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How I learned what I thought I already knew

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Abstract

Recently, I experienced cancer from the other side: I have had the privilege of sharing the cancer experience with an intimate other. It was while I lived through this experience, this hand-in-hand, heart-to-heart and soul-by-soul walk with my husband that I really learned what I thought I already knew about how oncology nurses alleviate suffering, help heal and lessen the burden of the cancer illness. The purpose of this paper is to provide the oncology nurse with a portal into a lived experience of a person dying of cancer and to confirm what we do know, describe what we do not know and to lovingly challenge some of our assumptions so that we may become better students of our real teachers: our patients.

Have you ever traveled to Cancer Country? Perhaps, like me, as an oncology nurse, you believe you are well-acquainted with this place because it is where your nursing practice and career has taken you. In the summer of 2002, when I really moved to Cancer Country, I was prepared, or so I thought, to take charge of navigating a new life through a familiar place, which consisted of organizing and getting my suddenly cancer-stricken husband to clinic appointments, blood counts, treatments, procedures, referrals, diagnostics, medication set-ups, central line care, dressing changes, mouth care, all things with which oncology nurses are familiar. I was thankful for my oncology nurse familiarity with Cancer Country, but this new life was surprisingly overwhelming and sometimes confusing, which resulted in feeling caught in a whirlpool. In the swirl of all this, when I stopped to rest, the pain of reality was so great that turning back towards the busy work was the best, perhaps my only option. This pace, however, was not sustainable, so I needed a safe place to reflect on my new world: a place where I could attempt to reconcile my past life with our new life in the world of cancer illness. I began an everyday practice of sharing these reflections with others through letters that gave sensation to my heart allowing me to hold all things in it without fear of it breaking while we lived in Cancer Country.

This sharing of story helped me stay on my feet whether we were on calm, choppy or seriously high seas. It provided me a way to understand the magical, mysterious, perhaps miraculous place called terminal cancer illness with its incredible beauty and most terrible pain, gut-wrenching sorrow and purest joy. Most importantly, I have come upon a Book of Stories upon which I have reflected and quieted down enough to relive my privileged life of

sharing the cancer experience with an intimate other, my beloved Garry, and through this experience, this hand-in-hand, heart-to-heart and soul-by-soul walk with him, have come closer to understanding the experience of a person living with and dying of cancer. It was in the reliving that I really learned what I thought I already knew about cancer.

What I learned about uncertainty

Uncertainty is a much-studied concept and the nursing literature is rife with description of the concept and research on its meaning and effect of persons living with cancer. I thought I understood that a cancer diagnosis could make a person wobbly, producing a state of confusion and indecision, making a person feel overwhelmed with bearings not firmly fixed. As oncology nurses, we observe the fear and anxiety that uncertainty causes and we believe the remedy for this uncertainty is to make as much certain as possible. But I really did not know anything about uncertainty until we were:

Plunged into the sea of cancer

I wrote the cover letter to the insurance company because Garry just could not write the words required. "On July 10, 2002, I attended the emergency department in an attempt to resolve the extreme upper abdominal and chest pain I was experiencing thinking that I was having a heart attack. My dangerously low hemoglobin of 67 caused investigation that resulted in being diagnosed with cancer of the stomach. The pathology report has confirmed that I have Adenocarcinoma of the Stomach, Stage IV-B. I have been assessed by an oncologist and will begin palliative chemotherapy shortly..." I also wrote to a dear friend to explain our new life: "I probably wouldn't sound so defeated except that sometimes you know too much and this is one of those occasions: 'He has a crappy disease with a crappy prognosis' as the family physician put it. The oncologist was a little more to the point, 'I will treat you, you will die. Without chemotherapy, your quality of life will deteriorate until you die; with chemotherapy, your quality of

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life will be maintained until it stops working, it all falls apart and you die.' As he spoke these words, he drew two corresponding graphs in the air and there was no difference in the length of the graph axis or the time to death noted..."

