The spirit of oncology nursing care

By Janice Post-White

Abstract

Cancer awakens the need to honour our spirit. The resiliency of the human spirit helps patients and families find strength and hope and move forward on their journey. As oncology nurses, we empower families by connecting with and sharing our own spirit, honouring and being present to their journey, and guiding them forward as they anticipate challenges ahead. Caring isn't about doing for, but being there and being the wind behind the sails. When we connect with our spirit, we stay open to the unfolding mystery of life. Allow mystery and discovery in your life to drive your spirit of caring and to remind you to look for the rainbows.

Note: This paper is an edited version of the opening ceremonies keynote address in Winnipeg at the 2002 CANO conference. Although many of the stories have been edited out, the author encourages readers to draw on their own rich and diverse stories revealed in daily clinical practice that exemplify the concepts of spirit, mystery, hope, and empowerment.

Addressing the spirit in oncology nursing care is a timely theme for me, as I spend six months in Hawaii reflecting on my research goals and direction, and the integration of my family's experience with cancer. Our son, Brennan, has been off treatment for acute lymphoblastic leukemia for two years. Living on a small, secluded Pacific island provides time and space to reflect, renew, and reconnect with one's spirit.

Each day, I marvel at the glorious view, consistently beautiful day after day, each day as beautiful as the day before. On Lanai, I watch patiently for the Spinner dolphins to make their occasional, but dramatic, appearance in Hulopoe Bay. The humpback whales are much more predictable as they migrate each season to the warm Hawaiian waters to have their pups. And just as the leaves are popping from the trees in the upper midwest and most of Canada, the garden spider predictably begins weaving his web through another seasonal cycle. The seasons in Hawaii are less dramatic. The subtleness requires you to pay attention.

There is predictability in each day. Each morning, as the sun rises above dormant island volcanoes, the birds chirp to their comrades as light infuses their world, and the waves crash along the volcanic shore. The tides are certain to come in and go out, twice a day, every day of the year, with the wave height predictably raising and lowering with the waxing and waning of the moon. And the stars proclaim their worldly view from far above the sleeping land. There is a certain comfort and security in predictability, a feeling that allows exploration, and energy for tending to the spirit. We watch and feel the biorhythm of the day – the rhythm of life. Taking time to reflect is certainly a luxury in today's busy world. But it is also a necessity.

Once you have lived the cancer experience, you see things a bit differently. Perhaps it is an awareness of the vulnerability of life, an enhanced appreciation for each day, or a more focused passion to your work. Nothing is taken for granted anymore. Your eyes see and your heart listens. But only if you stay connected to your spirit. By connecting with your spirit, you empower others to honour their own spirit and to stay open to the process and mystery in life. Renewing our spirit makes us more effective healers.

The uniqueness of how each individual responds to the experience of having cancer brings a sense of awe and wonder. The incredible dynamics of how they and their family transcend the cancer experience always brings me back to the resilience of the human spirit. It is the spirit in families that helps them readapt to a life with cancer and keeps them moving forward on their journey. Allow yourself the opportunity to just observe and appreciate how each spirit dances to the rhythm of the soul.

Renewing the spirit

Have you noticed how the search for spirituality rose in public consciousness at the turn of the millennium? In that transformational year, stories of the healing power of prayer and the search for meaning dominated the cover pages of popular magazines, and they continue to build momentum today. What is this search really about?

As oncology nurses, we have known all along that if two people have the apparent same disease (understanding that the disease is never identical in unique human beings), the person with greater inner strength, will, and motivation to overcome will most likely "do better" than the patient who apathetically goes through the motions of treatment or who has given up. It is the search for meaning that drives the spirit. And it is the spirit that gives life.

Having a life-threatening illness makes people think about who they are and what really matters to them. Some people are able to reset priorities and do things they have wanted to do, things that they have shoved aside all their life. Because of cancer, they are listening to their spirit. Instead of responding to the "shoulda, woulda, couldas" that come from the brain, they learn to respond to the "I want tos" that come from the heart. Cancer awakens the need to honour our spirit by being in touch with our heart.

