

chapter six

THE EFFECTS OF EXEMPLARY NURSING CARE

In chapter 6, I illustrate the results of using the three aspects of exemplary nursing care presented in chapters 3, 4, and 5: touch, silence and lightheartedness.

CONNECTING

Clayton, Murray, Horner, and Green define connecting as “the transpersonal experiences the sense of connection, between a nurse and a patient between nurse and important part of the exceptional nursing practice.



and feelings that lead to attachment, or bonding patient.”¹⁵⁴ This connection is a complex and phenomenon of excep-

Connecting, as described by the nurses, involves several components: noting the similarities between nurse and patient, recognizing that the patient was once well, and participating in the patient’s experience.

STEPPING INTO YOUR WORLD

There are moments when I feel like
I have stepped inside your world.
For just a flash,
I feel your pain,
I know your despair.
I sense what it's like to have cancer
from the inside looking out
at a world of people who are fit and well.
My God—it's so tragic.
My God—it's so unfair.

Recognizing the similarities

Maureen told me this story about a connection that occurred very naturally with one patient. This connection developed partially out of mutual recognition of their similarities.

A young mother of two kids had a brain tumour. This was a real warm relationship from the beginning. We shared — we were very close. I was overwhelmed sometimes by what she was going through. I remember how grateful I was for her that she had such a supportive husband. I was in awe of how much strength she possessed. Whenever you admire someone, you want to be close to them and study them. She wrote me a poem that I got just after she died. She taught me a lot about me, and made a real difference in my life. I may forget her name, but I will always remember her and the ways she was like me, and the ways I wanted to be like her.

YOU AND ME: THE SYMMETRY

As different as cold and hot,
soft and hard,
happy and sad,
you and me.

Yet even where differences are vast,
there are similarities.

We do share...
a desire to be needed,
a desire to be loved,
a desire to be acknowledged,
a desire to be remembered.

Marie told me this story of a patient she connected with, although on the surface they seemed very different.

She was sixteen years old. I'd been her nurse right from the very first admission day. We'd grown so very close. Unlike me, she was a mother, and now a very sick leukemic — just too much for her 16 years to handle. To me, she was just a young teenage girl in need of her mom.

She returned from a pass one Sunday and eagerly searched me out to give me a photo of her 12 month old baby girl, Amy. I remember how proud she was as she showed me the photo and how carefully she wrote on the back and handed it to me. We both smiled and talked about her little one. I listened intently as a non-mother. This would be the last evening we would spend together in such a happy carefree way.

Years later, after I had my own little girl, I was looking over an old desk calendar. Amy's photo slipped out, and I recalled that evening we had shared. I now knew the joy of being a mom — the pride of having your own child — and I realized that little Amy brought some beautiful rays of sunshine to a young teenage girl's last days.

IN ME, YOU

We recognize ourselves in others.

In you I see me,
my potential as a mother,
as a woman,
and as someone who will die soon.

The only difference between me and you
is that you are probably closer to your death.

This same nurse went on to tell me a story about connecting — finding a common bond — with a patient named Kenny. She said,

I remember Kenny because he called the hospital from his home up north and said he was never coming back to the hospital in the city again. He was a typical teenager — rebelled all the time, didn't do the things he was asked to do; he was non-compliant through and through.

After some coaxing, he did come back to see us for a treatment. I was his nurse. The only thing he really liked was fishing, and I thought, "Bingo — I can relate to fishing." I told him I liked to fish, too, and he said, "You like fishing?" with total disbelief in his voice. I

said, “Yah — I can get into it.” He tried some lingo on me about hooks and jigs and I passed. Then he said, “I’ve got something to show you.” It was a home video of ice fishing. The whole movie was of a hole in the ice. The odd time he would say, “Did you see that?” Then he would rewind until we both saw the fish. That was our connection. On each visit, I’d always start with, “How was the fishing?”

There is always a connection possible. If it isn’t going to be with me, maybe another nurse can do it for that patient.

OVERLAPPING REALITIES

We are different?

We are the same?

We are essentially the same!

Finding that point where we are the same,
makes caring for each other so natural.

Seeing the former you

The nurses described the ability to envision patients in their minds as the persons they were before they became ill as an important prerequisite to, and part of, connecting. Three of the exceptional nurses made these comments.

When you see that stretcher coming down the hall with a new admission, the patient at first means very little to you. But as you get to know them, look at pictures of them before they were ill, see their personalities and features reflected in their family members, you feel a lot different about them.

Your first contact with a new patient before you get to know them is hard. They are usually bald, jaundiced, thin — not nice looking. And then you go into their room and start talking to them and all that disappears. You see that person as the person they were before. As you find out more about them, you see the person inside — you see their spirit, their soul. I'm not sure what to call it — maybe their essence. The average person on the street would be repulsed by their appearance, but the people here who care so much see only their beautiful side.

I always try to picture what the patient was like before they got cancer. I ask questions about what they liked and didn't like — about their hobbies, their work, their family interactions. Knowing these things just helps me give better care.