Each day during those early months, came messages that told of grim times in our immediate future. The gentle-sounding palliative chemotherapy made for painful mucositis, treatment-related nausea and fatigue and the development of opportunistic infection. The only certainty was suffering and, as Garry explained to the shocked, dumb-founded, same-age and gender lawyer (who was assisting getting our affairs in order): *"You know, Sandy, we are all dying, the only difference between you and me is that I have a better idea of when I'm going to die."*

What is May?

I remember visiting with friends and listening to the chatting about vacation plans, upcoming birthdays, anniversaries, opening of cottages – all things that would be happening in May and thinking what is *May*? For the first time in my life, the upcoming May meant absolutely nothing to me: I had never understood that the future is nothing without the past and that past matters not to people living in the heart of Cancer Country. Their future can only extend to the line of the horizon, only as far as they can see on a given day in the present, but not much beyond that point. You see, what I learned is that whether we are living or dying, there is only uncertainty. We, in the wellness-world, *believe* in certainty, we count on it. We create futures based on certainty without realizing that there is no certainty in life and that the tightly held grip on what we believe to be absolutely true can prevent us from accepting the present, the now of life without reservation.

Garry told me early on in his disease he made a conscious decision to turn away from anger and bitterness and to take the other path. I believe he knew instinctively that to accomplish this he would have to embrace uncertainty. Perhaps the instinct he felt was how Pema Chodron, a Buddhist nun, describes uncertainty: *"When everything falls apart, we feel uncertainty, disappointment, shock, embarrassment [but] what's left is a mind that is clear, unbiased, and fresh...Our whole world falls apart, and we've been given this great opportunity"* (Chodron, 1997, p. 69). This is what I learned and now know about uncertainty: it takes great courage to embrace, it frees you from expectations and assumptions and, most importantly, it is necessary for true healing. We in the wellness-world have more fear of uncertainty than the people to whom we ascribe this phenomenon, persons living with cancer. So, be open to embracing uncertainty with that person, as they may fear more the being out of sync with the rest of us.

What I learned about hope

Here I will be blunt – hope is a completely over-rated commodity. This is, of course, the antithesis of what we learn in our professional education and what we inadvertently communicate to the intimate others living with cancer. However, hope is what surrounds the wellness-world and our day-to-day lives. We live in hope of the best outcome, of winning a lottery, of having a better future. Garry was dealt a *hope-less* hand of cards at diagnosis – the seemingly small ulceration inside the stomach seen during gastroscopy was revealed by CT scan to be a large vascular tumour located on the fundus of the stomach proximal to the gastric-esophageal junction, its tip having broken through the stomach wall and the bulk and mass outside the stomach pressing upwards into the diaphragm. This *iceberg-presentation* tumour (so described by one surgeon) had co-opted most of the local circulatory, clotted off the spleen, wrapped itself around the pancreas, appeared to have found the liver and produced a CEA of

1840. Completely unresectable – a surgeon's nightmare, Garry's disease was named, underscoring the original grim forecasts and poor prognosis.

The facts were inescapable – all of my experience told me there was no way out and, because of Garry's pragmatic and realistic nature, Garry was of the same view. The futility of our situation was clear and we accepted that Garry was in the last part of his life. Oddly and unexpectedly, it *felt* as though the health care professionals that surrounded us did *not* seem as accepting of these facts. I expected the oncologist's approach to focus mainly on the physical body, seeking to solve problems, repair dysfunction, perhaps eradicate and *cure* disease, just as I anticipated the oncology nurse to focus on the person's body, mind and spirit, seeking to promote adaptation, facilitate equilibrium, perhaps *heal* even if that meant death. Knowing that these two views are sometimes at odds, I suppose I thought our futile reality would be validated – that Garry's day-to-day successes would be positive responses, would be celebrated in the context of the bigger picture.

