TRADITION, HERITAGE AND SPIRITUALITY

Beyond Pain – The Search for Hope in the Patient's Journey

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Abstract

Hope is the foundation of the cancer patients world and it is when the darkness is most profound that hope emerges as the true reality. Hope remains the patients inner strength, a dynamism that grows more powerful even as the physical body weakens. We humans are always hoping for something and The Hope System addresses all levels of the entire cancer experience: physical, emotional, psychological and spiritual. By systematically learning how to recognize and honor patients hopes, each of us can support him/her from first diagnosis to last breath in a way that is healing and positive for all. Utilizing this simple, powerful tool enables us to tap into the patient's ever changing reality, the role hope plays in one's life while confronting one's mortality, and be able to listen, hear and accompany them each step on their final life into death journey.

Keywords: Cancer experience - hope - Hope System - confronting mortality

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The Hope System

"*Hope is the thing with feathers that perches in the soul and sings the tune without the words and never stops at all…*" Emily Dickenson has captured in this poem the deep reality that is hope in the cancer patient's life today and beyond into the future. I describe Hope as an intrinsic inner dynamic reality. It moves and guides us through life and is the beacon we all follow as we move toward the transition we call Death. I wonder if puppy dogs and pussy cats have hope, but I know that we who are human live in hope. Actually, hope has directed us throughout our lives. It is always there moving and guiding us from birth to death and for those with cancer, from the moment of diagnosis to their last breath.

Disease and death are part of life. It's hard to accept that, but we have no choice. Yet, we do have a choice in how we live until we die and our hopes speak of these choices. In the face of terminal illness, hope comes to the fore to show itself in its full glory and we find it to be deeper than "wishing," more intense even than desire. We find that hope has been all for us, all along; the thing that sparked our motivation, energized us and gave us voice.

Just a glance at the dictionary gives you an idea of what a strong advocate hope can be:

Hope is "*the feeling that what is wanted can be had or that events will turn out for the best*".

The very act of "*hoping*" is to "*look forward*" to something "*with reasonable confidence*".

A "*hopeful*" person is someone "*who shows promise or aspires to success*".

"*Hope*" is actively connected and engaged with "*believing*" and "*trusting*".

One look at all the positive feeling states and powerful actions associated with hope in a plain old dictionary and you begin to understand how simply the act of hoping itself contains tremendous healing power, what I call the for-power of hope.

I will show hope's positive potential as an advocate and how, in supporting a patient's hope, helpers can do their part in meeting the three basic needs of the dying: the need not to feel abandoned, along with the need for self-expression and hope; especially the third basic need: the need to access their own Hope System, to connect with their hopes.

Over the years, I have become convinced that hope is our primary motivator; that fundamental life force that moves and directs us throughout life and disease. It certainly is the primary internal advocate in those confronting life's end, as the most current research and literature about death and dying has begun to confirm. Next, I would like to share the up-to-date science on the subject of hope as it pertains to long-term and end-of-life care, before exploring my own theory, which forms the foundation for The Hope System, developed during my 40 years of working with the dying.

Jerome Groopman, M.D., who wrote The Anatomy of Hope – How People Prevail in the Face of Illness, cites the science behind hope: "*Belief and expectation – the key elements of hope – can block pain by releasing the brain's endorphins and enkephalins, mimicking the effects on fundamental physiological processes like respiration, circulation and motor function.*"

Hope is such an integral part of our being that it changes and grows as we grow and change; in fact, hope is so intrinsic within us that it may be not only a person's first response to change but also the catalyst of change. This primary motivator is called by many names: life force, inner-self, higher-self, the spirit within. Regardless of what we call it, Hope remains as the cancer patient's

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inner strength, a dynamism that grows more powerful, even as the physical body weakens. Along with others in the healthcare profession, I have chosen to call this dynamic inner reality "*Hope*" , in order to avoid relegating it strictly to any category (such as religion or psychology) that might exclude anyone. Whatever mantel we lay upon it, hope is first of all universal to us all, as well as inclusive of any belief system a person might choose to attach to it.

