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"When you can't fix it": A changing view of cancer nursing

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Abstract

The dehumanization of patients in health care is a challenge which we as nurses confront in our day-to-day practice. Increasingly complex technology and treatment modalities facilitate depersonalization of the care provided to persons with cancer and emphasize the view of human beings as "machines requiring repair". Traditionally, patients have been viewed from a biopsychosocial perspective which includes diagnosis of patient problems and the identification of interventions to alleviate or "fix" these problems. Patient related health problems are the realm of nursing practice. However, more and more nurses are identifying patient situations which they are unable to "fix", which are reflected in comments such as "I don't know what to say" or "I can't seem to take the suffering away". As we acknowledge patient situations which we cannot "fix", we are challenged to more clearly define our nursing practice.

This presentation will explore the human science perspective as an alternative to the traditional biopsychosocial model. Nursing models with a foundation in this perspective offer nurses the opportunity to "be with" and view persons differently, thus enhancing quality of life. Using a nursing framework based in human science, Parse's theory of Human Becoming, the author will explore the challenges which confront nurses when changing theoretical perspectives. Examples from practice will be used to illustrate the opportunities created when nurses move from a traditional intervention or "fixing" model, to a nursing model with a focus on the meaning of living with cancer from the person's perspective.

The dehumanization of persons in health care is a challenge which we as nurses confront in our day-to-day practice. Increasingly complex technology and treatment modalities facilitate depersonalization of the care provided to persons with cancer and emphasize the view of human beings as "machines requiring repair". Traditionally, patients have been viewed from a biopsychosocial perspective which includes the diagnosis of patient problems and the identification of interventions to alleviate or fix these problems (Carnevali & Reiner, 1990). As we identify problems which we cannot fix, we are challenged to more clearly define our nursing practice.

In this paper, I will explore the human science perspective as an alternative to the traditional

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biopsychosocial model. Nursing models with a foundation in human science offer nurses the opportunity to "be with" and view persons differently. Using a nursing theory based in the human sciences, Parse's theory of Human Becoming, I will explore the challenges which confront nurses when changing theoretical perspectives. I will speak about the beliefs and values which we commonly share regarding human beings, health and nursing and how those beliefs and values are shaped by the practitioners' theoretical perspective. Using examples from practice, I will illustrate the opportunities created when nurses move from a traditional intervention or "fixing model" to a nursing model which focuses on the meaning of living with cancer from the persons' perspective.

The idea for this paper began to germinate when I listened to the Schering Lectureship at last year's CANO conference. There, we heard a discussion of the impact of technology on our daily nursing practice. As I attended numerous other papers, I began to hear a recurring theme: That of where is the nursing? or what is the nursing? in our practice. There was evidence, in the general discussion, of nurses struggling to define their practice within an increasingly complex technological environment. Many of the same themes were evident in conversations I heard as I returned to work. In addition to

"QUAND ON NE PEUT LE RÉPARER": UNE VISION CHANGEANTE DES SOINS INFIRMIERS DU CANCER

ABRÉGÉ

La déshumanisation des soins de santé est un défi que les infirmières doivent relever dans leur pratique quotidienne. Des modalités de traitement et une technologie de plus en plus complexes facilitent la dépersonnalisation des soins dispensés aux personnes atteintes du cancer et renforcent l'idée que l'on a des êtres humains qui ne sont que des "machines qu'il faut réparer". Traditionnellement, on a traité les patients d'un point de vue biopsychosocial qui couvre le diagnostic des problèmes du patient et la détermination des interventions qui permettront d'éliminer ou de "réparer" ces problèmes. Les problèmes du patient qui ont trait à la santé sont le domaine de la pratique infirmière. Toutefois, de plus en plus d'infirmières s'occupent de patients dont elles sont incapables de "réparer" les problèmes, ce qui leur fait dire des choses du genre: "je ne sais pas quoi dire"; ou, "je n'arrive pas à faire disparaître la douleur". Nous devons reconnaître qu'il y a des situations que nous ne pouvons pas "réparer" et cela nous force à définir plus clairement notre pratique infirmière.

