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In the nighttime of your fear: The anatomy of compassion in the healing of the sick

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INTRODUCTION: WHY COMPASSION?

Has there ever been a more exciting and academically-stimulating time to be working in the field of oncology than the present?

Why, then, in this technologically-advanced and stimulating age, would one want to write about "compassion"?

The reasons are many. First, although the world of oncology appears to produce advance-upon-advance on a daily basis, there is a dearth of written material on the subject of compassion, and its practical relationship to patient care, in mainstream oncology journals. Although compassion is widely seen as an important component in the healing process, the clinical literature on the subject is sparse.

Second, who of us really understands compassion? Is compassion innate? Can one evoke compassion in others? Can one teach compassion? Can a theory of compassion find practical relevance to clinical care?

For those of us in the healthcare profession, compassion is fundamental to what we do every day. For most of us, our choice to become clinicians is linked to our so-called "compassionate" nature. Yet although the provision of "compassionate care" appears in the mottoes and in the mission statements of many healthcare institutions, compassion itself is a subject that attracts little or no attention during our medical training. An increasing number of publications nevertheless testify to enhanced health outcomes for those attended by empathetic health care professionals (Hardee, 2003; Chochinov et al., 2005; Perry, 2006). As the many recent technologic advances in cancer management extend the lives of our patients, many more in the future are likely to benefit from an empathetic relationship with their attending oncologist.

Third, the tragedy, from my perspective of a 30-year experience in the fields of oncology and palliative care, is that we are poorly prepared in our training as healthcare professionals in the study, development, and application of compassion. It seems that the more facts we learn about disease, the more complex technologies and treatments we develop and embrace, the more we risk marginalizing compassion. With the technologic advances that have come to play such an important role in decision making and patient outcomes, the time has come for a rebalancing, and a refocusing, on the essentials of healing and whole person care. Whereas illness and its medical management may devalue and depersonalize many aspects of a patient's journey, compassion revalues and revitalizes.

Compassion is not an examinable subject in the medical core curriculum; indeed it is rarely mentioned. As clinical teachers, we rarely ask our students what they have learned about compassion, nor do we regularly assess how reflective our students have become as a result of their interaction with patients. Where are our role models in demonstrating compassionate clinical care, particularly in the acute hospital setting? Has compassion become the latest taboo?

Reference has been made above to the positive health outcomes that patients and their families, experience, remember, and value from being treated with empathy and compassion. Further, it is also important to realize the potential health benefits that flow to clinicians who offer compassionate care to patients, a counterintuitive aspect of compassion, well - understood by the Dalai Lama in his statement "if you want others to be happy, practise compassion. If you want to be happy, practise compassion" (Exley, 1998).

AN UNNATURAL PASSION

Most of us probably have an innate sense that we are compassionate beings. However, the late theologian

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Henri Nouwen suggested that compassion is an "unnatural passion" because it "asks us to go where it hurts, to enter into places of pain, to share in brokenness, fear, confusion and anguish" (Nouwen et al., 1982).

Considered in this way, compassion may not be among our most natural responses in a world where success is equated with strength, invulnerability, and power exercised as control. Nouwen's definition of compassion may not be the same as that intuitive feeling that most of us sense is fundamental to being both human and humane. For many in the general community, it is clearly "unnatural" to embrace someone else's pain. For many of us, it is "unnatural" to embrace willingly someone else's suffering.

Then what is compassion? Or do we really need to know? Perhaps, like Thomas Aquinas, we would "rather feel compassion than know the meaning of it" (Aquinas, 1999). Is there a risk that, in examining the delicate salmon-coloured pink and orange petals of the "compassion rose" too carefully, we may perhaps devalue and destroy the object of our attention and fascination?

As commonly understood, compassion means "a deep awareness of the suffering of another, coupled with the wish to relieve it" and "a sense of shared suffering, most often combined with the desire to alleviate such suffering" (*Random House Webster's Unabridged Dictionary*, 2005). The essential elements of compassion are, by these definitions, a preparedness to develop a deep awareness of another person's distress, an understanding of the nature of personal suffering, and the desire to relieve suffering (and by inference, to promote healing).

The essential elements of compassion are distinct from the related concepts of sympathy and empathy. "Sympathy" (from "sym"/"pathos") arises when the feelings or emotions of one person evoke similar and therefore shared feelings in another person (but often not with the same intensity). But, the "shared feeling" may be at "arms length"; that is, there is no need to be personally affected by the other person's circumstances. Sympathy implies more "mind than heart" at work.

