

Living “Caritas-ly” —A Journey With My Son As He Lives His Dying

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Abstract: The following article is the result of an assignment that was designed specifically to meet the needs of the first author in attaining the objectives for our Theoretical Foundations of Nursing course, a component for the Advanced Standing Nursing Baccalaureate Program at the University of New Brunswick. A key component of our course involved learning about and living Dr. Jean Watson’s (2008, 2018) human caring/unitary caring science theory. The first author describes how she lives the Caritas principles in her journey of caring and advocating for her son, Noah who is living his dying in palliative care.

Keywords: nursing; Caritas; health; process; palliative; living

Introduction

The following article is the result of the first author (TJW) wanting to express her lived experience in how she lives caring science (Watson, 2018) in her journey of caring and advocating for her son, Noah, who is living his dying in palliative care. Through inspiration from Goldin and Kautz (2010), Tara captures the essence of Dr. Jean Watson’s (2008, 2018) human caring/unitary caring science theory as she artfully utilizes the 10 Caritas Processes.

This article will act as a teaching–learning resource for nursing students in the Theoretical Foundations of Nursing course, a component of the Advanced Standing Nursing Baccalaureate

Program at the University of New Brunswick (UNB) Canada. Caring is a philosophical underpinning principle of the program. A key component of the course involved learning about and living Dr. Jean Watson’s (2008, 2018) human caring/unitary caring science theory. Sitzman and Watson’s (2018) text, *Caring Science, Mindful Practice*, was also used to assist us in the teaching–learning process of this article. We were honored to have Dr. Kathleen Sitzman virtually join one class for a 3-hour presentation–question–answer session, mainly focused on the 10 Caritas Processes (Watson, 2008, 2018). Employing a storytelling format Tara will describe her lived experiences and perspectives in the following section.

Living Watson's Caritas Processes in My Life

At first, when learning about the 10 Caritas Processes (Watson, 2008) as I considered my own life and nursing practice, I (Tara) began finding myself challenged when trying to initiate the living of the Caritas Processes because of my own personal anguish and struggles when caring and advocating for my 20-year-old son, Noah, who is living his dying in palliative care. After reading the excellent article by Goldin and Kautz (2010), I felt renewed hope for how to deal with and view this most difficult time. Even more so, I found that by living the Caritas Processes in my own life, I am learning how to *be with* the grief of my son's passing *before* the event actually occurs. In this article I will elaborate on how I am living Watson's (2008) human caring/unitary caring science theory through the Caritas Processes to ease our family's journey with Noah living his dying. The Caritas Process will be written below with one word, which Watson (2018) describes as the opportunity to "gracefully invite us into the Caritas Processes and transpersonal consciousness as a guide to Unitary Caring Science Praxis" (p. 134)

Caritas Process 1—Embrace

Embrace Altruistic Values and Practice Lovingkindness With Self and Others

In reflecting on Caritas Process 1, I realized that my experiences of being a nursing student and my son's personal "nurse" for almost 20 years has left me tired and ready to share the responsibility for his palliative care. I decided recently that it was the right moment to seek a palliative care specialist who has helped me to organize a care team, which has taken over Noah's care, to a point, enabling me to focus on being his Mom, and not his nurse. I came to understand that I am only human and in need of emotional support and comfort too. I needed to practice lovingkindness with myself, as well as with Noah and my family. I have acknowledged that I cannot do everything on my own and that I deserve to be Noah's mother, especially at this time of separating. I am worthy of being healthy and happy, so eating right and getting enough rest have become priorities. After all, what good can I be to my son and new husband if I am not healthy myself?

Caritas Process 2—Inspire

Be Authentically Present, Enable Faith and Hope, and Honor Others

Caritas Process 2 was a little difficult for me, in that I had to permit myself to be vulnerable with others. Letting myself feel sad, angry, and frustrated with the unfairness of our life circumstances has allowed me to confront my thoughts and feelings with a couple of close confidants. They gave me safe spaces and nonjudgmental opportunities to be my authentic self, while guiding me through my own reflections, hopes, and dreams. I am so grateful to have these persons in my life. Letting me *feel out loud* instead of bottling up my emotions inside has enabled me to breathe huge sighs of relief and experience a few moments of pause. Recognizing the need to maintain a *one-day-at-a-time* approach to life has helped me to move forward with small, incremental and intentional steps, knowing that change can be very hard or difficult but that there is always hope. I rely on the strength of others, my husband, and my spirituality and faith to guide me each day.