Abandon hope

But this was not always our experience in Cancer Country and, with much good intention, we were given generous doses of hope along with the cisplatin, epirubicin and 5-FU. When these doses of hope were infused, we were genuinely grateful. But hope is a construct of the well-person world and when juxtaposed with our reality caused us to disbelieve those grim forecasts and shocking facts in favour of hoping for a cure. When this hopeless state is not affirmed by those around you who know the facts, you stop investing so much in the well-person world in which you once belonged. When you are offered daily doses of hope, you have two choices: you can jump on the *hope bandwagon*, likely along with your family and friends who want only for you to survive or, as Chodron (1997) suggests, you can simply "abandon hope". She goes on to say when you embrace *Hopelessness*, which is merely the constant, unpredictable change in which we all reside that ends ultimately in each of our deaths, you are "...facing the facts [with] no escapism... Giving up hope is encouragement to stick with yourself, to make friends with yourself, to not run away from yourself, to return to the bare bones no matter what's going on." (Chodron, 1997 p. 45). Garry showed me that hopelessness is your own true self's natural inclination: it is a great positive, not the negative we well-people perceive. Hopelessness does not mean that you give up on treatment or that you will turn away from cancer care; it means only that you are freed from the bondage of hoping for a cure and living only for an unreal, unattainable future.

Hopelessness is "Giving up all hope of alternatives to the present moment [allowing] a joyful relationship with our lives, an honest, direct relationship...that no longer ignores *the* reality of impermanence and death." (Chodron, 1997, p. 45).

Life in a bubble

And just as Garry turned away from anger and bitterness right at the start, I mindfully and intentionally committed myself – body, mind and spirit to Garry having his own self-directed experience and, when I listened with my heart, I was able to hear him say, "Abandon hope." Outwardly, we went through the motions expected of us, seeking a cure and hoping for miracle, but we lived in a bubble: we could mostly see, hear, taste and touch the wellness-world when we pressed against the bubble's iridescent sides, but we were not part of the well-world with its focus on past and future. In the luminous, iridescent sphere of the bubble, our life was the beautiful place of the *present*, the here and the now. The beauty was the uncovering of the truth – the present is all any of us ever have. Some months after her father's death, my daughter

remarked that the well-world expected her to be angry and sad about her loss, but she confided that she could not be sad about our beautiful life in that bubble, that amazing space in time in which we found ourselves. Sad he was no longer physically with us, yes; sad that it had happened, never!

So this is what I learned and now know about hope – most of us in the wellness-world have more fear of losing hope than the people who have already abandoned it. I learned we must be open to embracing this abandonment of hope along with the person living with cancer as it is a very difficult thing to do, whether sick or well, but do it we must, as we risk hurting the person living with cancer as they much more fearful of hurting us by disappointing the well-persons residing with them in Cancer Country.

What I learned about delirium

One morning I awoke to intense pressure on both sides of my jaw, as if I were being pulled by something very strong and powerful. When I opened my eyes, I found myself looking directly into Garry's face and realized the source of the pressure: his hands were pulling on either side of my mandible with considerable force. Strangely, I felt no fear. My clinical experience had me respond, not react, and I calmly asked Garry, "So, what are you up to?" to which he said "I'm taking your jaw off" to which I replied "I think it's okay where it is." This had him release his grip. It was this change in cognition that brought us into the hospital really for the first time. As nurses, we sometimes see the patient's physical condition more clearly and are better able to meet those needs than accurately perceiving the whole person. As a result, patients are often seen through this single lens that can focus on the physical facts, but has limitations when viewing the whole person. Patients can be understood through fact, but people are best understood through story. And this lens, or way of being in the hospital world had unfortunate consequences for Garry.

