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Healing conversations in the face of persistent or recurring cancer

By Carole Robinson

I am deeply honoured to have been chosen to speak in Helene Hudson's remembrance at this Fourteenth Annual CANO Conference. In my mind, it is particularly significant since we are in Winnipeg, Helene's hometown, and among those who were colleagues and friends. I have met with some of these women, and have had Helene's spirit brought to life through stories of her dedication to making a positive difference in the lives of patients living with cancer, her compassion, humour, and general zest for life. In her memory, I would like to begin our conversation about healing conversations in the face of persistent or recurring cancer.

Patients and families have long been clear that relationships with health care professionals are critical influences on their experience of health care and on how chronic illness is managed. It is also recognized that the transition from curative to palliative intent of treatment presents particular challenges to health care professionals in terms of communication. Thus, the shift in relationship that occurs at the transition between curative and palliative intent is often fraught with tension and risk that the patient and family will experience a sense of abandonment. We are asking families to shift their relationship with cancer and with us at the same time as we are encouraging continued hope and the ability to live well in spite of disease. In order to do this effectively, we need to call on knowledge and skills pertinent to family beliefs about cancer as a chronic illness, relationships between families and health care professionals, healing, communication, and emotional literacy.

This presentation will draw from research with families who manage chronic illness in ways that facilitate living well and ways that interfere with living well. Relational strategies for oncology nurses that draw forth healing conversations and support families living well with persistent or recurrent cancer will be highlighted.

What is healing? Rachel Remen (1996), physician, counsellor, and author, believes that healing is our innately human impulse to move towards wholeness. She characterizes healing as a life force that draws us toward continually becoming more of who we truly are, in our own unique way. Healing brings us closer and closer to our heart's desire (LeShan, 1994). LeShan's work with patients who have cancer helps us to understand that the diagnosis of cancer can be a powerful invitation to actively engage in the healing process by mobilizing for life rather than simply survival (see also Remen, 1996).

Helene Hudson - 1945-1993

How is it that conversations can enable and support the possibility of healing? You will remember the nursery rhyme: "Sticks and stones may break my bones but words will never hurt me." Think about this for a moment with me. Have you ever had the experience of words leaping from your mouth, followed immediately by a sense of horror and the wish that you could scoop them up and eat them? All this accompanied by a prickle of cold sweat and a churning in the pit of your stomach. Perhaps this has never happened to you, but it happens regularly to me. In talking with patients about their experience of receiving a cancer diagnosis, the memories and body sensations are vivid even years later. Words can hurt even more deeply than sticks and stones. As Robert Fulghum learned in kindergarten, "Sticks and stones may break our bones, but words will break our hearts." Words can change us, right down to our cells (Maturana & Varela, 1992).

Words are the currency of our relationships. Just as a conversation has the potential to wreak havoc, it also has the potential to generate healing, which always occurs from the inside out. In the context of our therapeutic relationships, aimed at alleviating suffering, words are strong medicine. Sigmund Freud said, "Words were originally magic." In my experience, this remains true. Chilean biologists Maturana and Varela (1992) who have studied the biology of cognition – that is, how we know what we know – assert that we exist as humans only in the social domain of language. "It is in language that the self, the *I*, arises as a social singularity" (p. 231).

Today, we will explore the nature of conversations that invite healing when families are faced with persistent or recurrent cancer. Why should we be concerned about this particular time in a patient's and family's life? The point at which curative treatment fails or cancer recurs marks a major transition point for families. The door that was open to the possibility of cancer leaving is closed and the valley of the shadow of death defines the landscape of life, with cancer being a constant companion. Chronic disease requires something different of families than disease that will or might get better and go away. This is what families have taught me about living well with chronic illness, a process that I have come to call "The Healing Process of Moving On" (Robinson, 1998a) (Figure One). Families have helped me understand that both living well and living not so well with chronic disease are mostly about relationships. The important relationships centre on relationships with the disease, relationships between family members, and relationships between the family and health care professionals.

The "Healing Process of Moving On" is comprised of five interconnected phases that families revisit again and again over time as the chronic condition changes or responses to the condition change.

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The five phases are: The Fight, Accepting, Living With the Chronic Condition, Sharing the Experience, and Reconstructing Life (Figure One). Despite the fact that the phases are interconnected, each influencing the others, there is a sequence to the cycle.