Cette présentation explore la perspective des sciences humaines comme alternative au modèle biopsychosocial traditionnel. Les modèles de soins infirmiers qui se basent sur une telle perspective offrent aux infirmières la possibilité d'être avec les patients et de les voir d'une autre façon, ce qui ne peut qu'améliorer leur qualité de vie. À l'aide de la théorie de Parse sur le devenir humain, un cadre de soins infirmiers fondé sur les sciences humaines, l'auteure explore les défis que devront relever les infirmières lorsqu'elles changent de perspective théorique. L'auteure tire des exemples de la pratique pour illustrer les occasions qui se créent lorsque les infirmières passent d'un modèle d'intervention (ou de "réparation") traditionnel à un modèle de soins infirmiers qui se penche sur le sens de la vie quand on a le cancer et ce, du point de vue de la personne atteinte.

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the technologic explosion, increased financial constraints in our health care system are forcing nurses to articulate, even more clearly, our role as nurses. Yet how can we articulate to others who we are as nurses, when we struggle with the answer to that question ourselves? I believe the answer to this question is vital; vital to our survival as a profession and vital to the health of those for whom we care.

When I ask myself the question "What is nursing?" I have always tended to come up with a variety of answers. If I were to ask that question today, I'm sure I would receive as many answers as there are people in this room. Being the "good researcher" that I am, when I started preparing for this paper, I did an informal survey of colleagues and found that the nurses with whom I spoke tended to talk about either what they did (such as coordination, specific tasks and activities) or what they thought nursing was (this included concepts such as caring, client centred, family centred or holistic care). Gadow (1980) suggests that nursing ought to be defined by its philosophy of care, and not by its care functions. Gadow (1980) states that by formulating this philosophy of care, nurses "transcend a particular concept of nursing only in order to realize a more developed concept, an ideal: A philosophy of nursing which unifies and enhances the experience of the individuals involved rather than devaluing and alienating that experience." (p.80). I believe that having an ideal is critical. In speaking about the future of nursing, Dr. Alison Tierney (1992) suggests that "idealism and realism must co-exist in nursing: For without idealism nursing will not flourish, and without realism nursing will not survive". My purpose is to share with you my experiences and a little about the way I am with persons, which helps me to reach toward my ideal of nursing.

We are all acutely aware of the realities of today's health care industry. Resources are limited; there is escalating pressure on the Canadian health care system to provide services to a growing number of persons. The number of individuals with cancer is increasing as persons are living longer, and surviving longer with cancer (National Cancer Institute of Canada, 1992). Services are being stretched to the limit as waiting periods for care increase. Short stay units, same-day admissions for surgery, decreased lengths of inpatient stay and increased pressure on ambulatory care clinics to see more patients and provide more care are common realities in the 1990s (Kohles, 1991). The increased pressure on our health care agencies to provide care decreases the tendency of the providers to view persons as human beings.

Further impinging on our ability to view patients as human beings is the technologic explosion which seeks to break the human body down into smaller and smaller pieces. Wondrous new technologies allow us to view the body at a cellular, or sometimes molecular level. We are able to use new technologies to stimulate or destroy specific cells and receptors. One theme which clearly surfaces is that if we could only break the person down to the smallest, microscopic level, maybe we could cure, or ideally prevent, cancer. And while this may be possible, we must exercise caution that we as nurses do not fall into the trap of seeing persons from this medical perspective. The focus of nursing is human beings and their health, rather than on cells and their responses.

Nursing has tended to view persons from a bio-psycho-social-spiritual viewpoint or perspective. This is the natural science perspective, which is anchored in empiricism, defined as a "practice of relying on observation or experiment" (Webster, 1990). Within this perspective, the person is viewed as being composed of different components, continuously in interaction with each other and the environment. Leonard (1989) suggests that nurses have continued to be "preoccupied with the notion of the person as an assemblage of traits or variables such as anxiety, control and self esteem" (p.41). Nurses attempt to identify and study these elements in isolation, to generate formal laws for the ultimate goal of prediction and control (Leonard, 1989). The role of nursing has evolved from this as the assessment of the person to identify problems or concerns, appropriate diagnosis of problems, and the identification of interventions to alleviate or "fix" these problems. Patients are usually

involved in the planning of care, but the ultimate responsibility and expertise lies with the nurse. This is one way of viewing nursing.

