now suffering many complications neuropathy, nephropathy, and retinopathy. She often came to the hospital with chest pain. The nurses in the intensive care unit did not believe her; they believed she was seeking attention. They said she liked morphine. Looking back, we did not understand central neuropathy and they did not consider that this pain was real—this happened over 20 years ago but was the start of my own growth as a nurse prepared at the graduate level.

I took care of Christine for 10 days. She was intubated and vented. She had several episodes of pulmonary edema which were frightening. She would sit up and throw her legs over the side of the bed; her heart rate would go to 180. Her respiratory rate would go to 60. I let her wrap her arms around me. I asked another nurse to get me diuretic and morphine. Other nurses spoke harshly to her and told her to get back in the bed. I built a trusting relationship with her. One night, her blood glucose was high. I told her what it was. I told her how much insulin was ordered. "No," she wrote, "that's too much. My blood sugar will go too low." So, I administered as much insulin as she would accept. She felt she had some control with me. Many other things happened. I always told her what was happening and I consulted with her. We were a team. I saw her about 2 weeks later. She was extubated and out of intensive care. She thanked me for my kindness and told me, "You really got me through. The other nurses were yelling at me. I knew they didn't believe me. But, you did. You made a big difference.'

Christine may not have been the first person that I allowed to have choice and control but she was the sickest. From her, I learned to partner with patients, to make decisions with them. I learned a new way to practice. Watson calls this a deepening path to practice. Christine died within the next year of kidney failure. I will always remember her and credit her for teaching me many great lessons.

My second story is about Catherine, a 94-year-old woman who lived alone. Her 7 daughters stopped by frequently. She no longer drove a car but she enjoyed going out with one daughter every Wednesday to a local store followed by lunch at a restaurant.

I met her in the intensive care unit where I was asked to do a palliative care consult on her.

Two days prior to admission, she had fallen when trying to get into the car. She sustained 12 rib fractures. She was transferred to intensive care for pain control. The anesthesia doctor put a catheter in her spine and dosed her periodically with an anesthetic to control her pain. Unfortunately, these can only be used for about 3 days and she was showing side effects. The anesthesia doctor asked me to hold a patient/family meeting so we could talk about removing the catheter and transitioning to intravenous morphine. Mrs. K was awake and alert but in considerable pain. She was grimacing and had irregular breathing. The nurses used a lift to get her out of bed to the chair. Two daughters were present. The anesthesia doctor proceeded with the conversation in a gentle way.

• "Mrs. C, you know that you have 12 rib fractures. We are using a nerve block to help with the pain but we can only use that for about 2 days. • Unfortunately, we are going to have to stop using the nerve block.

• We will use intravenous morphine to keep you comfortable.

• Your lungs are already showing signs of developing pneumonia.

• In persons your age, these fractures are often the beginning of the end because pneumonia usually follows.

• I am concerned that you will need very high doses of morphine to keep you comfortable. You will be very sleepy.

• Then, the doctor said something quite shocking to her for which I was not prepared. He said,

"I'm afraid that you will die from these injuries."

• Mrs. C listened intently and looked at everyone around the room. It was clear that this news was overwhelming to her.

• Her daughters were on each side of her, holding her hands with tears rolling down their cheeks. Mrs. C was not crying. She was trying to be alert and to hear and understand everything that was said.

Then, she said,

"Well, I always knew this time would come... I have a husband and a daughter who is waiting for me. I guess it's time to see them."

• I was amazed at her grace, her dignity, and especially her faith.

• Then, she began to offer support and comfort to those around her. She made some jokes. She invited the doctor back for some wine, which she and her family had the night before. He smiled and said he would be happy to have a drink with her.

• After the doctor left, I stayed with the family. I wanted to stay with Mrs. C to learn more about this incredible woman. I ordered intravenous morphine for her, which was started immediately.

• These meetings are happening more frequently in US hospitals and they are a standard of care in the ICU. They focus the patient/family/and health care team on the patient's primary goal. Mrs. C wanted to be comfortable even if she were sleeping and would eventually die. Her pain was excruciating. All of us agreed to keep her comfortable. This was on a Friday. She died on Sunday of respiratory failure. She was comfortable and attended by her family.

Older adult often do not survive trauma.

• Death is not the enemy. Studies show that persons fear uncontrolled pain. She knew that she would be cared for and attended by her daughters.

I was surprised at how quickly she died.

• When I left her, I expressed my love to her. "You are an incredibly strong woman, a beautiful mother, and I am grateful to have spent time with you today."

• This is the incredible part of my palliative care practice. Every person I meet has an amazing life's story. In fact, I derive strength from them.

• In praxis, we are very aware of how our care is received. When you try something new and you find it works, you put that skill in your tool box. Over time, you have more skills in your toolbox that you can use.

And do you know what the amazing thing is?

• The more you try new behaviors with patients and they respond with gratitude and joy, the more you want to practice in this new way.

• Clearly palliative care is a spirit-to-spirit practice that changes both persons forever.

In my final story, I want to tell you about a life-changing experience I had recently.

Our palliative care team was asked to consult on an 87-yearold woman who was hospitalized for a poor appetite and weakness. Mrs. D was diagnosed with metastatic cancer—a very surprising diagnosis. When we do a palliative care consult,

- we speak to the referring physician,
- read the entire chart,
- speak to the staff on the unit, the family, and the patient.