The problem with showers

Our Saturday was spent in a busy emergency room undergoing any diagnostic test that might explain the sudden mental changes Garry had experienced. By evening, he was admitted and awaiting an inpatient bed assignment. He seemed lucid and settled enough for me to go home overnight. So, I went home not realizing that I was the keeper of his story, the guardian whose role it was to ensure that Garry would be understood. It was not until later that I realized the patient admitted to the ward was *Garry Painter, 56-year-old, metastatic gastric cancer, patient admitted for confusion, sepsis and pain control* who provided a subjective comment of, "I'm not quite myself; I'm a bit confused". This was not the Garry who was prone to taking one's jaw off and, without me, the nuances of the story we told in the ER were not carried forward. That was the only explanation I could arrive at after learning of Garry's locking himself in the bathroom, cutting up his IV lines, repeating this activity using a knife from the breakfast tray after the first repair and managing to dress himself complete with winter jacket, boots and his beloved New England Patriots ball cap after the second IV repair so he and triple channel pump could attempt to slip off the ward undetected and escape from the hospital. When stopped by the nurse who asked, "Are you Garry Painter?", he thought providing a false name might allow him to pass and not result in the use of well-intentioned physical force to keep him from leaving. He told me later that all he knew was that he had to get home because *I* was home and home was where he belonged. Yet, no one asked him, "So, what are you up to?" He told me that he knew the nurses were mad at him, but he didn't know why. He told me the little hallway tussle led to his needing a shower and that water

temperature was not warm, in fact it was cold. He told me about the problem with showers and why I could never leave him alone and vulnerable again.

Garry's delirium was an indicator that we had come to the end of his life's road. The acute delirium softened into a different kind of consciousness, which he explained as his conscious and subconscious minds being separated by a rubber-like diaphragm and how he described how he would be talking with someone quite normally when, without warning, a sharp point would push through the membrane from below creating a small hole that allowed his subconscious to flood his consciousness with thoughts, ideas, words, even visions with no relation to reality, then just as suddenly, drain back through the small hole into the subconscious until the cycle would repeat itself. So, this is what I learned and now know about delirium – perhaps we, in the wellness-world, even as experienced nurses, do not always do a good job managing it. Perhaps, we do not listen to the patient's story intently enough, so that we know the person as best as possible. I learned we need to be open to seeing the whole person, the patient living with cancer, as more than their disease and realize in delirium the person is simply responding to things we well-people cannot easily understand.

What I learned about boundaries

An oncology nurse explained to me that we have to be aware of our ego, guarding against the buildup of self-importance, because it's about the person, the patient. She had noticed that not all nurses remove themselves from key moments at the end of a life because it is such a wonderful experience to have for yourself. She had seen people, unintentionally, push themselves to the forefront and assume the most important caregiver role without realizing the impact. She told me – it's not about you, you need to be aware of that. Garry had asked me to be his most important caregiver – he wanted no one but me to care for him. I got him up countless times of the day and night while in the hospital to go to the bathroom, or find a more comfortable position or get ready for bed. Every request of his was another opportunity for me to give to him and I saw each task as a privilege to be intimate, to show him my love for his very essence.

How I lost my place

An evening nurse established a routine where she would get Garry ready for bed during a 20-minute *break* I was encouraged to take. Garry, quite boyish and sweet in these last days, seemed to like the routine, so, against my powerful feelings, I would leave the room, taking my break in the small lounge at the end of the hall, in retrospect venting my anger by not turning on the light, by sitting in the dark waiting for my *break* to be over. Initially, I had tried to nonverbally communicate my displeasure and even said I needed no break, but she was persistent, which I believe was well-intentioned, just not perceptive. I grew to hate that time of day because it was becoming so difficult to maintain intimate contact with Garry and, after each of these breaks, I would have to make up ground to get back to where we had left off. We know in palliative care that the patient and the family are seen as a unit and unless there is dysfunction that separates the family, they should be nursed as a unit. So, when a friend asked me why I did not challenge the nurse and take control, I responded that I wanted Garry to have his very own experience and he seemed to like the interactions with the nurse, even though he was confused. I realized then what had caused my anger and subsequent hurt: It was my perception the nurse seemed to like the interactions more than perhaps Garry did. Otherwise, I think she might have been

sensitive to my palpable unwillingness to leave and she would have encouraged me to stay in the place I belonged. So, this is what I learned and now know about boundaries – be aware of your nurse's-self in every situation and remember it is up to you to direct the flow, to ensure that everything goes toward the patient and family.