I have experienced a shift in my thinking from this traditional bio-psycho-social-spiritual perspective to a different way of looking at people. I believe what promoted my changing view of persons was my frustration with the care I was providing for persons. I was frustrated that despite my years of experience and education, and despite consultation with other experts, there were still patient situations where I was unable to develop appropriate nursing interventions to achieve patient care goals. There were still patient and family situations and problems which I couldn't "fix". I suspect that we have all met those situations, times when we simply don't know what to say to people or when we don't know how to take the suffering away. Faced with these situations, I found my problem now became: "What do I do?". What is my role as a nurse if I do not have appropriate interventions to solve patient problems? In recognizing that I was unable to "fix" some of the things I felt I should have, I began to question my nursing practice. I worked in an environment where some nurses practised from a different perspective and realized it might help if I looked at things from a different point of view.

As I read and questioned and listened, I came to the conclusion that my success or failure as a nurse is not defined by my ability to resolve specific patient care problems. In actuality, success or failure can be measured by my ability to affect the quality of the lives of those with whom I come into contact. Thoreau stated: "It is something to be able to paint a picture, or to carve a statue, and so to make a few objects beautiful. But it is far more glorious to carve and paint the atmosphere in which we work, to affect the quality of the day - this is the highest of the arts" (Donahue, 1985, p. 9). I believe that we as nurses practise the "highest of the arts" in our work to affect the quality of the day for our patients and their families, and for each other. We each select our own way of affecting the quality of the day for the persons with whom we work. I choose to affect the quality of the day for persons through the realization of the goal of my nursing practice; that goal being quality of life from the person's perspective (Parse, 1981).

The change I made in my view of persons and nursing was a struggle which I lived for many months. Changing the way I viewed persons involved making a "paradigm shift". The nursing paradigm is the global perspective of the discipline of nursing, encompassing the concepts of person, health, environment and nursing (Stevens, 1985). The way you view these concepts depends upon the values and beliefs which underpin, or serve as a foundation for, your particular theoretical perspective. The four concepts (person, health, environment and nursing) remain the same, but how these concepts are viewed changes. For example, if one practises from a self care perspective, person or patient is viewed as object, subject to the physical forces of nature and embodied with self care agency to meet specific demands in relation to health and illness (Orem, 1981). Persons viewed from an open systems model are seen as social, sentient, rational, reacting beings and "each human being perceives the world as a total person in making transactions with individuals and things in the environment" (King, 1981, p.141).

One of the challenges I found in changing perspectives was re-examining the way I thought about people, health and nursing. For me, this was a time of intense discomfort in my practice, as I knew that I needed to be doing something different. This is not to say that what I was doing was wrong or unsafe or incompetent, but rather I felt that there had to be more. I began to explore the work of Parse (1981).

Examining the work of a nursing theorist involves exploring how he or she views the concepts of the nursing paradigm. The different nursing frameworks shape the way in which we view human beings, nursing and health (Stevens, 1984). The view of these concepts flows from the philosophical basis of the particular theory. Those philosophical bases can be grouped broadly into two perspectives: The natural sciences and the human sciences. The natural sciences serve as the foundation for the traditional bio-psycho-social view of person. The nursing theory which guides my practice, Parse's

Theory of Human Becoming, flows from the human science perspective (Parse, 1981). The term "human science" can be traced to the work of philosopher Wilhelm Dilthey in the 1880s (Mitchell & Cody, 1992). At its broadest level, human science explores all of the "experiences, activities, constructs, and artifacts that would not now exist, or would never have existed, if human beings had not existed" (Polkinghorne, 1983, p.289). Human science focuses on meanings, values and relationships within the context of life as it is lived by the person (Mitchell & Cody, 1992).

I would now like to discuss the major concepts of the nursing paradigm and illustrate some of the differences between the traditional bio-psycho-social perspective and Parse's Theory of Human Becoming. My purpose is not to proclaim one point of view as superior to another, but to simply illustrate a different way of looking at nursing practice.