In a sense, “knowing” the pre-illness person facilitates establishing a nurse–patient connection. Maureen commented, “It's just easier somehow to connect with the patient if you have known them since their initial diagnosis or at least if you see pictures of them from before [they got sick]. Then you have the total picture of that patient.” She went on to tell me this story.

The patient in room 18 was a sixteen-year-old girl with an astrocytoma. I knew she had been admitted many times before and had become a favorite of the staff, although I had never met her. I knocked on her door and entered the room. There in the bed lay a person; it was hard to know the age, or even the sex, of the body lying there staring at me with wide eyes. Her face was swollen — typical of the cushingoid syndrome that develops with prolonged

steroid use. Her hair was sparse and patchy, revealing her scalp. Her facial features drooped and her mouth sagged in one corner. Her body was swollen and her arm movements uncoordinated. There was evidence of anxiety in her eyes as she looked at my unfamiliar face.

I approached her, gently laying my hand on her arm, and said, “My name’s Maureen. I will be your nurse tonight.” Some incoherent noises came from her mouth as she acknowledged what I was saying. She pointed towards a list with words on it, showing me her name — Maureen. I nodded and said, “I know — your name is Maureen, too. You know, Maureens are the best people. We should have a great time tonight.” She grinned and pointed to a picture on her bedstand. The picture was of a beautiful, young woman with long, brown hair and a gorgeous smile. Maureen watched me — waiting for me to make the connection that this picture was of her.

I looked at her and smiled. “Is this a picture of you?” I asked. Tears filled her eyes as she nodded. Then I realized how important it was to her that I knew who she was before she got sick, and that she was still that person. She taught me something that night that I will never forget.

When I asked Maureen about this story she elaborated on the lesson she received that night saying, “I learned that, to provide the very best care, I need to know who that person was before becoming sick and to realize that person and their history is very important to the patient I am now caring for.”

Moria gave me the same message when she said, “You have to see past the smells, cachexia, crumpled, broken, misshapen bodies to see

the former radiance.” One day on the unit when we were caring for a patient who was in such a state, Moria said, “She must have been such a beautiful woman — just look at her skin and her hair.”

INSIDE THE PEBBLE

Every pebble,
no matter how chipped and broken,
potentially contains
a dusting of gold.

Participating in the patient's experience

When I asked Cindy how she defined a “good day,” she said, “I know I have had a good day when I make the connection with a patient, when I feel comfortable sitting on their bed or giving them a hug — when I am part of their experience.” Many of the nurses’ stories describe times when they made this connection with their patients by participating in their experiences through sharing their pain, suffering, joy, or an intimate moment with them. The following is one of Marie’s examples of such an encounter:

I want to tell you about one of my patients. He was a doctor himself — very ill, very uptight, very much in need of control over his care. I had known him only vaguely in his previous role as a doctor on the unit, and now here he was — my patient. I was called to perform a difficult procedure on him, and I remember thinking, “How can I handle this? How can I make a connection with him?”

Before I brought in all of my materials for the procedure, I went in and sat down with him. I told him my name and said, “You probably don’t remember me, but

I do remember when you were a doctor here.” I said that I really remembered him and that he stood out in my mind because he was so personable and that I was impressed by how he had treated the nurses and his patients. I would never have been able to tell him these things except for the situation — at that moment, he was in a more vulnerable position than I was. I just said what I felt — that I was really sorry that he had cancer.

That time together was important. It made both of us feel at ease and I was able to do the procedure then without anxiety. When he came back for another treatment a week later, he asked for me. I was glad I had taken the time to make that personal bond. He talked to me about his plans — the things he could never do that he wanted to do. Even after he knew that he was going on with his disease and he stopped the treatments, he would always stop by and talk to me. I really miss him.

In this example, Marie participated in her patient’s experience by spending time with him, sharing “secrets” with him, and giving of herself. All of these are part of sustaining the nurse-patient connection.

Marie shared this example of her participation in another patient’s experience.

She was young, sweet, and soft-spoken. I just wanted to mother her. She had been through so much. She didn’t really understand what disease she had — let alone that it was bad. We were like mother and daughter from the beginning. That was the nature of our relationship. With

her I would just say, “You have to do this...,” “Listen to me...,” “Come on, you can do it...” I wouldn’t use that approach with any other patients but, with her, it just really fit.

I feel as if I shared in her experience. I was with her — at least in mind — from the moment she was admitted until her last day. She was my patient; I was her nurse. When she died, so did a part of me.

THE CONNECTION

An unseen thread joins our spirits.
As we journey through this time together
we share ourselves with one another.

Things that would never be
appropriate to say to even my
closest friend,
are, with you, not only appropriate,
but necessary.

We both know that time is short.
To leave things unsaid now, is to
leave them unsaid forever.

AFFIRMING THE VALUE OF THE PATIENT

The connection between patient and nurse is related to affirming the value of the patient. An underlying focus of the care given by exceptionally competent nurses is an acknowledgment of the patient as an important and worthy individual — as someone who has value. This is a part of the nurses’ belief system as they enter into nurse-patient relationships; it is reflected in the nursing care they give, and it is an effect of their nursing actions and interactions.