The cycle begins with a fight. This is the beginning of the story and the beginning of the family's relationship with chronic illness. It is also a place that the family returns to again and again as things change over time. Sometimes it is the chronic disease that changes, placing new demands on the family. At other times it is a physical, emotional, cognitive, or spiritual response that changes and draws forth new demands. Even though one family member is diagnosed with the chronic illness, all family members have a relationship with the disease. In this way, chronic illness becomes a family member who influences the life of every other family member.

In the beginning, the family's relationship with the chronic illness is adversarial. The illness is an unwelcome intruder and space is closed for it. The fight is on. Families talk about two dominant elements to the fight – the fight for self, and the fight for life. The disease is experienced as threatening the “self” of the person diagnosed, and as threatening family life. Thus, there is both a scramble and a struggle for control, which involves pushing, ignoring the disease, carrying on, and waiting for it to be over, or for doctors to make it better. However, rather than gaining control over the situation, families report that life feels out of control and dominated by illness. The families resist getting to know the unwelcome intruder and, thus, the illness remains a virtually “unknown entity” that acts unpredictably causing pain and suffering. Fears of “giving up” or “giving in” to the disease constrain movement since giving the illness any ground constitutes making space for the enemy. Thus, there is often a desperate “hanging on” to hopes for regaining the life that was.

Frank's (1991) personal account of his experiences with a heart attack and with testicular cancer offers insights into why fighting is not effective over time when it becomes necessary to live with illness. He proposes that fighting separates oneself from the illness or condition, which results in splitting the body into two warring camps. The aggression involved in the fight is misplaced energy toward the self and, thus, is the antithesis of healing. “Thinking of tumours as enemies and the body as a battlefield is not a gentle attitude toward oneself, and ill persons have only enough energy for gentleness” (p. 85). As Remen (1996) emphasizes, it is important for ill persons to know that their bodies are on their side.

However, as Michael Kearney (1996), a palliative physician who illuminates healing possibilities in the dying process, asserts, struggle is essential to the process of living and dying with cancer. Courageous struggle that brings one to the edge of strength, to the edge of all possibilities, and to the edge of one's mortal wound, brings us to the place where choice is present (Kearney, 1996). It is a liminal experience that opens a doorway to transformation (Bolen, 1996). This is often where we meet patients and their families, embroiled in the fight. As outside observers, we often inaccurately label what we see as denial. These families did not deny the existence of sickness; they denied the disease space.

In order to live well, there is an inevitable movement toward acceptance. A choice is made to turn to face what has been struggled against (Kearney, 1996). This involves making some space for the cancer as part of the self and as part of family life. Like all of the phases, this is a process within a process and, thus, happens over time.

Finding some measure of acceptance that “life is different” and “I am different” enables living with the chronic condition rather than against it, as happens in the fight. This brings us to the third facet of managing well. Living *with* the chronic illness involves, to some degree, a peaceful co-existence of the family and the illness. This phase is a continuing, recursive process of figuring out how to do life with a chronic condition that hinges on making hard choices about “letting go of what does not count” and “hanging on to what is essential to one's sense of self and family.” Frank (1991) captured this eloquently, “As soon as I gave up fighting myself and let my body change according to its wisdom – with some additional direction from surgery and chemotherapy – I felt far more peaceful. There was no fight, only the possibility of change” (p. 85). Thus, in this part of the story, families shift from an adversarial relationship with illness toward a more negotiated relationship.

Sharing the experience of life with a chronic illness was the fourth facet of managing well. Most important for the primary caregivers, who were usually women, is having someone to count on (Robinson, 1998b). This “someone” offers unequivocal support and companionship, sharing the heavy emotional load and offering helpful help in the difficult journey of living with cancer. Having a sense of being emotionally accompanied is critical to managing well through undeniably tough times.

Reconstructing life occurs when there is enough comfort between the illness and the family such that life moves into the foreground and the cancer moves into the background of everyday existence. As can be seen in the schematic depicting the process (Figure One), the cycle reoccurs over time and enables healing, which we have defined as the movement toward wholeness (Remen, 1996). The cycle revolves around “making hard choices,” which has to do with letting go of what does not count in the new life of living with cancer, hanging on to what is essential to newly refined relationships, and picking up novel ways of doing life with cancer.