"Empathy," on the other hand, implies an identification with another's feelings or emotions. Empathy was first used in English in the early twentieth century to translate the German psychoanalytic term *Einfühlung*, meaning "to feel as one with" (Pigman, 1995). It has been said that empathy is "your pain in my heart" (Exley, 1998). Empathy implies an attempted understanding of someone else's distress. Unlike sympathy, empathy involves heart and mind.

"Compassion," on the other hand, is a response to whole person suffering. Compassion is a decidedly active concept. By being compassionate, we actively develop a deep awareness of another person's world, we actively attempt to understand the suffering of the other person, and we actively desire to play our part in the person's healing. The role of compassion is to enliven the healing process.

THE THERAPEUTIC USE OF SELF: A WHOLLY COMMUNION

The starting point in applying compassion stems from our readiness to develop a deep awareness of illness, its meaning, and its symbolism to our patients, and to recognize both mute and expressive phases of the suffering that may result from illness (Reich, 1989). That is, we need to be awake or alive to the other person, and to develop a readiness to connect with the "person" of the patient (Nouwen et al., 1982); as quoted by Coulehan (2009), the good doctor "must come close enough to recognise the patient fully" (Berger & Mohr, 1967).

Compassion implies that we "suffer with" the other person. Therefore, to be physically present during another's personal illness and distress is important. Staying, accepting stillness, engaging with the silence. Our training, however, places little emphasis on the importance of "being there" and "listening," in times of turmoil. Silences can often penetrate those places where words cannot go. Because our training as clinicians emphasizes "doing," "knowing", and "saying," it is therefore not unexpected that we may feel uncomfortable and self-conscious in confronting suffering and the agony of silence. It would often be easier to run away. In one of her earlier essays, Saunders suggests that it is sometimes simply enough for our patients to perceive that we are with them in their struggles, and that we are on their side. Accordingly, "we are not there to take away, or explain or even understand it" (Saunders & Clark, 2006).

It is important for our patients to know that we are a witness to their suffering, and that they are not abandoned (Periyakoil, 2007; Back et al., 2009). As witnesses, we affirm the suffering of our patients, we witness, and we hear their lament. We fully invest ourselves in the present, rather than being distracted by outcomes such as our own concept of "the good death." However, even when we dare to remain physically present, it is sometimes more comfortable to remain detached, or to withdraw to the confines of the traditional medical history, and unknowingly, conceal and imprison the distress of our patients within it (Coulehan, 2009).

The theologian Henri Nouwen uses the term "self emptying" to describe the process of being there, fully present in order to "pay attention to others in such a way that they begin to recognise their own value"

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(Nouwen et al., 1982). However, as health professionals, we are rarely "empty"; we tend to be in a state of preoccupation and our medical training can be a distracting influence, with its emphasis on diagnosing, investigating, and curing the physical aspects of disease. It has been said that modern clinicians have become "curers of disease" rather than "healers of the sick" (Egnew, 2005). Nouwen continues "every time we pay attention we become emptier and the more empty we are the more healing space we have to offer" (Nouwen et al., 1982). Several other authors convey similar sentiments. Mercier (Exley, 1998) states that "we must not only give what we have; we must also give what we are." Whitman (Exley, 1998) declares "when I give, I give myself," and Gibran (1980) explains that "it is when you give of yourself that you truly give."

Dobkin (2009) and Stewart (1995) emphasize the importance that physicians develop "mindfulness" as an initial step in fostering healing in their patients, and many commentators stress the need for physicians to better understand their own beliefs, feelings, attitudes, and response patterns (Novack et al., 1999). Mindfulness is characterized by learned mental habits, such as attentive observation of self, patient, and context: critical curiosity; a fresh mind; and presence ("being there") (Novack et al., 1999; Halifax, 2008). Mindfulness enhances the physician's ability to bring awareness to the treatment of another human being. It is not what is done but how it is done that matters most. It is not how much time is spent with a patient, but rather what transpires within that time (Halifax, 2008). It has been recommended that mindfulness be introduced early in medical education (Novack et al., 1999), recognizing the need to broaden training such that curing and caring are equally valued (Novack et al., 1999). Mental preparation in order to fully exercise compassion is a prominent teaching in Buddhism (Halifax, 2008; Rinpoche & Shlim, 2006), and other followings (Nouwen et al., 1982).