Sometimes, the spirit isn't quite as obvious. Defensive coping in the angry, rebellious, and resentful adolescent with cancer is really the spirit trying to make sense of and understand the anger, fear, and hurt. It reflects an inner struggle for meaning. When patients stop trying to find meaning, they give up. How do we help someone search for and find meaning?

Some people connect to their spirit through nature, through solitude and long walks in the woods or along the ocean, or even in

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their own backyard, where the senses are consumed by nothing but the world around. Some find connections through people – through the energy of other human beings sharing the adventure of life. Everyone finds their own way to stay in touch with their spirit. Sometimes, we need reminders to stay connected with our own spirit. We may lose sight of the importance of being who we are, or perhaps we get so busy “doing” that we forget to stay in touch with “being”.

Sharing your spirit can renew the spirit within you. One day this summer, after finally learning how to ride the waves, I discovered the healing powers of the ocean. I wanted to share my experience with a family that is facing the inevitable progression of their five-year-old daughter's astrocytoma. I wanted them to feel the healing too. I had no idea if they would find meaning in what was meaningful to me. But I took the chance in sharing my spirit. This is what I wrote for them, 4,000 miles away:

I only wish you could be here now. Just floating chest deep in the turquoise blue ocean water is healing. Imagine allowing the surf and tide to lift you up in spirit over each sway and gently rock you in and out and carry your fears away with the waves of the world. Once you learn to let go, you accept the natural rhythm, and allow the ocean to massage your body and spirit.

As you float together as one, I imagine the other children laughing and giggling as they chase the waves (and the waves chase them!) up and down the shoreline and splash belly flop-style into the foamy remnants of surf. And you will remember past joys and delight in watching pleasure once again encompass your family. And just maybe, if the dolphins are playful, they will spin and frolic with you, celebrating life in all of its joy and spirit. I wish this for you, someday, when the time is right. Much love and aloha (bringing you love within).

It is hard to watch suffering. We want to take the hurt away. Cancer, at times, is lonely, uncertain, and terrifying. Through suffering, we discover what is most important and we find the courage to live according to it. We use our strength to make the changes we need to be consistent with our deepest values, our spirit. But it isn't always as easy as it sometimes appears.

In our study on hope (Post-White et al., 1996), we defined spirituality as “the search for meaning and existential purpose in life in relation to self, others, and a higher being” (p. 1572). At the time, I was a little skeptical about the chaplain's insistence that we include the relational component. Spirituality seemed like such an independent journey. But now I realize that feeling connected is an important component of spirituality. Sharing our spirit gives meaning and purpose. When you strengthen the life around you, you strengthen the life within you (Remen, 2000).

When I contemplate what spiritual connections mean for oncology nursing, it makes me wonder what happened to the spirit in the first place. Why do we need to get something back that should have been there all the time? Is it there and we just aren't paying attention to it, lost amidst budget cuts, short staffing, high acuity, and intense therapeutic protocols? Is our connection to our spirit gone, and we need reminders to find it and honour it? Whether it is missing or just not as evident today, spiritual connection is more than just caring for our patients. It is a deeper connection originating from the heart. It doesn't show up in the laboratory values on paper, x-rays, or treatment protocols. Spirit is evident only when we connect to the person. Its presence is known through the stories we hear.

How do we stay centred and connect with our own spirit, let alone with that of our patients? We listen. The same letters in

“listen” spell “silent.” And we reflect. Our spirit knows what is meaningful in our life. We just need to stay in touch with it. If you listen with your heart, you will hear. And, if you stay open to discovery, you will see. Meaning helps us to see in the dark as we watch the day dawn. It strengthens the will to live – each day in the journey of life.