This is the story of families' changing relationships with chronic illness and what it looks like to live well. We have the plot for a success story that can guide our understanding and participation; for, families tell me, we are significant influences to the unfolding story. Hearing the words that curative treatment has failed, or that cancer has returned, demands a change in relationship with illness. The news will likely bring the family back to the fight, even if only briefly. For those families who have experienced illness as temporary, the news may propel them into the process of living the story of life with *chronic* illness for the first time. For all, fears for

Figure One

the person with cancer and for family life rise up as, stunningly, life takes another turn that cannot be stopped and the kaleidoscope shifts.

Thus, at the same time as the sick person's relationship with his or her body changes, the family relationship with illness changes, and the relationships between family members and health care professionals change. Families have taught me that not only does the family life story shift when illness becomes a long-term member, but relationships with helping professionals are mediated by different expectations. While cure is a possibility, the expectations of patients, family members, and professionals tend to be aligned without a great deal of communication effort. All the participants are aimed toward cure. Patients and their families will often endure whatever it takes when seeking cure. However, when cure is no longer a possibility, expectations change and are not so easily aligned. The desired outcome of care will be a life worth living in spite of cancer. What constitutes a life worth living? Only the patient and family will know this, as it will be based on unique beliefs, dreams, and aspirations that can only be communicated through conversation. Sometimes the best treatment for cancer from the medical perspective is not the best intervention for a life worth living from the patient and family perspective. Thus, we move into territory where differences in perspective are common and health care relationships demand a shift in orientation.

I would like to offer you a map of relationship possibilities when patients and families are living with chronic illness (Thorne & Robinson, 1988, 1989). When families first engage with the health care system, they come to us in a position of naive trust. They have complete faith in the system based on the assumption of shared perspective and understanding with their health care professionals. This means families believe we know what is in their sick member's best interest and will act accordingly to make them well. Naive trust is characterized by passivity and expectancy. The pivotal belief is that if they trust completely and absolutely, all will be well. The family waits patiently for us to make things better and, in the case of acute sickness, this usually comes to pass. However, when illness is chronic, there is an inevitable shattering of trust.

This leads to the stage of disenchantment. Families find themselves in an intensely vulnerable position of needing care but being without trust, feeling that the sick family member is at risk in the system. Family members describe being confused, frustrated, angry, self-doubting, and hyper-vigilant. Anxiety, hopelessness, and despair run rampant. It is at this time that we see behaviours which we may describe as "interfering" and "out-of-control." However, knowing that continued care is necessary, there is a desperate need to trust someone.

The need to re-establish some measure of trust propels the family into the stage of guarded alliance. Here, there is a shift in the family's sense of responsibility. No longer do they believe that health care professionals will know what is in the patient's best interest. Family members understand that they must take an active role in ensuring care that meets patient and family needs. The family selectively reconstructs a measure of trust in particular health care professionals that both recognizes and acknowledges limitations in the health care system. This reconstructed trust is conditional. It must be earned and nurtured. There are four "faces" to guarded alliance that are organized around dimensions of trust (Figure Two). The two dimensions of trust are: trust in the health care professional (vertical dimension), and trust in one's own ability to manage the illness (horizontal dimension). Four relationship possibilities arise that offer us clues about what is expected of us as critical participants in the story of living life with cancer (Figure Three).

As you can see, when trust in the health care professional is high but trust in one's own competence to manage the illness is low, the preferred relationship is "hero worship." Here the chosen hero is placed on a pedestal (a very precarious position) and management or treatment decisions are in the hands of this professional who is the headliner in the story.

When trust in both health care professionals and in one's own competence is low, this leads to a place of resignation and withdrawal from relationships. Instead, the body is submitted for necessary care only; however, there is no real expectation of receiving effective help. Health care professionals become a "necessary evil" in the story line.

Consumerism is the orientation when trust in one's own competence to manage is high; while trust in health care professionals is low. Patients and family members take on the

Figure Two

The "faces" of guarded alliance

- Two dimensions of trust

- ❖ trust in the health care professional
- ❖ trust in one's own ability to manage

Figure Three

The "faces" of guarded alliance

responsibility of making decisions and seek professional input as necessary. Here the patient and family take starring roles while we become members of the supporting cast or are relegated to cameo appearances.

Finally, there is team playing, which occurs when trust is high in both the health care professional and in one's own competence. In this relationship there is a negotiated partnership between the family and health care professional that acknowledges all participants' strengths and limitations. Thus, patients, family members, and health care professionals share star billing in the story.