It appears that there are at least four major means by which nurses communicate to patients that they are valued. Specifically, nurses help patients to be remembered; they help patients to create meaning out of their experiences; they treat patients with respect to help them maintain dignity; and they help patients see their possibilities — to find hope.

Helping the patients feel they will be remembered

In an interview, Julie said,

People can take almost anything — but they can't take being forgotten. Anybody, if they have one wish, they want to be remembered. Every person wants to make some significant contribution. Sometimes it is part of my role to help them with this.

—

REMEMBER ME

When I am gone,
I have only one request,
remember me.

Say my name,
and remember me.

Touch my things,
and remember me.

Recall my smile,
and remember me.

I simply have to be more than dust.
Dust is just dust,
and when the wind blows it scatters
and is forever
lost.

—

Julie wrote this story:

A young mother of a three-year-old was facing her own death. She had brain mets that were interfering with her cognitive and motor abilities to complete the many handicraft projects she wanted to finish and bequeath to her child. The disease was progressing quickly; she was overcome more and more with fatigue and confusion. She asked me to finish a counted cross-stitch picture for her, but instead we packaged up the partially finished picture — thread and all — with a note that said, “My dear, dear child...When you want to, please finish this picture, and it will be something you can say we did together...My hand will guide you. Love, Mom.”

Jane said, “The patients — especially near the end — just want to be assured they will be remembered. No one can bear the thought that after they are gone, they will disappear and not matter anymore.” I asked her how she responds to these concerns, and she answered, “Usually, I just help them believe that people will remember them. I say, ‘Let’s talk about the people who will remember you,’ and we talk about specific differences they have made in other people’s lives.”

Lana said, “Sometimes we have to be part of the group that remembers the patient.” She talked about the responsibility she feels to remember certain people — especially those who may not have family members who will recall their memory. The nurses told me about gifts, poems, and letters they or the nursing unit had received “in memory” of specific patients. They felt it was part of their role to carry on these memories. Maureen, in telling me about a patient who had written her a poem that she had received just after the patient died, said, “I may forget her name, but I will always remember her. It is just part of what I do.”

Jane commented, “A part of remembering is recognizing the uniqueness of individuals, because, in remembering, we recall what made that person special. There isn’t a patient that isn’t special in some way.”

Helping the patients find meaning in their experiences

Marie stated, “Probably the hardest question I am asked is, ‘Why me?’, and all the patients ask it in their own way, in their own time. What can I say? It’s really, really hard.” What she was addressing is the role the nurses play in helping their patients create meaning out of their cancer experience.

Frankl writes about the importance of finding meaning in our experiences. He says,

To live is to suffer, to survive is to find meaning in suffering. If there is a purpose in life at all, there must be a purpose in suffering and dying.... If one succeeds, one will continue to grow in spite of all indignities. He who has a why to live can bear with almost any how.¹⁵⁵

It seems from the examples provided by the exemplary nurses that they work together with their patients to help them find their whys. Expert nurses work at helping patients find meaning, or more precisely, they help their patients make sense out of what is happening to them. In a similar vein Burke commented, “Each person strives to create meaning out of his existence in the world and attempts to gain freedom from crippling fear, anxiety, and guilt.”¹⁵⁶

Some nurses suggested that, when confronted with the possibility of death, the urgency of this search is accelerated. Simultaneously, due to the devastating nature of the disease, this quest becomes more difficult. As Lana said, “How can a person be expected to find meaning in suffering and death? How much more difficult can it get?”

Although the nurses acknowledge that it is a difficult task, they recognize their role in helping the patients with their search for meaning within the limits of their individual circumstances. Julie told me this story of a man she helped to find meaning in a life that had been devastated by more than cancer.

He was a tall, good-looking man. At his request, there was a “No Visitors” sign on his door. He drew pictures; he discussed world politics. He didn’t cry — he didn’t laugh; he watched. He gave single word answers. His patient history report said he was an atheist. He had attempted suicide because he did not wish to put his wife through the excruciating process of slowly watching him die. He was admitted to prevent any subsequent suicide attempts.

I personally believe that, given enough opportunities, even the hardest rock can be — if not cracked — at least warmed by the sun. Initially, that rock was all I saw, but this man taught me about the “sands of time” and the importance of approaching every situation with caring and honesty — and to never judge.

I am good at making people feel comfortable. I enjoy helping them get rid of a lot of emotional garbage. I knew he needed to have his inner fears affirmed — to come to terms with the grief and the multitude of losses he was encountering. He needed, at least, to search for answers to the question, “Why?” I recognized his loneliness and his fear. How was I going to let him know I was there to help?

The opportunity finally arrived one evening. He all of

a sudden said, “Do you believe in God?” I answered carefully, not wanting to shut the doors. I said, “I really don’t know about God *per se*. But I do believe in angels.”

Regardless of my attempt, his part of the conversation quickly changed to the practical matters at hand — like the size of his pajamas. However, with the passing weeks, we did discuss angels, a little bit about God, grief, anger, hate, and how unfair this was.