There are fundamentally different ways of viewing human beings, and this influences the way in which we, as nurses, are with people. Human beings may be viewed as a sum of parts, composed of bio-psycho-social-spiritual aspects. This is in contrast to the view of the unity of human beings, whereby persons cannot be reduced to parts: Persons are more than, and different from, the sum of parts (Parse, 1981). Studying the different parts does not provide an understanding of the whole. Polkinghorne (1983) speaks of this as the concept of emergence; when different parts are combined into the whole, what results does not resemble the parts, nor can you understand the whole by studying the parts. The concept of emergence can be illustrated with the example of water. Two hydrogen atoms and one oxygen atom combine to form the water molecule, but this chemical compound does not begin to describe the utility, the wonder and the beauty which is water: Water, in all its presentations, shaped by the forces of nature in which it exists.

The second notion in the view of human beings is the contrast between linear causality versus the view of person as "co-author and co-participant" (Parse, 1981). Linear causality suggests that persons are predictable, existing with cause and effect relationships with the environment, and that persons may be reduced to parts for analysis (Jonas, Pilkington, Lyon and MacDonald, 1992). Human beings interact by coping with or managing the environment. An alternative view is of human beings as co-author and co-participant, whereby persons are continuously creating their unfolding lives in mutual, simultaneous interrelationship with the environment (Parse, 1981). Life is always moving toward greater diversity. As we make choices and decisions based on our values and beliefs, limitations and opportunities are created. Human beings have the freedom to choose; choosing happens at many levels of awareness and is more than simply doing what we want when we want. Even choosing not to choose, is making a choice. We create a unique pattern of living through the choices we make in our lives (Parse, 1981).

Health is another concept of the nursing paradigm. Traditionally, health has been viewed as physical, mental, social and spiritual well-being in relation to standards or norms of health and illness (Jonas et al, 1992). Health may be considered the absence of disease, or optimum well-being, and is something to be obtained and maintained. Parse's theory states that health is the process of becoming as experienced and described by the individual, health is the living of what is important to the individual (Parse, 1981). Each person is the expert in her own life and is the only one who can describe what life is like for her, what experiences or events mean to her. In cancer nursing, the area of pain management is one example of the notion of person as expert in his life. Nursing and medical researchers have spent many years and more dollars attempting to describe, measure and control the experience of pain. At one time, pain was believed to be a simple physiologic response to the stimulation of pain receptors. Most nurses now generally accept McCaffery's definition: "Pain is whatever the experiencing person says it is, existing whenever the experiencing person says it does" (McCaffery and Beebe, 1989, p.7). This definition clearly acknowledges the person as expert in his life; the person is the only one who can truly understand what the pain is like for him. It is only

the person who can tell us what methods or techniques are effective in alleviating or controlling the pain and it is only the person who can tell us what the experience of pain means. The role of nursing is to work with persons as they choose how to be with and manage their pain.

The goal of nursing has traditionally been viewed as the prevention of disease and the promotion of health. The central phenomena of nursing include self care, adaptation, goal attainment and caring. The nurse assesses and diagnoses the patient's problems in order to prescribe interventions which will alleviate or "fix" a person's problems. The nurse works in collaboration with the person, but is ultimately responsible for fixing those problems. One of the difficulties in having the responsibility for "fixing" problems, is that eventually there will be something or someone whom you cannot fix. I have learned through my years of practice that there are many situations and persons which I cannot fix. I don't have the answer for the 16-year-old who is dying, and who looks at me and says "Why me?". I cannot take away the suffering of a young mother grieving for the fact that she will never see her children grow up. I've learned that there are times when I cannot make things better, when I cannot answer the questions which are asked, and when I cannot take the suffering away.

When I practise nursing from the Parse Theory of Human Becoming, my goal as a nurse is quality of life from the person's perspective (Parse, 1991). My role is to be with persons as they experience their lives. I do not try to control or fix people, but rather go with them in their struggle to change in the way they choose: Nurturing them as they grow and unfold. I am not the expert in people's lives, but rather a co-participant with people in their situation (Parse, 1981). I am truly present with them as they find their way in life situations. I have experienced an unburdening in feeling that I am no longer responsible for "fixing" the person, but am there to "be with" and witness the person's experience.