All of these kinds of relationships have a place in the story of managing life with cancer. The patient and family members may have different kinds of relationships with different professionals at the same time or over time. From the family perspective, team playing is often the most desirable relationship type; however, it requires a health care professional who is willing to share responsibility, which is sometimes difficult to find. In terms of living well, what matters most seems to be the shift toward high trust in one's own competence.

We have talked about the marked disruption that occurs when curative treatment fails or cancer recurs. The story of living with cancer shifts to the fight. Trust in relationships with health care professionals can be shaken; as can trust in one's own competency to manage the problems that chronic, life-threatening illness brings. So the question for us to consider becomes, "How can we participate in the evolving story in a way that alleviates suffering and nurtures healing?" Again, families have taught me what it means to be helpful.

Healing conversations occur within the sacred space of a therapeutic relationship, where the other is held with love. When love defines our relationships, one opens space for the existence of the other beside oneself (Maturana & Varela, 1992). The other is both acceptable and whole at the same time, which is rather a unique occurrence when the prevailing pattern is to edit ourselves in everyday life and surrender our wholeness for acceptance (Bolen, 1996; Remen, 1996). "It is as rare to find someone who loves us as we are as it is to find someone who loves themselves whole" (Remen, p. 35).

Healing conversations require us to show up, in our entirety, in the moment, guided by a desire to relieve suffering. As Rachel Remen (1993) reminds us:

The worst thing that happens in life is not death. The worst thing would be to miss it. A friend of mine says all spiritual paths have four steps: show up, pay attention, tell the truth, and don't be attached to the results. I think the great danger in life is not showing up (p. 351).

I believe that when we show up, we enable those we care for to show up as well. Families have told me that showing up in a way which invites healing involves participating in conversations as a curious listener, compassionate stranger, nonjudgmental collaborator, and as a mirror for family strengths (Robinson, 1996).

Stories require listeners and the listening that is called for is "deep listening" (Frank, 1998; Stein, 1998). When we listen deeply, it is with a quality of attention that hears both what is spoken and what is beneath. Speaking out loud enables the storyteller to access the wisdom of inner experience, which, in turn, weaves intimate connection with life. This alone may invite seeing things in a new way that opens possibilities and supports life-nourishing choices. We participate through patient, still, attentiveness seasoned by the judicious use of "good" questions that arise from unquenched curiosity. Thus, we are curious listeners to the tale. Our "good" questions are those that invite a reflection – a process of knowing how we know (Maturana & Varela, 1992). It is an act of turning back on ourselves, which

allows us to become aware of that part of ourselves we cannot see in any other way. This is a special moment because we are not keyed to reflection in our society, but to action. We tend to approach our knowing as "fact." What we say reflects what we live. By seeing what we live, there is an opportunity to see that which no longer fits and let it go.

We need to be curious about such things as the meanings associated with illness and symptoms, for example, the meaning of pain. Is this a pain that can be helped with medication or is this another kind of pain? In my experience, some of the most helpful questions are difference questions (Wright & Leahey, 1994). These questions ask the teller to draw a distinction about what is most important to the story at the moment. Who is suffering the most? What are your ideas about the best way to treat your illness? What would you most like to be doing these days? From the family perspective, it is more important to have helpful questions than right answers.

We are also helpful as compassionate strangers, mastering the steps of the dynamic dance between connection and distance. Compassion means feeling for another's sorrow or suffering, which leads to the deep desire to relieve the other's suffering. To be compassionate involves the intertwining of feeling and doing. Compassion draws us close enough to witness and honour suffering. This in itself may be helpful, for "when we know someone recognizes our pain, we can let go of it" (Frank, 1991, p. 104). Empathic communication is our most powerful therapeutic tool to give evidence to the patient that we have heard and understood their emotional experience (Platt & Platt, 2001). "To feel heard and understood is perhaps the most precious gift in life" (Stein, 1998, p. 215). It is what comes of listening deeply with a compassionate heart.

It is important to be touched by a family's suffering and, at the same time, to remain part of the solution, not part of the problem. Thus, at the same time as we are drawn close, we are able to maintain distance from the story by virtue of being outsiders or strangers. This enables us to see old difficulties or concerns with new eyes, which opens space for offering new solutions. Our outsider status creates a safe haven for conversations. Family members can be fully present to their own stories without the editing that occurs when the teller is afraid of overburdening the listener. Further, we can be on everyone's side when inevitable differences of opinion arise.