He told me a lot about his life. He had been a young family man during the war — an army officer. One day he and his wife went for groceries, leaving their two boys at home. While they were gone, their home was bombed. Their home and family were destroyed. As postwar refugees to Canada, his wife bore another son who died shortly after birth. In an attempt to gather some semblance of normality after all this heartache, they adopted an infant. This child was now in his mid-thirties and mentally handicapped.

I think of him often. I was fortunate to be with him in his last moments. I held his hand. All I could do was stand there and hope that he was seeing his kids. I prayed, “Please, if there is a God, this man deserves to see his kids.”

I don’t know if it was just the effects of his drugs or what, but when I said to him as he was dying, “Your sons are there,” he squeezed my hand. He really did. He squeezed my hand and died. And I sobbed.

FINDING MEANING: THE FIRST STEP

You listened to me with openness.
 Into your willing heart I poured
 my fears, my sadness, my guilt.
 Now that I am free of these chains
 there is a chance I may find serenity.

Just by listening to this patient and helping him to relive his stories, Julie set him on the way to being able to find meaning in his experience. Without this opportunity to free oneself of the guilt and pain of past failures and sorrows, it would be difficult for any patient to think clearly about what part the cancer experience plays in his or her life. As Levine said, “When the mind is clear, we can see all the way to the heart” and “when the heart is exposed there are no obstacles in the mind.”¹⁵⁷

Once the “emotional baggage” has been addressed, the nurses talked about the important role of a spiritual element in helping their patients create meaning. As Jane said, “Even if you have never really believed in God or some higher power, it crosses your mind when you face your own — or someone else’s — mortality.”

Most of the exemplary nurses described their own well-developed spiritual beliefs. Having faith in the existence and mercy of a higher being was important in their ability to help patients create meaning. For example, Julie told me,

If patients are really struggling with the “Why me?” and “What will happen to me?” questions and they have no faith of their own, I let them cling on to mine until they can find their own. Some of them never do, but I am glad I can help them in this way. I couldn’t if I wasn’t sure myself — if I hadn’t already found my own way.

Marie said that the patients often found meaning in their disease by first considering it part of their destiny, “God’s plan for them.” As Lana commented, “Once they accept it, they can start to see the glimmer of good in the devastation around their worlds.” Jane said, “Acceptance of their situation lets them get back control so they can make sense of the chaos and disruption the illness can cause.”

SOARING TO NEW HEIGHTS

Past the bottom there is an end,
your wings will find their strength once more,
flight again will be your friend,
and onward, upward, you shall soar!

Treating patients with respect and helping them maintain dignity

Treating their patients with respect and helping them maintain dignity was another way these exceptional nurses showed their patients they were valued. The respect they have for their patients prompted their concern for maintenance of patient dignity. In many of the stories told, this concern underlay the nurses’ choices and actions. Frequently, the nurses were patient advocates in an attempt to provide the patients with quality of life as they defined it. As the following story illustrates, doing so can foster patient dignity.

He was only nineteen years old — far, far away from home and desperately in need of a bone marrow transplant. His home was in a small Native community in northern Canada. He was Native, and this was his first trip outside the area in which he lived. Naturally, I expected that my task would be to support him and prepare him for his trip to Toronto for his transplant. But the more time I spent with Ralph, the more I realized he did not

share those plans and hopes. Ralph always amazed me because he was insightful, spiritual, and truly at peace with his situation. He was also very alone, frightened, and intimidated by the hospital surroundings. A bone marrow transplant would mean more loneliness and a greater separation from his family and home. A transplant at this stage of his lengthy illness provided only limited hope for a prolongation of life.

Ralph confided in me that his only desire was to return home to be with his family, to experience a familiar sunset before he died. I knew in my heart this could be the only choice for him...Ralph was an inspiration to me. His decision was not popular with his physician who was disturbed by his "giving up," but Ralph never gave up on his decision.

I, along with my colleagues, were resolved that going home was the only correct plan for Ralph. We presented Ralph's position to the doctors, and defended it adamantly. The bone marrow transplant was cancelled.

Ralph never did return home, but died in room 72 surrounded by his mother, brothers, and sisters. He was at peace, and so was I. I truly missed him for some time after. The medical goals of cure and treatment may often be less important when we can clearly distinguish between quality and quantity of life.

LINKING RESPECT AND DIGNITY

Your body,
your right
to decide
its future.

My role,
to respect that right
and help you
maintain your dignity.

Patient dignity was also maintained through nursing actions that helped patients know that they were still important, that their lives still mattered. The following is an excerpt from a letter I wrote to one of the exceptional nurses documenting my observation of her in such a situation.

Dear Moria:

Today I watched in reverence as you cared for your patient. So gently you removed the mountain of bandages that covered what once was his back and buttocks. You respected his privacy by placing a tiny towel over his chest — the only part of his body that didn't need to be exposed during the procedure. I was moved by this symbolic gesture. You respected him; he was more than a patient to you — he was someone you cared about. The smells when you removed the dressings were so bad. I wanted to turn away, but you showed no sign that it bothered you at all. In fact, you moved closer — carrying on a cheerful conversation with him about his life, his work, his grandchildren. In doing these things, you maintained the dignity of a man who probably had only a thread of it left.