We therefore connect by emptying ourselves and listening actively. It has been said that the most valuable thing we can give each other is our attention (*our emptiness*); taking the time; being genuinely interested; and not being distracted by professional title, by what I think I have to offer or what I want the outcomes to be. My essential self is sufficient (Halifax, 2008). It is possible to create an empty space in our busy internal worlds to allow suffering a form of expression, and for our patients to give a name, shape, and sound to the turmoil. As a less-attuned oncologist in the past, I recall visiting patients with gifts, a new drug and new treatment plan, or a new investigation. But these were just gifts of straw to many of my patients. Now, I just bring myself and my emptiness, and allow mystery to happen.

The recent interest in teaching communication skills to healthcare professionals is both encouraging and overdue (Maguire & Pitcheathly, 2002; Smith, 2003). However, the communication techniques that are taught do not necessarily guarantee connection and better communication. Little emphasis has been placed on the fundamental role of communion before communicating; the teaching of communication skills alone without true underlying communion, will predictably be seen by patients as gratuitous and superficial at best, and demeaning at worst. For many patients, communication "techniques" will only be of benefit when they are used in the context of a deep awareness that has already been established. Saunders suggests that patients "need someone will come to this meeting not bearing any kind of technique, be it therapeutic, pastoral or evangelistic, but just as another person" (Saunders & Clark, 2006). We may even need to "unlearn" aspects of our traditional medical training ("the search to be human") before we become the good doctors who contribute to the relief of suffering. As observed by Sackett, widely regarded as a father figure of evidence-based medicine, "the most powerful therapeutic tool you'll ever have is your own personality" (Smith, 2003).

The importance of connecting with patients, and becoming aware of the therapeutic use of ourselves, is usually not taught formally in medical schools (Maddocks, 1990). Many aspiring young doctors perceive that to be "professional" also means becoming detached (Rinpoche & Shlim, 2006; Coulehan, 2009). Providing a listening ear may involve the risk of opening up our own vulnerabilities. There has been an unwritten caveat that getting too close to patients could be dangerous, both personally and professionally. Personally, because so much perceived pain, negativity, fear, and loneliness could prove to be overwhelming and may lead to emotional exhaustion. Professionally, because emotional exhaustion among young doctors could compromise good sound clinical decisionmaking and on-the-job learning. As Shlim (2006) describes it "the only way they [doctors] feel they can care more for patients is by not caring too much." Remen (1996, 2001a) has contrasted the important clinical roles that doctors have in fixing, helping, and serving patients. In discussing the clinical role of service, Remen also suggests that "we can only serve that to which we are profoundly connected, that which we are willing to touch."

IN THE BEGINNING WAS THE WORD, THEN CAME THE STORIES

Although compassionate care has its root in developing a "deep awareness" of the patient, and in

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understanding the nature of idiosyncratic suffering, it is the "wish to relieve suffering" that sets compassion apart from its related counterparts of sympathy and empathy. By communing, we empty ourselves and we create a space wherein patients can begin the reconstruction of putting the shattered and broken pieces of their lives back together again. Many patients have "become like broken pottery" (*The Holy Bible*, 1978). Compassionate clinicians move from the stage of interpersonal communion to the stage of being a companion. Compassionate clinicians, aware of themselves in the moment as therapeutic tools, look for a relationship that will allow patients to tell the stories that must be told. In doing so, compassionate clinicians assist patients to redefine themselves. Ultimately, acceptance and peace may be found as patients incorporate their pain into a new sense of self, and into a new meaning, or understanding, of how they now relate to the world.

Although it has been said that "everyone has his or her own story," it is equally true that "everyone is a story." Each story is unique. I particularly enjoy the quotation attributed to Fred Allen when he suggested that "a human being is nothing but a story with skin around it" (Havig, 1991).

Stories, our own stories, define who we are. Human experience is framed and interpreted in terms of our life stories. Amato (1990) has said that "with no story to tell, we are no people at all." It has been said that we live in stories not in statistics. Others have summarized the point well, saying that we "continually author our own life stories as we reflect, interpret and re-interpret what happens in our lives, and tell and re-tell our stories to other people and to ourselves" (Gillies & Neimeyer, 2006). Stories help us to make sense of that which is not sensible, to explain our view of the world. Storytelling can be regarded as one of the oldest healing arts.