The third element to our participation in healing conversations is as nonjudgmental collaborators. When families are intimate with the health care system, they become sensitized to being judged, blamed, and criticized. These actions all close space for healing conversations since love is squeezed out. Further, there is worry that negative judgments will have negative implications for care. It is important to understand that judgments are sharp sticks that wound. "The life in us is diminished by judgment far more frequently than by disease" (Remen, 1996, p. 35).

Therefore, in addition to being compassionate strangers who listen deeply and with curiosity, families want us to be nonjudgmental collaborators in their stories. In conversations, we offer ideas and interventions that the family will accept or turn aside, based on whether they fit. Families describe our mutual involvement this way:

It wasn't them telling us what to do. It was them helping us to realize what we needed to do and then we did it together. We weren't looking for a fortune teller you know....It was more like the saying "God helps those who help themselves."

Finally, families ask that we be mirrors for their strengths. The explicit noticing of positive things is stunningly powerful for families, because this is unusual behaviour from health care professionals. Our problem orientation seldom opens space for

us to see what is right within the family. As one woman, worn down through years of caring for a chronically ill child tearfully told me, "Nobody's ever told me before that I was doing a good job."

Families are accomplished problem-solvers. However, when they are vulnerable and suffering, problems can become so weighty that strengths, competencies, and resources are lost from view. It is our job to shine a light on these hidden treasures. Our orientation to strengths, successes, and possibilities is life-affirming. This orientation nurtures hope, and families experience it as both uplifting and healing. A recent study looking at differences between patients with COPD, cancer, or AIDS (Curtis et al., 2002) underscores the tremendous significance of hope in the lives of those for whom we care. Each group of patients identified a unique theme that was qualitatively more important to their experience of receiving high quality end-of-life care. For patients with COPD, it was patient education, for those with AIDS, the unique theme was pain control, and for patients with cancer, it was maintaining hope despite a terminal diagnosis. This study made me wonder, how it is that hope is uniquely significant to patients with cancer?

The one skill that families highly recommend we acquire is the giving of commendations (Wright & Leahey, 1994; Wright, Watson, & Bell, 1996). Wright and Leahey define commendations as "observations of patterns of behaviour that occur across time (e.g., 'Your family members are very loyal to one another') whereas a compliment is usually an observational comment on a one-time event (e.g., 'you were very praising of your son today')" (p. 106). These therapeutic comments are situation-specific and, as one young mother told me, "Not the big generic cover of all things that you would get from someone on the street." Commendations are, "in essence, conversations of affirmation and affection between the [nurse] and the family and, thereby, open possibilities for healing" (Wright et al., p. 178).

As I was preparing for this time together, I had many conversations with myself. One of the questions that arose a number of times was: if Helene Hudson were here now and able to join in this conversation, what would she say? One of her friends, Marilyn Bruce, helped me with a possible answer. This is what Helene did say about nursing when cancer continues to be a life companion:

Reflections

As an oncology nurse at the Victoria General Hospital for more than 12 years, I have been able to define what "nursing" is to cancer patients. I do not consider lack of cure or progression of disease a failure. Death is not a failure either. There is a place for skilful and creative nursing care for these patients, from diagnosis to cure, or to death.

Before caring for a cancer patient, the nurse must herself reflect upon death and its various meanings. The "act of death" is singular and final, but the "act of dying" is variable and subject to human intervention. It is vital for nurses to distinguish the difference between these two issues. Our knowledge of a patient's death too often leaves us with a feeling that all our efforts are useless. We overlook how much we can do to help the patient through the act of dying, and how important that help might be.

The opportunity to reach out and help another human being in a meaningful way should not be taken for granted. It is the essence of "nursing." Working with cancer patients brings joy, satisfaction, and meaning. Patients I have worked with have touched my life in a very special way. Health care professionals are valiant soldiers in the war on cancer, but the real heroes are our patients, whose courage and vitality serves as an inspiration to us all (Hudson, c. 1989).

In addition, I think Helene might say thank you for showing up today and each day. Your presence is a power to be reckoned with. Thank you for the loving compassion that provides a safe haven for your patients. Thank you for the conversations that enable healing. 🍀

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