Caritas Process 3—Trust

Be Sensitive to Self and Others by Nurturing Individual Beliefs and Practices

I have always had a strong spiritual belief system, although it has not always been easy to rely on it at times. In the past, I went through a very dark period of blaming God for Noah's health challenges, my broken marriage, and lost family connections, all of which had left me filled with bitterness and loneliness. After a great deal of discussion and consultation with spiritual leaders, together with deep reflection and meditation, I have come to realize that no one is to blame, that each of us is on a unique journey to fulfill our true potential and become our highest selves.

Noah has brought so much joy into my life; he is a special gift to me. I appreciate him and always will. During my journey of enlightenment, I have learned Transcendental Meditation (thanks to a funded research study for students and faculty members, which took place 2017–2018 when I was in first year of my Advanced Standing Nursing Program; Aquino-Russell, Aldiabat, O'Donnell, & Whalen, 2017). I have incorporated this practice along with a change in my eating and exercise

patterns. Having rituals in my day brings a sense of calm and familiarity, which have helped me to remain focused on my school work, my relationship with my husband, and being Noah's mom.

Caritas Process 4—Nurture

Develop Helping–Trusting–Caring Relationships

As a nursing student, who wants to specialize in palliative care, using my own experience has helped me to connect with patients and families in deep and meaningful ways. I have a true sense of what they may be feeling and going through; I *get it* and am *in it with them*. Albeit, it is important for me to always ask them what it is like for them prior to sharing my own experiences because each person's and family's experiences and needs are unique to them (Balzer Riley, 2017). Being able to bond with patients and develop trusting relationships when they are at their most vulnerable times is a sacred privilege for me. I am very sensitive and empathic. These qualities are part of my authenticity (Orloff, 2017). Balzer Riley (1999) wrote "sometimes [our] own experiences, briefly shared in a moment of empathy, can be a special gift" (n.d.). Through mutual sharing I will not only have the privilege of helping them, but they will help me by filling me up and reminding me of why I chose this path of becoming a registered nurse. I have learned that death is but a moment in the journey of life and that it carries different meanings for different people. I am fortunate to learn what those various meanings are, to care for people in ways that are best for them, and I feel blessed that each person I have the honor of comforting is shaping the 'who' I am being and becoming.

Caritas Process 5—Forgive

Promote and Accept Positive and Negative Feelings as You Authentically Listen to Another's Story

Over the years I have struggled, as a single mother, with having negative feelings of guilt. I believe that many mothers do indeed struggle with guilt. I have suffered from remorse, because at times I could not help Noah nor could I prevent his health challenges. I have tasted the bitterness and resentment of his illness (Cerebral Palsy and Epilepsy), and its cause (prematurity at birth) for making our life together so challenging. But at this moment, I think the most culpability I feel is about the amount of relief that may come with his passing.

This journey has been grueling, and I am extremely exhausted. Yet, I am learning to accept the fact that I have always done my best for Noah amidst the joyful times, days of misery, and nights of darkness and despair. I believe it is common to feel relief after a major struggle, so it makes sense to my logical mind that not only Noah will be relieved from his constant and unrelenting muscle contractions and severe pain, but I will be liberated too. We are in this paradoxical restriction-freedom (Parse, 1998) journey together. Each and every decision over the years has been made with the best and most honorable intentions for my son. I should be proud that I have been a strong advocate for him during his 20 years of being totally dependent, nonverbal, and wheelchair bound. I believe that accepting my own positive and negative feelings and experiences benefit me now and will assist me, as a registered nurse, when I spend time listening authentically to another's story without judgment, especially given my own lived experiences at this time in our journey.

Caritas Process 6—Deepen

Use Creative Scientific Problem-Solving Methods for Caring Decision-Making and Creative Solution Seeking

Finding creative solutions to assist with my own problem-solving is important to me. One activity that I love to engage in is writing. Penning has offered me an outlet for pouring my thoughts and feelings onto paper, so that I do not hold the hurt inside; taking the weight off of my shoulders and placing the burden onto the paper in my journal. I even wrote a book to help other parents in similar situations (Weston-Isenor, 2014). I found literature which also described journaling to be proven to diminish stress (Crocker, 2017; Varvoli & Darviri, 2011; Wehrenberg, 2017). Physical activity is also another stress reducer (Varvoli & Darviri, 2011), which I continue to engage in. I do enjoy walking. For me, walking is a great way to reflect on my past, to contemplate my present, and to deepen my thinking and problem-solving for my future while hiking through the woods or strolling through a park. I find myself reading more and enjoying narratives about spiritual awakening and growth. Each activity is an opportunity to delve deeper into knowing myself. Through reflection, I am tuning into my own authenticity (Avolio & Gardner, 2005; Watson, 2018) and striving toward self-actualization (Avolio & Gardner, 2005). As a

student nurse, if patients so desire, I have been able to counsel them on the positive aspects of journaling (Crocker, 2017) and meditation (van der Riet, Levett-Jones, & Aquino-Russell, 2018) as effective strategies for their healing journeys.