Here I would like to make the distinction between what we call "*hope*" in our daily lives – a word that is often interchangeable with (head) "*goal*" or (emotion) "*wish*" and the powerful motivational state of (heart) "hoping," which expands and deepens as life's challenges intensify. It evolves from the simple hopes of childhood, continuing on as we mature to include the more esoteric hopes that forge our adult lives. For example, "*I hope to be able to ride my tricycle or two-wheeler*"; "*I hope to make the team*"; "*I hope to be asked to the prom*"; "*I hope to become a lawyer*"; or, the one we expect to hear from every beauty contestant, "*My hope is for world peace*". From the ridiculous to the sublime, hope is always demonstrating its unique ability to change. Hope moves, creates and recreates itself within the individual, in response to the many changes life brings us. This ever-changing quality is a reflection of the inner dynamism that defines hope at the core. This dynamism builds under duress, from hope's object as a notion (noun) to hope as an active vital force (verb).

At this time I would like to introduce the concept of the for-power of hope, the premise on which The Hope System was developed. The "*for*" emphasizes how much of an advocate within us hope truly is. This can't be emphasized enough, because traditionally, the concept of hope has been relegated to the sidelines, like an unreasonably avid, blindly optimistic fan. Too often, we use phrases such as "*hoping against hope*" or "*hopelessly unrealistic*" to describe a positive attitude that flies in the face of negative odds, whereas, in fact, for a person face-to-face with cancer, hope functions as the most realistic guide of all. In my experience observing and communicating with the dying, the role that hope serves in the transitional process could almost be described as like that of a second brain. Indeed, the most current research on hope is the biological sciences, as if hope were part of the human anatomy, possibly no less vital than another organ.

It is important to believe in thepower of Hope System as a guide with effective results, to observe the ways in which various hopes manifest themselves in the patients and be alert to it's messages. Then I show how hope has functioned as an interior force in my patients; usually as a conscious motivator, yet, sometimes at first unconsciously. You will see the way in which hope itself gives us a rationale for feeling hope when nothing else does. Even when circumstances seem to give us no grounds for hope, the act of hoping itself, establishes its own rationality – hoping is a reasonable act in and of itself, according to the dictionary again. Although a particular hope may appear to be irrational to others, humans are rational beings and we are hoping all the time; living and dying with hope intact.

It is important to recognize the for-power of hope for several reasons:

∑ In acknowledging hope as a positive force, caregivers strengthen the cancer patient's strongest inner advocate, which promotes healing. ∑ In listening without judgment, caregivers support fulfillment of the cancer patient's second basic need for self-expression. ∑ The patient's feeling that their hopes are respected and heard enables them to retain their identity as a person, not just a patient, fulfilling the first basic need, not to be abandoned by the living. ∑ From birth to death, hope enables us to shape and reshape our concept of self-identity so that we can thrive in alien territory and even against the seemingly insurmountable odds of a terminal illness. ∑ Hope is an integral part of the life-death process; it is the mechanism by which we gain access to the reservoir of our own (and in the universal) intrinsic life force. ∑ Since to be alive is to keep one's hope intact – in accepting the expressed hopes of the cancer patient, caregivers support quality of life for the patient, which often enables them to outlive their prognosis.

The Hope System within each of us either finds or actually is that place from which we draw the strength for life's challenges and struggles; the courage to face change, from birth to death, with equanimity. This is apparent throughout our lives, but is all-pervasive as we proceed on our journey toward death, the final stage of human growth.

I have cared for and observed countless numbers of cancer patients during my 40 year-career and I always felt from the beginning that there was something different about them, something we were missing, but I couldn't put my finger on it. Then I heard a patient named Jeff say it: "I hope this chemo works," and there it was, all the time, that little word that means so much to anyone with a life-threatening illness.

No matter how we define this somewhat mysterious and fascinating four-letter word, we probably agree that hope is not passive; it has an intrinsic energy within it that seems to direct, guide, move and change people through their life situations. Never is this dynamic force more apparent than when one is confronted with the reality that one's own life is limited and will, in a certain matter of time, come to an end, that moment when we face our own death.