PRIVACY IN A VERY PUBLIC SPACE

Masterful creation
of the illusion of privacy
does wonders to protect the
last remaining grains
of pride and self-respect.

Often times, it was just the respectful ways that the nurses carried out their nursing tasks which communicated to the patients that they were important. The following field notes documented some of the little things the nurses did for the patients that I believe helped the patients to feel valued.

She takes an infinite amount of time with each patient. Mrs. Long asked to have her legs elevated. Moria makes minute adjustments to her leg positions until the patient indicates that the angle and the supporting pillows are perfectly positioned. Even after the sign of approval by the patient, Moria waits to make sure everything is satisfactory.

The attention to detail is remarkable. Warming the towels in the drier so they are cozy after a bath, warming the lotion in the microwave, warming the milk at bed time — all of these take time, but the actions seem to help the patients feel important, valued, more worthy. No request is too much for these nurses. In fact, the patients seldom need to ask. The nurses anticipate needs the patients don't even know they have. The patient is ringing her bell every few minutes. When the nurse I am watching answers her call, the patient's complaint is

that she can't find her bell. Later she rings again to tell the nurse she doesn't want to be disturbed. Each time, the nurse answers the summons with sincere interest and pleasant patience.

Peter said to me, "Helping patients to feel important can be as simple as knocking on their doors before entering their rooms or asking them what time they would like their baths." Marie concluded,

Making the patient feel like they are the most important person in the world, even if it is just for the moments you are with them, that should be our goal — that has been my goal. Patients are the priority. It's the little things that make a patient feel important, like the way you enter a room. I consciously slow down my pace as I enter. I take time to sit down in the patient's room and really listen to their concerns. I attend to their needs in short order, not waiting to be reminded. If possible, I anticipate their needs before they ask — like offering them an extra pillow or dealing with a red skin area. You just let them know that they still matter. Even if it is just for this moment, you matter.

The nurses I observed continued to show respect and maintain the dignity of their patients — even after they were deceased. In a field note I wrote,

As we enter the dead woman's room, the nurse dims the lights, and tiptoes across the floor to draw the curtains. She talks softly to the woman as she prepares her body for the morgue. In a very quiet voice, she bids the woman, her patient, goodbye.

The importance of showing respect and maintaining patient dignity is supported by Benner. She writes, “Almost no intervention will work if the nurse-patient relationship is not based on respect.”¹⁵⁸

Helping the patients find and maintain hope

By helping the patients find and maintain hope, the nurses caused the patients to feel they still mattered. The following untitled, anonymous poem, posted on the wall of the nursing unit where this study took place, is a concrete symbol of the importance of maintaining hope.

Cancer is so limited...
 It cannot cripple love,
 corrode faith,
 eat away peace,
 destroy confidence,
 kill friendship,
 shut out memories,
 silence courage,
 invade the soul,
 quench the spirit.

The greatest enemy is not the disease,
 but despair.

After reading this poem, Jane said, “If the patients see no hope — no possibilities for even their immediate future — they are left with despair. But it is part of my goal to help them see possibilities, and set goals that are attainable.”

Julie described some of the ways she helps patients realize and accept their limited potential without taking away their hope. She said,

First, you have to be honest with patients. People can take a “yes” or a “no” very easily as long as you are being straight with them. When someone is lying there dying, nauseated, and in pain, the last thing they want to hear is, “It’s going to be okay.” At that moment, it is not going to be okay, and that moment is a year long. Cut the crap.

If they say, “Am I dying?”, you say, “Yes, you are dying.” They are so content with that because someone is telling them the truth. You say to them, “I’m not going to lie to you.” Lying to patients destroys their hope. It lets them down. If you lie to them and tell them they will be able to do something and then they can’t, they won’t chance hoping again.

If they say to you, “Will I be able to walk?” and they won’t, say, “No — but let’s try sitting up in a chair.” If they ask you, “Can I go home again?” and they can’t, say, “Probably not but let’s try a pass for two hours or maybe you can just get out of your room.” Just give them something. We don’t have the right to destroy their hope. I never promise my patients something I can’t deliver.

SEEING POTENTIAL

Your body has been cruel to you,
harnessing you,
limiting your possibilities.
I am here to free your shackles
and set your spirit soaring,
just by helping you see your choices.

Hope is a belief that something good lies ahead. It is not denying reality. Realistic hope can help the dying person face reality, while it also gives strength to go on living. Jane said, “I think giving patients hope is important. I used to think that being cheerful was a way of giving hope, but now I know it is helping them find courage.”

INFECTIOUS HOPE

Hope.
It cannot be taught,
or bought,
but can it be caught?

In this story, Maureen described how she used her nursing skills to help her patient maintain hope.

This patient was in a lot of pain. We had given her breakthrough medication, but it didn't work and she was crying out. The nurse who was assigned to her was upset and didn't know what to do. She asked me for help, so I went into the room and calmly said, “We are going to try something different.” I didn't have a plan when I walked in or even when I said we were going to try something different; I just knew we had to give her some hope.