Caritas Process #7—Balance

Share Teaching and Learning That Addresses Individual Needs and Comprehension Styles

I treasure a close friend, who has gone through the journey of losing her son. Just as I walked beside her at the time and witnessed that sorrowful experience, she is now doing the same with me, as I live with Noah's dying. Making connections with others who share your truths are opportunities for developing steadfast pillars of strength, for learning more about each other and myself, and finding comfort in the situation (Crocker, 2017). Accepting help and support was very difficult for me. My new husband is a gift from the heavens. He has taught me to learn how to rely on others instead of only myself, which has been a blessing and has since provided a huge sense of relief, now knowing that I am not alone. The weight of the world is not resting solely on my shoulders, as I felt that it was for the majority of Noah's life.

Through others' teachings, and my learning to accept of my own grief and establish new routines and new goals for myself, there comes the creation of new hopes and deeper meaning in the experience of living and dying, bringing death into my consciousness as "a sacred place in the beauty, mystery, and celebration" of Noah's life (Conscious Dying Institute, 2019). My friend has helped to teach me that while Noah's physical self is coming to a point of rest, there is still joy in knowing that his soul is perfect and will be moving into a pure light and state of being. This image resonates with me as it cushions my deep and heavy sorrow.

Caritas Process #8—Cocreate

Create a Healing Environment for the Physical and Spiritual Self That Respects Human Dignity

One of the best aspects of taking the *Theoretical Foundations of Nursing* course, is that we were introduced to beautiful Caritas cards (Watson Caring Science Institute, 2019; Watson, 2008). These cards have key words, as mentioned above, that signify opportunities to "tap into an unconscious

association with each card," allowing me to begin to learn to live "Caritas-Veritas Literacy" (Watson, 2018, p. 134) in my personal way of being and my professional nursing praxis. As part of my career goals, I plan on reviewing each of the 10 Caritas cards and focusing on implementing/living them in my own ways of being, while working as a nurse in my future nursing workplace. I also envision myself influencing the entire healthcare organization! I will be grateful to become employed and to have the opportunity help to cocreate a healing environment for myself and others. I want to inspire and instill these loving, holistic practices so that each and every patient feels valued and cared for by loving health professionals within the healthcare environment. As a basis for my own praxis, I will model my actions by following others' previously successful implementation strategies within other institutions (Sitzman & Eichelberger, 2017; Sitzman & Watson, 2018).

In relation to creating a healing environment for my son, over the years I have ensured that Noah has a very special bedroom space. I purchased a new adjustable bed with a thick memory foam mattress and cover him with soft blankets. This bed gives him maximum comfort and prevents skin breakdown issues from pressure points. The walls are adorned with pictures of things he loves, like the ocean and sailing, all in serene natural colors. Memorabilia, from travels he has taken on family vacations, decorate his shelves. A chair in the corner is a place to sit and spend time with him. When not in use by a human, his favorite teddy bear, named Cuddles, sits there. Noah loves his teddy bear collection which includes bears from around the world. A large flat screen television plays an array of his favorite shows and movies. We also have a large number of audio books for him to choose from. Noah is always given his choice of meals and snacks throughout the day. He is nonverbal with words but has his own sounds which indicate his agreement or disagreement when responding to yes/no questions. Noah's favorite times are spent with family and friends while sharing a meal. My child should own stock in 'Dairy Queen' for the amount of hot fudge sundaes he has eaten from there—his absolute favorite! One important feature of his room at this time, is that all medical supplies and equipment are hidden in drawers and in the closet. I wanted his room to be his personal healing space reflective of him as an individual and not of his health challenges.