The three processes which guide nursing practice from Parse's theory include true presence all-at-once: Illuminating meaning through explicating, synchronizing rhythms through dwelling with, and mobilizing transcendence through moving beyond (Parse, 1987). Illuminating meaning occurs through explicating, whereby opportunity is created for the person to discover new meanings about familiar circumstances. Meaning is a person's reality and is created by the person together with others. Meaning changes through the living of new experiences (Mitchell, 1988). Moving with the person as they speak about their life situation is "synchronizing rhythms through dwelling with" (Parse, 1987). The nurse does not try to direct or control the discussion, but rather goes with the person wherever they lead, wherever they are. Going with the person and dwelling with his personal meanings sheds light on his experiences in new ways. As we dwell with personal meanings, paradoxical patterns arise (Parse, 1981). Paradoxical patterns emerge as individuals move and think in one direction while struggling to move in the opposite direction at the same time (Mitchell, 1988). An example might be a person who is both impatient to have his or her surgical biopsy done and thus learn his or her diagnosis, yet does not want to have the surgery because of fears of what will be found. Nurse-person activities arise from the paradoxical patterns of health (Mitchell, 1988). "Mobilizing transcendence through moving beyond" occurs as people picture and move toward their hopes and dreams for the future (Parse, 1987). "Most important to the practice is being truly present with persons as they find new discoveries of self. Viewing human beings as co-creators of life and human mysteries guides the nurse to be present while thinking about the person's ways, what is most important to them, (and) their hopes and dreams" (Jonas et al, 1992).

I would now like to tell you two stories from my experience, which will, I hope, tell you about my practice as a nurse guided by Parse's Theory of Human Becoming. The first story I would like to share with you involves my work with a young man who was struggling with his fears and anxiety around continuing his chemotherapy treatment. I had known this person and his family for several months when they

were confronted with the death of a patient to whom they had become close. When I was called at this particular admission, the nurses were most concerned that both the young man and his family were in crisis and needed information and intervention. The health care team was mobilized to provide the patient and family with answers to questions which they were asking. They received all the appropriate reassurance which we could give, including a reminder that everyone is unique and each person responds differently to treatment. But it was very obvious that none of our reassurances could make them feel better. I knew that there was nothing I could say, no promise I could make that would take away their pain. I spent time with this young man and family as they sought meaning in this situation. Of particular importance to him was the meaning of the death of the other patient. He shared with me his hopes, fears and dreams. He shared with me his fear that this death meant there was a possibility that he might die as a result of either his treatment or his disease. This terrified him. He described the feeling of being at a crossroads. He felt that his life could go one of two ways, either towards a long and healthy life, or towards a death that was much too soon for him. He said that treatment lay at that crossroads, and that he had always thought of treatment as leading down the road to long life. Now that was not the case, and this was the first time he considered the possibility that this might not be the case. He talked about wanting to continue to take treatment, because it offered the only chance of cure for his disease. Yet he was terrified by the thought that the treatment might actually "do more harm than good". The paradoxical pattern of health which emerged was wanting to take further treatment because it might cure his disease, and not wanting to take further treatment for fear the treatment might eventually kill him. In exploring what helped him to get through this time, he talked about how, when he felt physically fit and was eating well, he felt he could survive anything. He had been very active until the time of his initial diagnosis, but since then had not been exercising or eating particularly well. He spoke about what was important for him and what helped him get through. He wanted to begin exercising again to try and build up his physical energy. As he spoke about differences between himself and the other patient, and as he planned how he could care and do for himself, he stated that he did begin to feel better. He chose to continue with treatment, deciding that treatment offered him his best opportunity for long life, and long life was the most important thing to him right now. The crossroads kept appearing for him, but the way seemed more clear for him. My role as nurse was to be present with him as he sought meaning in the situation and moved beyond as an expression of his hopes and dreams. As expert in his own life, he made choices which helped him toward quality in the life he was living.

The second story I would like to share is of a man I worked with for a number of months. This experience was a turning point in my shifting perspective of the way in which I viewed both my role as nurse and the persons I work with. I was asked to see a 70-year-old gentleman who had been admitted to our psychiatric unit with a diagnosis of pathological grief reaction related to the loss of his wife two years previously. In my role as a clinical nurse specialist, I was asked to provide bereavement counselling, although Mr M. had been unwilling to speak to any staff members. When I first met Mr. M. he was most explicit that he had no desire to talk to me, or anyone else, about the death of his wife. He had agreed to come to hospital on the urging of his daughter, but he was here for "some medication" to make things better, nothing else. As a nurse guided by Parse's theory, I asked him what life was like for him right now. He spoke to me about wanting to get out of hospital and back to his life. He stated that he was concerned that people would think he was crazy, because he was in a psych unit. He knew he was not crazy, but sometimes he felt like he was going crazy. In moving with him, I asked him what this was like and he talked of how "things" would become disorderly and out of control in his mind. Mr M. said he had always managed to keep things in control by having a very orderly mind, but that lately it had become harder and harder to keep things in order. He spoke about how all his thoughts had a place to be, in a box or a drawer or a shelf. Some experiences, like family or work, were so big that they had their