First, I tried visualization — a Hawaiian beach; that didn't work. So I went into muscle relaxation and, sure enough, it worked — probably because the analgesic had kicked in by then, too. But the distractions of trying these alternatives kept her mind off her pain and let her know we were not going to give up on controlling her pain.

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HOPE IS TO LIFE

Hope.
Without it what is life?
Bleak,
onerous,
hopeless?

Hope.
With it what is life?
Lively,
promising,
possible?

—

In commenting about hope, Lana said,

It is probably the greatest need our patients have. Those without hope just give up and lead a poor quality of life. Those with hope have power over their disease and live a good life until they die. The only problem is, hope is difficult or maybe impossible to dispense because it is a quality of the spirit.

One of my field notes reads,

It seems strange to write about death and hope in the same sentence, but where would the dying be without hope? Those who can't find it collapse inwardly and die before they are dead. Those who somehow discover or choose hope have the elusive quality of life the nurses I'm watching desire for their patients.

On the importance of hope for the dying patient, McHutchion writes,

The hope for the miracle of cure becomes hope for a miracle of care. Patients and families believe that when pain and symptoms of the disease and side effects from treatments and medications are controlled, the patient and family caregiver are freed to live toward a good death.¹⁵⁹

In another journal entry, I recorded an encounter where a dying man was helped to find the strength to continue hoping for the miracle of care.

A physician approached the nurse I was watching and asked her to come take a look at Mr. Bill Selsby. Entering the room, we find a man lying in bed — silent, and staring at the wall, his eyes fixed. The doctor concludes that the patient is close to death and that the diagnostic test scheduled for Mr. Selsby that day should be cancelled.

After the physician leaves, the nurse does her own assessment of the patient. She goes close to him and studies him very intensely. Placing her hand on his forehead she says, “Bill, are you sad? Are you sad because today is your birthday?” She stays in this pose for a few minutes — waiting for a response, a signal, a clue from the patient. I see nothing. She sees what she needs to see.

Leaving the room, the nurse walks up to the doctor and says, “I think you are wrong about Mr. Selsby — his eyes are reacting. He is not dying; he is just down and depressed.”

During the day as we visit Bill’s room, he becomes more and more responsive. The nurse talks to him about his life — asking him questions about his children and his

birthday wishes. At first he doesn't say much, but eventually he begins to talk.

Just before change of shift, the nurse gathers her colleagues together to help her surprise Bill with a cake. Together they sing the most rousing and sincere happy birthday song I have ever heard. The man who was supposedly taking his last breath cuts the cake and eats a piece with his tea, which the nurse had carefully steeped to his liking and served to him in a china cup.

In a final demonstration of caring, she places a birthday kiss on Bill's forehead — setting an example for the other nurses, who follow her lead. As we leave the room and bid Bill a happy evening, I see the sparkle of life that has returned to those eyes. Bill has hope.

—

HAPPY BIRTHDAY

“Happy birthday to you.

Happy birthday to you.”

You sing with enthusiasm.

You sing with warmth.

You sing in unison.

In the lines

between your words

you sing this message...

Bill, you may not have many

more birthdays,

but let's just celebrate

this incredibly important birthday moment,

and the hope that it brings.

—

AFFIRMING THE VALUE OF THE NURSE

As the patient is affirmed by the nurse's actions and their interactions, the nurse is also affirmed. From the observations and the comments of the nurses, this seems to happen in two major ways. First, the nurses come to know that they are making a difference in the lives of their patients or their patients' families. Second, like the patients, the nurses also find meaning in their experiences.

Human beings need to feel they are important. One way that they do this is by helping or adding happiness to other human beings. The exemplary nurses often commented that they found their work rewarding — in part because, through their work, they were able to make a difference in the lives of others. When asked to elaborate on their feelings about their work, participating nurses made the following comments:

A lot of nursing is doing for others. When I do something for my patient and it is successful, I feel valued — like what I do is constructive, and I am worthy. It's a great feeling.

I just know that almost every day when I come to work I am going to change somebody's life. It's an awesome power. I take it really seriously. These people with cancer, they are so vulnerable, so needy. I am privileged to be part of their lives at this time when they need me so much. I always feel needed by my patients — and when I can meet their needs, it really makes me happy.

The most rewarding thing for me is taking patients from situations where they are in a lot of distress, or confused and cognitively impaired, and doing a few simple measures that help them to be alert so they can talk to their

families and be comfortable...It is so satisfying to give them some quality back to their lives.

The rewards are the little things — seeing individuals come back when they have been through a long journey and seeing them triumph. It's a real joy to share that with them. Even if the patient has died, to have the family members come to you and greet you like you were a real special part of their lives is a great feeling. I think of few careers where you can interact with people so closely and feel so helpful to someone, and I feel I really make a difference. It is important to me that what I do is worthwhile.

—

TO BE VALUED

I am so alone,
my companions likewise.