In my personal life, I enjoy a comfortable and inviting home environment. I choose colors that appeal to me and no longer allow the opinions of others to dictate how to decorate my home, or how to live. I love fresh flowers, so I often have a fresh bouquet each week, to admire and delight in their fragrance. I surround myself with beautiful pictures and various artifacts that I have acquired over the years from my/our travels. I believe that life is meant to be beautiful and that you do not need to have a lot of material things in order to be comfortable. I am fortunate to live in a location with stunning nature and exquisite scenery, which feed my soul and create a healing environment for me and my spiritual self to flourish and grow.

Caritas Process #9—Minister

Assist With Basic Physical, Emotional, and Spiritual Human Needs

Being a single mother for some time meant relying solely on myself for everything that Noah needed. However, over the past two and a half years I have remarried to a partner who exemplifies love in every aspect of his being. He does everything for me; he cooks, cleans, and looks after our son's basic physical and emotional needs, while working from home, so that I can focus and complete nursing school. At first, this took a long time for me to get used to as I was guilt-ridden for taking him up on his offer to help me to achieve *my* dreams. I have come to realize that out of love all things are possible. Because he loves me and Noah unconditionally, he believes that by assisting me in achieving my dreams, he will benefit from my happiness and contributions to our family unit. I have never had the kind of unreserved support that he has given us. I feel so valued and respected. Noah loves him too. I want my patients and their family members to feel revered through my support of them.

I have also started planning mini events like spa days and nights away with my husband so that we can have a break from the daily stressors of Noah's palliative care. Again, this is new to me and I see the importance of having things to look forward to and to take the time for our own self-care and rejuvenation. In professional nursing practice, I spend time *pampering* my patients, by doing little *spa* treatments, such as massages or painting of nails and doing their hair. During these times together, patients have the opportunity to be silent or to

speak of their experiences, wishes, spirituality, beliefs, and faith with me. I listen attentively and authentically. I want to convey the same level of comfort and rejuvenation to my patients so that I know I have done something special for them—this is the kind of nurse I wish to become.

Caritas Process #10—Open

Open to Mystery and Allow Miracles to Enter

It is my belief that life is filled with mystery, that the spirit moves to a new level of consciousness or state of being once it departs from its human coat. Essentially, we are souls or spirits temporarily occupying a physical body (Pandya, 2011). This understanding has given me a deep sense of peace about my son's living his dying and his eventual passing on. In nursing, patients have varying beliefs and ways of dealing with health challenges. I appreciate learning and participating in different spiritual practices and sharing in the energetic exchange with others (Sitzman & Watson, 2018). In my nursing practice, I have been able to be open to acknowledge and discuss various meanings behind the phenomenon of death in helping to bring some peace during patients' deaths and family members' grieving processes.

I am often reminded by my peers to protect my heart, as I tend to give all of myself to each and every patient. As well, it is important to recognize when I need to *refill my own cup* so that I can keep on giving. I would heal the world if I could, as I truly feel like my heart strings are attached to every human in need on the planet, I believe we are all connected energetically (Watson, 2018). I have found that when I put intentions out into the universe through positive thoughts or prayers, I always receive a response. It might not be what I was expecting, and sometimes it is even better than I had hoped. For instance, my son had a need for an expensive piece of equipment in the past that was not covered by insurance. When I mindfully sent this requisite out into the universe, it turned out that through word of mouth an application was submitted on our behalf by one of Noah's medical practitioners and the equipment was donated to us. This is an example of being open to mystery and allowing for miracles. In my nursing praxis, being authentically present and focused with patients assists me to help them to heal *their worlds* and in turn to heal *my own world*.

Conclusion

As I complete this article, I notice that by reviewing and contemplating all of the Caritas Processes (Watson, 2008, 2018), I am astounded at how far I have come in changing the way I think and feel about this experiential journey that I am on with Noah as he lives his dying. I believe I, myself, am in a constant rhythm of change and that it is essential that I go with the ebbs and flows of life, the mysteries, and the miracles. To me, being resilient and open to the possibilities means acknowledging that change is inevitable, that it can be good, and that it is alright to have a variety of feelings about it—dare I say it is *normal!*—Or at least: it is *normal for me!* Along the palliative care/conscious dying path, I will be authentically present with Noah, and open to giving my love and receiving his love in all that I do. Being in love with my husband and receiving deep, committed love from him as he travels on this journey with me/us is sometimes hard to put into words. As I “caritasly” journey hand-in-hand with my son along this mysterious pathway to his new cosmic address, I hope to transcend the grieving process with love and begin anew, just as he will. Note: Noah passed away in his mother’s arms at 11:55 am on Dec 17, 2019.

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