Stories also allow us to tap into the state of suffering (Kearney, 1996). The experience of illness, particularly life-threatening illness, can have a shattering effect on the whole person, and may change one's perception of many things. Not only shattering from a physical point of view, but life-threatening illness can result in a shattering of the past, as well as the present, a shattering of hopes, our reasons for living, and everything that is apportioned to our dreams and our aspirations (Reed, 2003). Life-threatening illness can shake the very foundation of personhood. Illness can also be a depersonalizing and dehumanizing experience for many patients and their families, and the health system may contribute to depersonalization, compounding the sense of being shattered and broken, and may retard recovery.

Suffering arises from the meaning ascribed to events, and is commonly expressed as a personal narrative. Drained of meaning, and cast adrift in the foreign world of sickness, this is never how life was meant to be. Sometimes, in the context of profound loss and distress, our stories may be all that we have, the only things about ourselves that cannot be taken away, the only things that remain coherent and intact.. And from our stories, hope may gently trickle into our pools of pain. The poet Lesley Marmon Silko (1977) wrote the following "I will tell you something about stories, they aren't just entertainment. Don't be fooled. They are all we have, you see, all we have to fight off illness and death." Stories, according to Mount et al. (2007), are one conduit through which "healing connections" may be created, so that patients may be able to move from suffering to a sense of well-being. "Meaning," according to Gillies and Neimeyer (2006) "is embedded in our life stories and can be evoked by accessing peoples' stories in their own words."

In the health system, there are a large number of parameters and outcomes that are assessed – outcomes such as length of stay, infection rates, waiting times, responses to treatment, survival times, and treatment-related toxicity. But, if it is accepted that a core activity of the healthcare system is about the relief of suffering, what is really known about the prevalence of suffering in our health system? More than a quarter of a century ago, Cassell (1982) argued that physicians do, in fact, have a professional responsibility to understand and to treat suffering at an existential level. But often, there are no simple answers. In addition to attending meticulously to physical symptoms and seeking other sources of suffering, *listening* to the stories of patients is one conduit by which clinicians can tap into that state of suffering; the *telling* of stories is the conduit by which patients endure, reflect on, redefine, and may finally transcend their state of suffering (Gilbert, 2002; Chochinov, 2006; Egnew, 2009).

There is no agony like bearing an untold story inside of you; far from relieving suffering, healthcare professionals can increase or prolong the state of suffering by ignoring it, by walking away, and by ignoring the stories that need to be told. There is a need to hear the voice of lament. The cartoonist Leunig (2006) encourages "teach us to embrace sadness lest it turn to despair." Of course, many clinicians do not even get past the standard medical history; unwittingly, we may imprison our patients within the confines of the medical history, never having the skills, time, or capacity to listen, explore, and draw out a patient's story, with all its contours, colors, textures, and layers. The direct question" Do you feel that you are suffering? "does not yet appear to have found its way into our routine assessment of patients. A recent Consensus Conference provided strong

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recommendations for the implementation of a spiritual history and spiritual care in patients with life-threatening illness (Puchalski et al., 2009). How many patients were suffering today in our hospitals? How many stories remain unborn?

To be a witness to a person's story is a validating and re-personalizing activity. *Yes, this is really happening to you. No, it is not a dream. And I am a witness to your story. And, I will tell your story.* "Besides talking himself," Broyard (1992) suggested, "the doctor ought to bleed the patient of talk." The physician–healer, according to Egnew (2009), becomes a therapeutic instrument by drawing out the patient's narrative experience, and then "helps the patient to create or discover a healing narrative with new meanings that transcend suffering." While "bleeding the patient of talk," the healthcare professional also helps to infuse the patient's narrative with meaning. As observed by Frankl (1984) "suffering ceases to be suffering in some way at the moment it finds a meaning."

Mount et al. (2007) have reported that meaning-based coping is associated with the capacity to form bonds of connection, healing connections with either self, others, nature, or with a higher power. Meaning is not an end in itself, but the by-product of a relationship experience. There is often a new way of seeing things, a new interpretation of the events in our life stories. There develops a new hope, and the possibility of a new future. At a practical level, we may be able to engage the patient in a range of deeply evocative, expressive, personal, and self-reflective activities that lead to connectedness. Indeed, "the ways in which we heal are as unique as our fingerprints" (Remen 2007). Implications for therapy are significant, and recent interventional research work has contributed enormously to the development of novel therapeutic approaches to promote healing (Breitbart, 2002; Chochinov, 2002). Even in the setting of advanced illness, there is still life to be lived; a life toward which compassionate clinicians can reach out to touch and nurture. "Compassion," according to Patel, "acts like rain upon dry ground"(Exley, 1998).