Process and mystery

Although some aspects of life are predictable, life is filled with mystery. By honouring life as a process, we acknowledge our need to grow. And by acknowledging the mystery of each phase of our life, we listen to our spirit within.

Everyone sets goals in life. Reaching our goals is a process. Sometimes we reach our goals, and sometimes we don't. Sometimes we learn they aren't realistic, and we let them go. Once we achieve a particular goal, we celebrate and then we set new ones. We move forward, building on our experiences. Through this process, we understand better who we are and we learn about our spirit and what is meaningful to each of us.

The same is true for our patients. Goals don't stop when you have cancer, although they certainly seem to, especially at first. Goals may get redefined. Or perhaps put on hold. Or even let go. In the process of understanding what cancer means in life, some people learn that what they were striving for wasn't true to their spirit. And they learn to let it go, sometimes with great reticence, and sometimes with great relief.

Just as the process of reaching a goal provides insight, the process of having hope keeps one reaching forward. Hope resides in the process of searching for meaning, relying on self-determination and inner resources, accepting help from family, friends, and health care providers, living each day one at a time, and anticipating the future (Post-White et al., 1996). It isn't what you hope for (whatever goal you set), but the process of hoping that gives life. This is sometimes a hard concept to understand, particularly for those of us who are so focused on attaining the desired outcome!

But even an eight-year-old can grasp it. When I asked my son what hope meant to him, he replied, “That I know I can do it. That I believe in myself and know I can get through this.” With this perspective, he had the strength to overcome whatever he needed to, not just the goal of the moment. The process of believing gave him hope and strength to meet each day, whatever that day brought.

By valuing the process as much as the outcome, we learn to be present in the moment. When we live in the moment, we connect with our spirit and allow the process to unfold. By staying in the moment and focusing on his own response, my son learned a powerful message of being in control, while letting life evolve around him. He had the power to determine how he would respond. It isn't the event itself, but our response to it that determines how we will do.

Elizabeth Kubler-Ross introduced cancer as a process. She suggested patients with cancer go through phases – phases of denial, anger, bargaining, despair, and acceptance (Kubler-Ross, 1997). We recognize now that it isn't the same for everyone. It is a tool to help us understand the response to cancer as a process. Sometimes the process isn't evident until patients and families reflect back on the growth and can see where they have been. Reflecting provides insight and meaning.

Reflecting

As I was looking back over the pictures Brennan drew during his first year of treatment, I discovered his perspective, his process of making sense and getting through each day as a four-year-old with cancer. It helped me to appreciate his emotional expression and subconscious insight.

The first day in the hospital, he drew a picture of a little yellow bird captured in a house (Figure One). There were red and black spikes of fear and anger. Something was on the outside reaching in. There was a warning to stay away. Two days later, he drew another birdhouse. An arrow directed others how to enter. He slowly developed trust and allowed his caregivers in to help him. It was brightly coloured, and there were toys and lights – “to look pretty for Mom,” he had said. To protect Mom from the hurt and pain he was feeling, I thought. He drew a picture of a sailboat sailing amidst clouds, rain, and sun. Even a four-year-old somehow knew deep within that life had changed overnight.

Brennan learned of his strength as he moved on through that first year of induction, consolidation, delayed intensification 1 and 2, and finally into maintenance. He was attracted to the story of the headless horseman. After reading it repeatedly, he drew a picture of the headless horseman with a candle for his head, to help him find his way. I imagine that he felt empowered to find his own way through the darkest days. He drew pictures of his bones, where he envisioned a red heart and a black brain, for he knew a heart and brain were vital to life. And, in summer, when we had a reprieve from the intensity of treatment, he drew a single flower, growing tall and flourishing, surrounded by blue swirls, rain, and sun (Figure Two). In the midst of the chaos, there was sun and water and earth to nourish it. He had folded the picture in organized little rows like a fan, and handed it to me. “It’s for you,” he said. In the process of carefully unfolding the picture, I was once again giving life to the strength that lay within.