All of us can live with the knowledge that we have an incurable disease, but none of us can live with the thought that we are hopeless. Let us examine this phrase that plays such a key role in describing what follows. The patient's acknowledgement of having an incurable disease occurs first on the intellectual level. Then, in time, this knowledge of possible incurability slowly filters through the mental, emotional, physical and spiritual levels and certainly has a deep effect. Faced with this devastating knowledge, this person can still live out and complete life. One knows it is possible to live, even with the slow progression of disease robbing vitality until death arrives. None us can exist in this world with the thought of hopelessness, for hope is an integral part of all levels and aspects of each individual. Could you live with the essential condemnation of you as a person, of your very

essence, who you really are? Being labeled hopeless is like being declared a non-being, an object; not a human being, with all that entails – no history, no present, no future – truly a death sentence far more devastating and destructive than the disease that my be spreading unmercifully throughout your body.

We humans, when devoid of our hopes, feel robbed of the essence that defines us on all levels.

Surely none of us would want to be thought of as "*Room 308 – just a hopeless case*" . This type of insensitive statement demonstrates a somewhat prevalent attitude still among some health-care providers today: "*Since there is nothing I can do for the patients, since I am not able to cure them of their diseases, why stay involved with them at all?*" Thus, the abandonment of a cancer patient can subtly begin.

People need to die as they live, with their intrinsic life force, their individual hope system, in place. If we want to relate to the dying as human beings, we must not deal with them as hopeless cases, but rather direct our energies to accompanying them on their final journey. In order to do this, we must be willing to help them unearth their own hope systems.

Everyone's hope system can enable them to live each day until they die as the whole person they want to be, no matter what the depth or extent of the physical disease they are enduring. Despite all their suffering on a physical or emotional level, hope opens for them the possibility of realizing their full human potential. Indeed, the crisis of impending death can create tremendous opportunities for growth in many dimensions of who we are as humans. It is deep interior hopes that enable the dying to live each day in the face of incurable disease, until they are ready and able to let go and face death.

The Hope System approach to the cancer patient reaches into and relates to each person's intrinsic hopes, for we are what we hope. In order to understand the key concept for The Hope System, it is necessary to emphasize that hope, our interior life force, is merely changing. It is never destroyed. Hope is always present within each person experiencing the final life-into-death passage and it motivates each one to live through the dying process from the moment of the fatal disease or condition's diagnosis, until death.

I realized very clearly that we need to view the patient as a whole person, rather than as a disease or as being at a certain psychological stage in the dying process. Taking up where Elizabeth Kubler-Ross left off and with her blessing to take the next stop beyond her approach; I developed a unique framework for understanding the person with cancer and responding to what they are experiencing internally as a whole human being. My approach expands and deepens. Kubler-Ross' stages. It keeps the patient's family and the caregivers focused on the cancer patient as a whole person, fully present on all levels physical, emotional, mental and spiritual. When we relate to our patients in this way, we are being a fully-aware person ourselves.

I named my approach "*The Hope System*", which prompted Kubler-Ross to call me "*The Hope Lady*". My approach enables the caregiver and the family to understand that the patient's hopes are central to his/her wholeness and must be respected fully. Thus, The Hope System goes well beyond both Kulber-Ross' psychodynamic approach and the disease, medical model, by bringing back the concept of the whole person as the focus of how we think about and relate to the patient with cancer.

Table 1. The Four Stages of Hope

Hope for a Cure: "*I'm going to beat this thing!*".
Hope for Treatment: "*I hope I'm in the 29 percent that chemo helps!*".
Hope for Prolongation of Life: "*I hope to walk my daughter down the aisle at her wedding*".
Hope for a Peaceful Death: "*I hope I die pain-free and alert*".

The four stages of hope (see Table 1) alert the caregiver and the family to what is going on in the inner world of the dying person, as their hopes change in the face of life-threatening illness and impending death.

If we acknowledge that, at a core level, the patient himself is hope itself, we can see why hope is where we need to center our expectations, both as family members and professional caregivers. As the terminal illness progresses, hope actually comes closer to the surface than ever before. When a person is presented with a terminal diagnosis, hope begins to rise from the inner depths, on call now, on guard, our corporeal sentinel and guide. Spend one day with someone recently diagnosed with a terminal illness and you will understand the power of hope.

One may think that I get the hope thing, but how can I help the patient on her journey to find hope? Actually, it is quite simple for hope as we have discussed, is found within the cancer patient, not outside of them. So our role as professional caregiver is to help the patient with cancer to unearth her own Hope System by asking the simple, yet profound question, "What are you hoping for?" and listening for the answer.

In particular, one patient of mine illustrates how effective this question can be in facilitating understanding and communication between everyone involved: patient, family and professional caregivers alike.