But, if I can be vital to but one other,
even for a moment,
I increase my own happiness
by at least one hundred fold.

—

Maureen told me a story about making a difference in a family's life. She said,

This is a story about a young couple. He was diagnosed with colon cancer, and he was only 32 years old. He had two children and so did I. He was really withdrawn all the time and the only thing that could get to him was humour, so I used to joke with him and that would get him talking a little. He was in excruciating pain, but he didn't stop doing the things he

loved — like driving his tractor. His wife and I really hit it off; we had a lot in common. She would call me about his pain and other things. One day she called. He was really in trouble, so we asked her to bring him to the hospital.

When he got here, I could see he was near death. He was confused, dehydrated, atrophied. I took his wife aside and talked with her. I told her exactly what I was seeing. I said that I noticed a big change in him since the last time I saw him. I didn't have to tell her that he was dying; she already knew. She told me that it was important to him to die at home, so I set about arranging things, medications, home care — all the things they needed to make it possible, and we sent them home. He died the next day.

It was an extraordinary time for me because I really felt like I made a difference in their lives. They were important to me — not because they taught me a whole lot, but because they made a difference in my life, too.

Julie wrote a story about feeling like she made a difference in a patient's life with a very small, but authentic, gesture of caring.

There's the time I was "out for coffee" (I don't even drink coffee) with the wife of a former patient. Meeting me again was difficult for her as I represented a very sad time in her life. I had shared the approach to, and death of, her husband. They had obviously shared a special, loving relationship. She wanted to talk with me again, but it was not without a flood of memories. While we drank our coffee, she described to me a moment that the

three of us had shared, to which she had often returned during her bereavement. This is the moment.

One time on my perpetual medication rounds, I entered her husband's room. I found her and her husband both asleep. He was lying on his bed. She had her head on his chest, and he had his fingers interlaced in her hair. It was a peaceful and loving sight. I could not interrupt, so I simply wrote them a note on the first scrap of paper I could find — a little, yellow sticky. The note said, "Was here — please call when you're awake. You looked so peaceful, just couldn't interrupt. Your Med. Nurse."

Much to my surprise, she had kept the note. She pulled it from her purse that day. It was dog-eared and tattered, but she still had it! Her husband had a huge funeral. There were probably hundreds of Hallmark cards. It had been more than a year ago. She had travelled, she was doing well, but she had saved this little seemingly insignificant yellow sticky note. It was a reminder to me that, yes, we all may secretly wish for fame and fortune — the big things are so obvious — but it's the little things that really do make a difference. My little thing had made a big difference to her. I felt so good.

When I asked about the most satisfying aspect of her job, Marie told me this story.

Last week, a patient's wife came in and wanted to talk to me about her husband's passing. Weeks earlier when I was his nurse, I felt like I was one of her family, and it was a really rewarding time though there were a lot of difficult moments. Now, after his death, she was

reaching out to me again. There were many people she could have chosen to reach out to, including family members, but she chose me.

The display of thank-you cards on the nursing unit is another concrete acknowledgement of the difference the nurses make in patients' lives. During visits to their homes, some of the nurses showed me personal cards, tokens, letters, and poems they had received from their patients. These were prized symbols of the difference they had made in the lives of others — stored over the years, kept with a sense of sacredness. The following are excerpts from these messages sent to the exceptionally competent nurses.

My grandmother's life ended with dignity and self-respect. By giving this gift to her, not only was her death respectable, but her life (to the end) was surrounded with love.

What comfort and peace you brought to my Mother.
I will never forget you.

Once in a while you meet someone who is really special.
You are my special angel.

As I think back over all that we have been through together, I realize that I couldn't have done it without you. I am eternally grateful.

THE MIRACLE CIRCLE

Sometimes,
when I think about
the vastness and complexity of the world,
I am overwhelmed.
I feel so unimportant,
so insignificant.

Then,
I meet you,
and with a small gesture, lovingly given,
I make you feel valued.

The result is a miracle,
when you feel important,
so do I.

It's so simple.
It's so profound.

Finding meaning in the experience

As the nurses found meaning in their own experiences with caring for cancer patients, they came to feel valued. Like the patients, the nurses struggled to find this meaning. Making a positive difference in the lives of their patients and the patients' families is one of the ways the nurses found meaning. However, they did tell me of other ways this meaning was realized.

Exceptional nurses value continued personal and professional learning. They seek challenges that facilitate this goal, and their work provides these challenges. For many of the nurses, having this opportunity for ongoing enhancement was a part of finding meaning in their work. As Jane said, "Everyday, I learn something new about cancer, or about caring, or about me." This finding was reflected in other comments.

When I first started here, I planned to stay maybe a year — but now it is two years later, and I am still here. When I ask myself why, I realize it is because I still have a lot to learn here.

I just can't imagine a job where you know it all — where you could do everything perfectly all the time. This work is so demanding, so challenging, so dynamic that knowing it all would never happen. That's good. That's the way I like it. That's why I stay.

I really enjoy the opportunity to continue to learn. I go to cancer conferences and come back inspired, proud of what I do, and full of new ideas. I read journals and I'm happy to have the chance to try out the new ideas with my patients.