As he ended his first year of treatment, he moved on in his journey. He drew a lighthouse to guide his sailboat for him and his brother. It was the first time he included his younger brother in his pictures. He felt a new fire within as his energy began to return. He drew pictures of a house filled with flames, a bold red sun rising to a new day, and a soft pastel rainbow overhead of three flying grey birds. I started to see the process, his growth across time. From a bird captured and frightened to a bird soaring with life, he created his own rainbow to brighten his life after the storms. If a five-year-old with cancer can find

the rainbow, we all can find the rainbows in our life. We just have to remember to look for them. Being present to the process allows us to discover our strength. Being present is about allowing life to unfold, and being responsive to following our spirit when it calls out to us.

Reflecting on where we have been helps us to see where we are going. When we hurry to get somewhere, we miss the beauty and opportunities along the way. Rachel Naomi Remen (Remen, 2000) talks about mystery in her book, **My Grandfather’s Blessings**. She tells the story of her decision, against the advice of two architects, to design the entrance to the front door of her house not to be visible from the street, but to emerge along an obscure and winding path. She describes how you enter, by going through a gate, up a flight of stairs, over a landing, up more stairs, across a deck, and up a few more stairs just to see her front door. The door is not visible from the street or along the steep climb up. Along the way, however, one sees a magnificent tree, her well-tended rose garden, a breathtaking view of San Francisco Bay, and a magnificent mountain beyond her quaint little meadow backyard. In reflecting on her decision, she concluded, “knowing where we are going encourages us to stop seeing and hearing and allows us to fall asleep” (Remen, p. 289).

When we stop and reflect, we often see things in a different way. How many of us are asleep in our routine? Are we missing important messages in our daily life? In the process of discovery, we live in the moment and appreciate the mystery. If we can allow some mystery in our life, we can remain open to our spirit. When mystery ceases, hope is lost. Haven’t our patients taught us that?

Discovery

Serendipitous findings in research are examples of the importance of staying open to mystery and discovery. We set out with prescribed hypotheses of what we expect. We anticipate where we are going and what we hope to find. We design the study to test these effects, and we conclude yay or nay with a p value greater than or less than .05.

Figure One

Figure Two

We have been taught to see things as black and white, cause and effect, and to have answers to hypothesis-driven questions.

Sometimes in the process of trying to explain, however, we lose the spirit. We head off in a certain direction, expecting to see what we anticipate. In seeking one response, we miss seeing other, perhaps more important findings. Sometimes the real discovery lies in what we don't measure or in what we uncover along the way, not in what we set out to determine in the first place. Mystery sometimes requires that we relinquish our search for answers.

The field of psychoneuroimmunology embodies mystery and intrigue. For the past 20 years, scientists have attempted to uncover just what it is that connects our mind, body, and spirit. Descartes believed they were separate. But the miraculous stories of healing, the stories of survivors who beat the odds, the sense of wellness some individuals have despite rampant disease, all defy the logic of biologic processes. We know that the mind and body communicate via neurohormones and neuropeptide transmitters. We are finding that certain thought processes and emotions, such as anger and fear, signal immune responses, such as higher interferon gamma and lower IL-2 (Post-White et al., 2003). But the interactions are complex, with feedback loops and signals that "turn on" or up-regulate and signals that "turn off" or down-regulate. The more we learn, the more we realize we don't know. In our footsteps, we often create more questions than answers. Science contributes to clinical knowledge and expert practice. Each step along the way, we think we understand more. But knowing is much more than testing and analyzing.

Presence

Oftentimes patients and families don't need answers per se. They know there is uncertainty in cancer. But they do need reassurance and a listening ear to ease the fear of the unknown. Pam McGrath interviewed 12 Australian families of children with cancer (McGrath, 2002). These families reported stress of uncertainty, shock of diagnosis, and a feeling of being trapped in an unpleasant roller coaster. They said that what they needed was honesty from the health care team, an opportunity to share feelings in a safe environment away from the child, and affirmation of the harshness of the situation. They needed someone to "be with" them in their grief, to be there in spirit for them when they needed reassurance or a listening ear. Someone who understood how hard life was at the moment.