What I learned about grief and mourning

I had anticipated my Garry's last moments as a time of genuine connectedness. In the days leading up to his death, his body underwent all the shocking physical changes the oncology nurse knows: gross lymphedema of lower extremities and groin, jaundiced skin, remarkable emaciation, but I could not see it. I could only see Garry's own-true-self, a beautiful pure-boy shining with beauty, now and forever asleep. It was a matter of waiting for Garry's body to tire.

I think the angels must have come for him

I kissed him goodnight, that Friday evening, and crawled into my sleeper chair. As always, the night nurses came on rounds and assured me that if anything changed over night, they would wake me. I drifted off to sleep, anticipating no interruption. I sensed a light tap on my shoulder and I opened my eyes – it was still dark. As the nurse told me Garry was not breathing, I sat bolt upright in bed, completely shocked. Once at his bedside, I knew it was true, he was gone: All that remained was his earthly shell on the bed, with his essence, so palpable for days even though he no longer spoke, or moved or even grimaced, was absolutely, completely gone. It was minutes before 6 a.m., just barely dawn, April 17, 2004. I was stunned having not anticipated this scenario. Why did he slip off like that, why didn't he give some sign, some warning so that I could have prepared and been there with him. I spoke to him from my heart telling him I wanted to gather our daughters so we could share those last moments, realizing as I made this plea this would have been far too complicated, and then just admitting that I wanted to say my real goodbye.

I have pondered these moments for many, many months. Had Garry been angry with me, had I disappointed him, was I too selfish in begrudging that evening routine with the nurse I did not like? I have gone over every detail of the days leading up to that final dawn. Was it because I watched television instead of paying sufficient

attention to him? Did I forget to kiss him? I thought I had, but maybe I had not. Perhaps he left without notice because that Thursday I had decided to pack up Garry's clothing, his clean underwear, T-shirts and his coat, boots and his ball cap, because I knew he would never use them again. Did that hurt him without my knowing? How could I explain that now? Who could I ask which of these terrible things were the cause of his leaving when I was sleeping and not looking? These questions have burdened me for a very long time and I have gone over these scenes in my head always arriving at the place, a place I did not believe I *actually* deserved. I decided that the angels came to Garry early that morning and asked him if he was ready. Knowing he was, he looked over to me wanting to wake me to say good-bye, but he saw how deeply and peacefully I slept and knew that I would feel pressure to try to gather everyone and this would cause me pain and that enough pain had been had already. So, he told the angels he was ready and they lifted his beautiful soul out of his battered body, passed on out of our room, over the Red River and into the very early morning sky, with its stars softly glowing, travelling where he could be placed into the hearts and arms of those who waited for him. And while he left only his earthly shell, he left within me all the lessons he taught in what I thought I already knew...

In Joan Didion's (2005) *The Year of Magical Thinking*, she describes grief as *a state of emotion and mourning as an active, participative process*. The book tells the story of the shock and grief and mourning she lived after losing her beloved partner. She says the book was structured, or pieced together as story so that it replicates the experience of grief – the way in which you obsessively go over the same scenes again and again and again trying to make them end differently. This is the *magical thinking* at work. I, too, have experienced this magical thinking even though Garry's death was anticipated, known and understood, as far as we were able. It was tasted, touched and lived every day for many more months, not a sudden event like the one Didion experienced. When it came, though, it was a shock because no matter how much I thought I knew about the phenomenon, death, I knew almost nothing. My going over the scenes, vignettes, stories, served to quiet me down so that I could listen to my soul and perceive the hidden patterns in our world: these archetypal patterns help us make sense of our experience, but only emerge and become visible when the work is completed – when we have done sufficient asking, searching, and reflecting. Only then was I able to understand what we are really made of: flesh and bone, heart and soul.

What I learned about grief and mourning that I thought I already knew is that our grief, like our stories, cannot be forced out into reality on command; grief must be lived through as mourning. I learned about the magical thinking that has the potential to be the power of story. I learned a remarkable story of a privileged journey through the living-towards-dying-world with the one I will always love.

A life well-lived: Garry, 1989.

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