own rooms. And it was in one of these rooms that he had put all the memories of his wife. He had nursed her through 14 years of illness preceding her death, the last two years of which he provided almost constant care and attention. The day before she died, she was so ill that Mr. M. had taken her to hospital. He had wanted to spend the night in hospital with her as he was concerned that she not die alone. Mr M. described how the medical and nursing staff had encouraged him to go home, because they felt he was too exhausted and didn't need to stay. Mr M.'s wife died that night, in her sleep, alone. After the funeral, Mr M. sold their home and gave away all of her, and most of their, belongings. He had even thrown away all their photo albums, so he didn't even have a picture of her he could show me. He said that he wasn't able to throw out all their memories, so he had put them away in their own room in his mind, and closed and locked the door. And he saw that door in his mind every single day. I continued to go with him, and asked him to tell me about the door on the room of memories about his wife. Mr M. described in detail the huge, metal-bound, ugly door. He described the locks and the hinges. He created the picture of a huge iron strapped door with giant metal hinges which were stretched to the limit. As he talked about the hinges and the locks, he felt that the door was a bit shaky right now, and might in fact open on its own. I asked him what it would be like if the door opened. As he began to picture his hopes, dreams and plans for the future, he began to change toward that which he hoped for. He was frightened, he felt that if the door were opened, he would be flooded with memories that he could not handle. Yet at the same time, he wanted to be able to relive the happy memories of his relationship with his wife. The paradoxical pattern emerged of wanting to remember his wife as they had many happy memories, yet not wanting to remember because it was too painful. As we continued to speak, he was able to think of a less painful way in which he could remember his wife. He decided that each day he would share one good memory of her with me. As time progressed, he was also able to share one memory a day with his daughter. He was eventually able to return to his daughter's home. My work with Mr M. taught me a great deal. I believe that the reason I was able to work with him was because I did not expect him to come where I was, but rather went where he was in his grief. I did not judge, I did not label his grief as pathological, but rather saw him as a human being with his own meanings assigned to life.

I have seen changes in my practice when guided by Parse's Theory of Human Becoming. Changes in the practice of other nurses have been reported in several qualitative studies conducted to evaluate the implementation of this theory in practice settings. One study, evaluating implementation of the theory on an acute medical nursing unit, identified six distinctive patterns of change in the practice of nurses. These included: Changed perspective of patient from problem to person; changed morale in nurses; less judging and labelling - more talking and listening; respecting the patient's right to choose; and enhancing the quality of the nurse-person relationship (Mitchell, 1991). Further evaluation of the theory in an ambulatory care setting revealed additional themes including: Nursing practice is more meaningful and satisfying; not having enough time yet having time to listen; comfort-discomfort with letting go of fixing and telling; being more aware of the person and his or her perspective; appreciation of being with others; struggling to live new beliefs; and more understanding and closeness among nursing staff (Jonas, 1991).

I have experienced some of these changes in my practice. Struggling to live new beliefs is a challenge that I continue to live. I found it hard to change the way in which I view persons and my practice. I continue to struggle with the giving up of fixing and telling. I have spent many years learning what I now know and I continue to try to find a balance between fixing/telling and being with. Yet, I have come to the realization that my role as a nurse is not defined by what I "do to patients" by fixing/telling, but rather how I am with persons.

In summary, I have provided you with a description of the road that I have travelled in shifting perspectives. I have shared with you

my struggle to define my nursing practice, and have suggested one method by which we as nurses might accomplish this definition. I hope that my discussion of Parse's theory, and the two stories I have told, have helped to give you a sense of my practice as a nurse guided

by Parse's theory. My struggles with practising from a different perspective continue, but I believe that is the nature of change. The struggle challenges me to continue to seek the answer to the question: "What is nursing?"

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