We found similar results when we asked adult patients with cancer how health care professionals gave them hope (Koopmeiners et al., 1997). They replied: by being there, listening, providing information, and caring. Oftentimes it isn't what we say or do, but our presence that counts. Our presence communicates our willingness to listen. Listening is a powerful tool for healing. Sometimes it's the simple things we do that make the greatest difference.

In a recent study (Post-White, Kinney, Bernsten, Savik, & Lerner, 2003), we tested whether the presence of a caring professional alone influenced emotional responses and physical symptoms in comparison to patients receiving massage or Healing Touch. In 230 adult patients with cancer, we found that presence wasn't any different from standard care (the control period). Massage and Healing Touch had significant immediate effects on blood pressure, heart rate, respiratory rate and pain, and had longer-term (four week) effects on anxiety, fatigue, mood disturbance and NSAID use (Post-White, Kinney et al., 2003). We concluded that our presence, in combination with our interventions, is more powerful than either one alone.

Empowerment

So what is it that we provide in addition to our presence that helps families on their journey of cancer? The most important thing we can do for families is to empower them to collect information, make decisions, mobilize resources, and direct their journey. We can also help them realize their inner strength and their connectedness to others along their journey.

When we empower, we foster resiliency. Resiliency is a sense of confidence and mastery, feelings of self-worth, and the ability to self-transcend the situation (Haase & Heiney, 1999). Resilience is a dynamic process. It builds on skills of adaptability, cohesion, and communication. Resilience is supported by coping that is confrontive and supportive, rather than exhibited by defensive or avoiding behaviours. It relies on the ability to find meaning and hope in a difficult situation.

How do we foster resiliency in individuals and families? Six months after Brennan's diagnosis, I drew the metaphor of cancer as a sailing journey (Post-White, 1998). I envisioned a sailboat, with the family hurriedly and uncertainly preparing for their journey ahead, being shoved away from shore with the necessity to quickly learn how to balance their load, recruit reliable team members, chart their direction to an uncertain destination, capture the wind in the sails, and keep afloat through stormy seas, all while centred on the journey ahead. Families also learn to celebrate the sunny days and to look for the rainbows following the storms.

It is intimidating taking the helm. It is a comfort for them knowing that we are with them every step of the way. Consistency is very important as they establish trust and connections. We empower them on their journey by being the wind behind their sails. A sailboat doesn't sail without a gentle and consistent wind. If you don't know how to be the wind, think about how it feels to be the tugboat, invariably pulling a load greater than yourself, dragging them forward in the direction *you* think they should be heading. Imagine now how that feels to the family you are tugging.

Then step back and imagine yourself as the wind, billowing the sails, gently moving the boat forward on its journey. The boat's sails have to be up, the patient and family ready. We accompany them on their journey, learning when to blow harder and when to quietly watch. We help them navigate unfamiliar waters by preparing them for the challenges ahead. Knowing that stormy seas disrupt smooth sailing, we learn to stay in touch with our spirit, so that we can better guide and respond to theirs. We celebrate sunny skies and offer encouragement on cloudy days. We are present to the individual cancer survivors and their resilient families who chart their new journey.

The spirit of caring is about empowerment. We can't solve the mystery for our families. They need to live it. Caring isn't about doing for, but being there and being the wind behind the sails. Just as a great teacher empowers students with motivation to learn, we serve, not by doing for others, but by helping families adjust their sails to catch the wind and sail forward. As a result, they will be better prepared to respond to the illness demands they will undoubtedly confront throughout their journey.