Years ago, as part of my role as a clinical nurse specialist in oncology, I was asked by the staff of a medical oncology unit to see a man named John. They said that he seemed a bit down and maybe needed someone to talk to. A former policeman, he was a perfect example of the strong, silent type, but the staff had sensed sadness in him recently. In my visit with him, we got to know each other some. He spoke openly about his diagnosis and prognosis and lovingly about his wife of fifty years and his family. During our conversation I asked him, "*What are you hoping for?*" . He replied quickly, "*I hope the Mets win*". So we both smiled and exchanged baseball stories. After chatting a bit more, I told him I would return to see him again and then I left, understanding from his response that John did not want to explore anything more deeply with me at that time. This simple question drew John out of his medically-defined role of the compliant patient and gave him the opportunity to regain his sense of self as the full person he was before his diagnosis, not simply as a cancer patient. Several days later, as I was walking down

the hall, I heard my name called and turned to see John walking toward me with his ever-present IV pole. He was accompanied by four men, each one taller and bigger than he. These were his four sons: two policemen, a fireman and a detective. "*Cathy, I want to talk to you*," John said. "*Remember the question you asked me the other day? I want you to ask me it again*". By this time, John and his giant sons had surrounded me—I felt like a small sapling, gazing up at giant redwoods—and I responded dutifully, "*I asked your father what he was hoping for*". Looking directly at me, John gave his real answer: "*I hope my sons will understand that I don't want any more chemotherapy. I want to go home and be with their mother and see my grandchildren, without vomiting my guts out, for as long as I have left to be with them*". The sons looked at him and then at me and I can assure you, there was not a dry eye among us.John went home that very day. He spent quality time with his wife, his children and his grandchildren, just as he hoped he would. And then he died peacefully at home, his wife and his sons beside him, assisted by a local hospice team.

One of the things I really love about the Hope System (see Table 2) is that it helps cut through what I call the patient's garbage and returns them to person-hood for themselves and their loved ones; it enables us to contact them where they are living at each moment of their journey toward healing or toward death. When we relate to our patients in this manner we are helping them unearth their own hope system. As I've learned from the journeys of my patients, very few move through the four stages of the Hope System in a predictable and orderly fashion from Stage 1 to Stage 4. During such an intense time, their hopes change in more of a back-and-forth zigzagging pattern than in a linear continuum. But the patient and their family may be experiencing different fluctuations and be out of sync with each other.

The most important lesson of all is that when you acknowledge whatever stage of hope the patient is currently going through, you are being there for then when it counts; you are serving as a listening presence.

By learning to track which stage of The Hope System the patient is going through over time—what their specific hopes are and how they are changing—you become able to engage with them on the deepest level, on a continuing and ongoing basis. In becoming aware of the changing hopes of the patient and resonating with these hopes, we avoid the trap of projecting our own hope system onto them. We actually hear what it is they are hoping for, instead of hearing what we imagine they are hoping for, or what we think they should be hoping for.

Making such a meaningful human connection—by asking the one simple question, "*What are you hoping for?*" –is healthy for all concerned. It is sure to foster clearer communication, a vital factor in ensuring appropriate medical treatment and patient-directed care from the moment of diagnosis all the way to the moment of death. That this approach should be as effective as I've found it to be with thousands of patients and their families isn't that difficult to understand: after all, we are what we hope—the dying, as well as the living. Our own humanity and wholeness are enlarged by asking this critical question and listening to the answer. By acknowledging their hopes at every stage, we are more in touch with our own hopes, both before and after our loved one or patient has died—and are more fully able, as survivors, to live our own lives without regret or guilt, knowing we helped them live or die as they hoped they would.

Table 2. Hope System for Care-Givers

Hope to be heard, to say the right thing.
Hope to be able to listen.
Hope not to hurt,
Hope to be able to help.
Hope to be present to those who need us.
Hope to always be able to respond.
Hope to be able to say "no" and mean it without feeling so guilty.
Hope to be able to survive the stresses.
Hope to be able to say "enough" when the time comes.
Hope to be able to leave with the thought of a job well done.
Hope to learn from the dying what life really means.
And live it to the fullest.
Hope to be remembered as someone who cared.
Hope (when all is said and done) to have made a difference.

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