The consult was to establish goals of care. Again, if you do not use that term, it means that everyone is agreeable to the plan. I read her medical record and learned that Mrs. D, a widow, was the mother of 8 children. When I went to visit her, she was alone in her room.

She was sitting in a chair with a table in front of her. I said, "Your doctor has asked me to visit you today." She smiled warmly and I sat down across from her. I soon learned that Mrs. D had moderate dementia. She still had social graces (she was polite, smiling, and conversational) but only every 5th sentence made sense.

I meet patients with curiosity, anxious to learn, "Who is this spirit-filled person before me?" During a palliative care consult, we do not go in with a strict agenda. Rather, we are there to learn what is important to patients and families. She began:

"I have had something that has been bothering me for a long time. I don't know why you came here today but I need to tell you."

Mrs. D then said, "I think God has forgotten where I am."

You can imagine my surprise and amazement by her remark. "What makes you say that?" I asked.

She knew what she wanted to say but it took a long time to form coherent sentences. However, in palliative care, we have time—more time than others do. So, I sat and listened to her speak—listening very hard to follow her thinking.

"Well, I used to go to Mass and I don't think I go anymore. I don't know why. I just don't go...so I don't think God knows where I am."

That was a powerful metaphor to me. Was she really telling me that she was lost? Did she feel lost? Did she suffer great anxiety because the world was not familiar to her anymore? Did she think God was judging her for not coming to church?

The genesis of palliative care was in cancer care. It has since spread to chronic diseases like heart failure, chronic obstructive pulmonary disease, and kidney disease. But, we have not really entered the world of dementia very effectively. I sat for many more minutes and listened intently, trying to follow her conversation. At the same time, I was keenly aware what she was teaching me. I was open to learn all that I should.

• Persons with dementia suffer with anxiety; many cannot express it in words.

• Mrs. D had a lifelong practice of attending Mass. She derived comfort from this religious practice. In her advancing years, her family had stopped taking her to Mass and she no longer had that comfort in her life. She was missing it. She realized that something was not quite right.

I sensed anxiety and spiritual distress. I sensed loss.
But, I wasn't really sure what to do about her believing that God had forgotten where she was.

 She was a beautiful woman with sparkling eyes and a lovely smile.

I took her hands in mine. I said,

• "You are a beautiful daughter of God. He loves you and he knows exactly where you are.

• He is pleased with you. You have been a devoted wife and loving mother of 8 children. These hands (I squeezed them) have changed many diapers. You have lived a life of service to your family.

• God knows where you are and he is encircling you in His arms."

• With an astonished look on her face, she said, "Where did you learn to talk like that? Nobody's ever talked like that to me before!"

• She continued, "I've been worried about this for a long time but I haven't been able to tell anyone. I feel so much better telling you. How did you know to visit me today?"

• I told her that her doctor had sent me. She thanked me for coming and said that she felt so much better.

• I hugged her.

• When I left her room, I was filled with gratitude that I had met this woman. Every time I do a consult, I leave the room feeling privileged to meet such wonderful people. I have such a great job! I felt like I was truly an instrument in God's hands.

• I was thinking about everything she said and how she tutored me in what goes through the minds of people with dementia.

• I met her children in the corridor and told them that I had a wonderful conversation with their mother. The son rolled his eyes and said, "I bet...."

• In fact, it was one of the most transforming encounters I had ever had in my career.

• I listened intently. I responded to her spirit. I alleviated her anxiety and left her with what? Well-being! I don't know how long she would remember the conversation. Maybe a few minutes? After all, she had dementia. But, for a few minutes, my presence was comforting to her.

• And for months afterward, this human-to-human connection was comforting to me. It then went on to change my practice. I became devoted to reaching the deepest parts of the minds with persons with dementia. I learned to use my smile and touch to reassure them.

• By its definition, transformational presence results in a permanent change in both the patient and the nurse.

From Dr. Watson again, "The process of being with another in a nonjudgmental way as that individual expresses his or her feelings generates a mutual trust and understanding. This process serves as a core foundation that sustains the authenticity of a caring relationship and affirms the shared humanity."

In summary, being intentionally present, listening intently, asking questions, valuing other, and experiencing permanent, transformative change in the transpersonal moment is what is required in palliative care. But, all nurses can be with patients in these very personal moments which can help others heal. It took me 45 minutes but you can also experience this when you are completely focused on that spirit-filled person before you. You can smile when you enter a room. A smile lets the person with dementia know that you are a friend. A smile brings comfort. A gentle touch. A song. A prayer. What do you have the courage to do?

"Within the Caritas context, expressions of caring intentions could further include centering on the person in-the-nowmoment; holding loving consciousness for preserving the person's wholeness, dignity, integrity; having reverence for what is emerging from the subjective inner processes; and approaching others with authentic presence, open to creative participation with infinity" (Watson 2005).

[Watson, Jean. Nursing, Revised Edition (Kindle Locations 1431-1432). University Press of Colorado. Kindle Edition.]

"It is through being present to and allowing constructive expression of all feelings that we create a foundation for trust and caring. When one is able to hold the tears or fears of another without being threatened or turning away, that is an act of healing and caring. When one is able, through his or her Caritas Consciousness, to enter into the life space of another, connecting with the inner subjective life world of emotions and thoughts, one is connecting with the deeper spirit of self and other. This is the foundation for a transpersonal caring moment and a healing relationship."

It is my wish for you to experience transformation in the caregiver-patient/family relationship. In addition, I want to remind you that transformation, or what I call, "the magic" happens in this third domain, the independent practice of the nurse.

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