How do we help? All patients and family caregivers question their abilities at times. All caregivers wonder if they should be doing more, or they are overwhelmed with what they are already doing and feel guilty for not doing more. They need reassurance – genuine reassurance – that they are doing a good job. Sometimes we are too busy worrying about the job we are doing to reward them for the job they are doing. Families need to hear the words, "You are doing a great job!"

Families become experts and they become very resourceful at finding answers and direction. But caregiving is an incredible responsibility, one that is extremely draining of spirit and energy. Cancer is a family journey. The family is more visible in pediatric oncology, but it is equally important to acknowledge, coach, and support the caregivers in adult oncology.

I still recall the very first time I was asked, "And how is Mom doing?" It was eight months after Brennan's diagnosis. It was the first time I had been asked how I was. By asking how I was, this seemingly simple question empowered me to step back and evaluate just how I really was doing. It brought to my awareness that it was okay to think about me, and that it was important to do just that. It also validated

that my feelings were important too. Or maybe it was comforting just knowing someone cared enough to ask about me. Something that seems so simple can be so powerful.

We are better able to empower when we discover what each family's strengths and needs are. In McGrath's (2002) study, caregivers stated that health care providers' understanding of their needs was one of the most helpful factors in caring for family members with cancer. They also said it was helpful to have providers acknowledge the difficulty of the situation and to support them in whatever way they were coping. Families need reassurance, even if they aren't doing the expert job you think they should be doing.

Renewing your spirit

The American Hospital Association's number one response to the nursing shortage is to foster a meaningful work environment (American Hospital Association, 2002). Don't lose sight of what makes work meaningful to you. Maintain your spirit in the midst of the external health crises around you (see Table One). How we respond to the crises will determine how well we will do.

Imagine being Tiger Woods. He fascinates me. Yes, I admire his incredible strength and accuracy in hitting drives 300 yards on target. But more importantly, I admire his centred spirit, his calm response to incredible pressure, and his ability to stay in the moment and focus. How does he do it? With incredible training, determination, and spirit. Reflecting on this, he said, "I think people try to make things that are simple more complicated than they really are. To me, it's all about balance. I just try to keep everything as simple as possible and as balanced as possible" (Newport, 2002, p. 139).

Tiger makes golf look easy. Despite what many perceive, the game of golf is about relinquishing power and control and finding balance and rhythm in your swing. Perhaps life is also about relinquishing power and control and finding balance and rhythm in your life.

When we connect with our spirit, we stay open to the unfolding mystery of life. Mystery has the power to uncover awe, wonder, joy, and aliveness. People who wonder don't burn out (Remen, 2000). Allow mystery and discovery in your life to drive your spirit of caring.

Mystery is how our patients can hold out to the very end, hopeful of a miraculous breakthrough. When mystery ceases, hope is lost. Our patients have learned a new way of living. We can too. ♣

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Table One:

The Power of the Spirit

The power of the mind
The power of the spirit
Like the power of the ocean
Accepts no other truth
Than that which lies within.

The mind will sometimes try to override the spirit
And capture the heart
In order to make sense of life.
But the power of the mind
Speaks not through itself and its knowing
But in connection with the spirit.

It isn't when the mind talks that the spirit listens
As a child listens to a parent.
It is when the spirit talks
That the mind should be still
and listen.

Just when you get too comfortable
Too accepting of the way things are
The ocean waves crash to the shore
Pummelling their message
To remind you of the power within.

Our spirit cries out to be remembered.
In our quest for success, happiness and love
It isn't we who bring ourselves happiness.
When the connection to the spirit drifts
The harder we try to make it work
The more disillusioned we become.

It's not unlike a golf swing
The harder you try the more errant your aim.
In trying to force life to comply
We distance from our spirit.
Life is about staying centred and balanced
Connected to your spirit.

Discover the mystery in your spirit
And share it
Your gift is in the aloha you bring
That is where your power lies
The mystery of your unique spirit
Within.