Stories have healing power. Not only in the *content*, but in the *telling* comes healing. Unlike the predictability of many clinical outcomes in medicine, the outcomes resulting from interpersonal communion may be neither predictable nor understandable. Remen (2007) recognizes that interpersonal communion is "an experience of mystery, surrender and awe." When we do listen to people's stories, we make room for mystery and healing to occur. A healing effect on the teller as well as a healing effect on the listener:

> Wal came in to see me the other week. Wal is 79 years in the shade. He lives on his own in Sans Souci in the sun. I treated Wal 8 years ago for prostate cancer. I think he is cured. Wal shuffles in; his fair skin makes him look anaemic. Wal has a problem with his weight, but he doesn't care. What he lacks in teeth he compensates with a big thirst for his favourite beers
>
> Wal wears old faded fawn shorts and green thongs. Wal has good knees. In my honour, Wal has not shaven for a week.
>
> I sit with my two students, it is 11.30 a.m. on a Friday, the end of a long follow-up clinic. And so close to lunch.
>
> "How are you doc?" "How are you mate, what's news?"
>
> Wal and I are friends. We talk. He reaches back into the half-full pockets of his colourful past. The stories come, they start to flow. His stories about the War, his stories about life in the tropics, his work as an engineer, Mr Fixit; how he could make things work when others couldn't. A cheeky smile breaks across his ancient seafarer-face; a toothless grin.
>
> The students shuffle their feet. One looks at her watch. The other at the floor. They look at me (how much longer?)
>
> We finish – I thank Wal for his stories and for coming. "Your prostate cancer is under good control Wal, and your PSA is normal." "See you in another 6 months time."
>
> Wal stands, we shake hands, he turns to leave – and dissolves in tears.
>
> "All I wanted was someone to listen."
>
> No one speaks. He hugs me. None of us can speak.
>
> Wal left. We were no longer hungry. There was silence.
>
> We have communed over the broken bread of Wal's life stories. And we were sustained. We sensed a healing had occurred for all of us.

Remen (2007) makes the common observation that "dying people often have the power to heal the rest of us in powerful ways. Years afterwards, many people can remember what a dying person has said to them, and carry it with them, woven into the fabric of their being."

Finally, stories may represent a patient's quest for "immortality," and they remain a legacy for others (Chochinov, 2002). Our patients may therefore say, as if in the words of Byron (2006),

> But I have lived, and have not lived in vain;
> My mind may lose its force, my blood its fire, and my frame perish,
> Even in conquering pain;
> But, there is that within me which shall tire Torture and Time, and breathe when I expire.

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In the end, the value of our patients' lives may not be measured so much by what they knew, nor by their possessions, but by what they have to tell in their stories, enabling them to know at last who they are and how to come to peace with life and death. Our patients live on in their stories; our story becomes woven with theirs – two, but also one. We, then, become custodians of what we have heard and witnessed. *I will be your witness; I will tell your story.*

In his letter of 1549, Michelangelo Buonarotti (1999) suggested that sculpting is a process of "taking away," in contrast to painting, which was seen as "adding on." It is up to the sculptor to reveal the soul imprisoned within the stone. Michelangelo carved in order to liberate, to set free, the figure imprisoned within the marble. We see this effect most powerfully in some of the unfinished statues of slaves. The figures seem to explode from the stone. In fact, the power of the figures is enhanced by the very fact that the statues are unfinished on purpose. Complete, although unfinished; whole, although imperfect.

In conclusion, three recommendations regarding the clinical application of compassion appear appropriate:

First, understand the nature of compassion and appreciate idiosyncratic suffering: as a result, you will learn more about yourself.

Second, understand and appreciate the stories that your patients need to tell you: as a result, you may become healers, and

Finally, never underestimate the therapeutic potential of who you are, whether student, intern or senior consultant. In the words of Remen (2001b) "who you are may affect your patients as deeply as what you know. You will often heal with your understanding and your presence things you cannot cure with your scientific knowledge."

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