We can still keep on learning. Even if you have learned the lesson once, you still have to be reminded from time to time. That's the beauty of this job. You never, never stop [learning].

—

CHALLENGE SEEKERS

You only become greater
if you are first confronted with
not knowing how.

In your wisdom you recognize this,
and seek
and welcome
the obstacle of challenge.

—

The exceptional nurses recognized that they were not perfect nurses or perfect people — that they were not finished their journeys. They suggested that they did not ever expect that they would achieve perfection, although they enjoyed working toward that unattainable possibility. The result was a yearning for continued learning and growth. In a letter to Peter I wrote,

I am impressed with your interest in continuing to learn, developing your nursing abilities along with your personal qualities and philosophies. One important point that you helped me to bring to light is that exceptionally competent nurses are not perfect. I think most people equate exceptional with infallible, but that isn't true for any of the nurses I observed. What is true is that exceptional nurses are self-aware, they know their own limitations and their strengths and they adjust their practice accordingly. In addition, they have a desire for life-long learning. I believe this may demonstrate a level of maturity that only rare people reach.

Beyond seeking and overcoming challenges, there were other ways that the nurses I studied found meaning in their experience. For example, Jane described how helping the patients create meaning from their experiences actually helped her create meaning from her experience. She said,

Working here, I have come to grips with a lot of the heavy issues — you know, life, death, religion, love, family. You have to help the patients with these issues first, but when you do, you can't help also working through the same issues in your own life. It just happens sort of naturally.

As we discussed it further, she began to debate in her mind which comes first. She said,

I'm not sure if you deal with your own issues first to prepare you to help your patients, or if being confronted with their issues forces you to quickly determine what life is all about. Maybe you go back and forth; you do a little work on your own, and then you help your patients, and then it's back to you. Yes, I think that's it — I work on it with the patients. Confronting their issues with them forces me to face my own circumstances.

In addition, many of the nurses suggested that they found it necessary to find meaning in their lives outside of work in order to find meaning in their work. Again, this was a simultaneous process — working on discovering meaning in all parts of their lives at the same time. However, the agreement was that they found the searches mutually supportive.

FOG LIFTED

What a vague idea,
the search for meaning.
Yet, once found,
it becomes crystal clear.

JOINT TRANSCENDENCE: LIVING THE EXTRAORDINARY

In writing about transcendence, O'Banion and O'Connell suggest, "Transcendence changes things, the past, the present, and the future. Once transcendence occurs there is no retreating. It is more than the ordinary."¹⁶⁰ Watson is more specific in her description of transcendence, placing her discussion within the context of the nurse-patient relationship. She says,

When both care provider and care receiver are co-participants in caring, the release can potentiate self-healing and harmony in both. The release can allow the one who is cared for to be the one who cares, through the reflection of the human condition that in turn nourishes the humanness of the care provider. In such connectedness they are both capable of transcending self, time and space. Neither stands above the other.¹⁶¹

In an earlier work, Watson writes about “transpersonal caring,” a situation in which “both the nurse and patient are changed by the actual caring event.”¹⁶² She describes this situation as having a “field of its own that is greater than the occasion itself and which allows for the presence of the spirit.”¹⁶³ To expand further, Watson suggests that when both the patient and the nurse are fully present in the moment there is a feeling of union with the other. In her words, “the event expands the limits of openness and has the ability to expand human capacities.”¹⁶⁴

In some ways, all of the narratives and observations described in this book illustrate a part of this effect of exceptional nursing practice I have called joint transcendence, or what Watson describes as transpersonal caring.¹⁶⁵ Yet, no one story or observed moment illustrates it completely. O’Banion and O’Connell describe the difficulty encountered when one attempts to write about transcendence. They conclude that transcendence “is an experience so far beyond the ordinary...how can we speak of it in everyday words? Of course we cannot.”¹⁶⁶

In following their advice, I have decided to use few words to describe this core concept. Instead, the poem “Shared Journey” attempts to distill from the collection of stories and observations what is meant by joint transcendence.

SHARED JOURNEY

Together,
nurse and patient
rise above the pain,
suffering,
and despair
of cancer,
and climb to the top of the mountain that
has no summit.

They take turns
carrying one another.
For they know that neither
can make it alone.

In their time together,
they share through touch,
silence,
and lightheartedness.

In their time together,
they learn about themselves,
their needs,
their strengths,
their limitations.

But most important of all
they learn about their similarities.

They both share the common fate
of mortality,
an understanding which makes
the pleasures of life more intense.

They both possess the potential

for knowing joy,
awe,
and wonder.

They both can understand
that though the physical body
may be diseased,
disfigured,
distasteful,
the spiritual body can be healthy,
beautiful,
and whole.

Through the intimacy of their
relationship they discover
they are valued,
they are worthwhile,
that they can,
and do,
make a difference.
Each, in their own way,
creates meaning out of their experience.

As they reach
higher and higher planes
the patient may leave
to take up challenges elsewhere,
while the nurse,
having gained strength
from the journey
is able to carry on.
