THERAPEUTIC USE OF SELF AND THE RELIEF OF SUFFERING

John H Kearsley
Faculty of Medicine, University of NSW; Radiation Oncology, Cancer Care Centre, St George Hospital, New South Wales.
Email: john.kearsley@sesiahs.health.nsw.gov.au

Abstract

Suffering is a universal human experience, which may be engendered by the onset of illness, especially if illness is perceived to be life threatening. This paper examines the essence of suffering and the common sources of suffering in the setting of illness and the health system. It is proposed that many health care professionals, despite mastering the diagnosis and treatment of physiologic dysfunction, may be at a loss when it comes to helping to relieve patient suffering. At an existential level, suffering arises from the meaning ascribed by patients to events of illness, and is commonly expressed as a personal narrative. In order to help alleviate suffering and to promote healing, clinicians are encouraged to recognise themselves as therapeutic tools in understanding the nature of suffering, listening proactively to the narratives that patients need to tell so that narratives with new meanings can be created.

Nature of suffering

Suffering is a universal experience whose boundaries extend beyond the horizon of our understanding and its depth may be unfathomable to our enquiry. According to Cassell, suffering "arises from perceptions of impending destruction of an individual's personhood and continues until the threat of disintegration has passed or the integrity of the person is restored".[1] Life threatening illness represents an assault on the whole person, the physical, psychological and spiritual. Furthermore, suffering is experienced by whole persons, not bodies. Coulehan suggests that suffering "is the experience of distress or disharmony caused by the loss, or threatened loss, of what we most cherish".[2] The experience of suffering is idiosyncratic, mysterious and may vary in terms of intensity and duration. Reed characterises the intensity of suffering as a continuum extending from distress, through misery, anguish to agony.[3] Perhaps the major themes of suffering are expressed most succinctly by Manon in Puccini's eponymous opera, when she tearfully declares herself to be "sola, perduta, abandonata",[4] – alone, lost, adandoned. The four great themes of suffering, variably expressed in their intensity, are isolation, hopelessness, helplessness and loss. Concomitant with all suffering is some element of fear because according to Reed, "the patient's world view and sometimes his or her very existence are threatened by the disease or circumstances".[3] According to Gillies and Neimeyer,[5] it is a common observation that "illness threatens the integrity of personhood, isolating the patient and engendering suffering". Furthermore, suffering alienates the sufferer from self and society, and may engender a "crisis of meaning".[6] As restated by Neimeyer, "profound loss perturbs these taken-for-granted constructions about life, sometimes traumatically shaking the very foundation of one's assumptive world".[5] For many of our patients, drained of meaning and abandoned in the foreign world of sickness, "this is never how it was meant to be".

The experience of suffering is often idiosyncratic, intensely personal; the expression of suffering to clinicians includes patients describing themselves as being shattered, broken and disconnected. For many, their world simply falls apart and they fall to pieces. They become like "broken pottery".[7] Suffering is therefore associated with a disintegration of self, a disintegration of values, belief systems, traditions and even daily routines. There is also disintegration of hope. Kearney considers suffering as "the experience of an individual who has become disconnected and alienated from the deepest and most fundamental aspects of him or herself".[8] Kissane refers to this constellation of feelings and perceptions as the "demoralisation syndrome", in which hopelessness is the core construct, and involves negative cognitive attitudes such as pessimism, stoicism and fatalism, despair, loss of purpose, sense of failure and meaninglessness.[9] Disintegration of interpersonal and community connectedness is common. Others refer to the condition as "spiritual pain".[10]

Sources of suffering in the context of illness

Of the many sources of suffering, the distressing effect of physical pain and other somatic symptoms cannot be over-emphasised. However, suffering may exist in the absence of significant physical symptoms,[11] and suffering may even continue despite careful attention to physical distress. The suffering which may result from survivorship after cure of cancer has been recently highlighted,[12] as has been reported the finding that a significant percentage of patients with advanced cancer do not consider themselves to be suffering.[13] Undiagnosed depressive and anxiety disorders, unrecognised family dysfunction, fatigue, communication breakdown and emotional distress have been found to be additional important sources of suffering in palliative care patients.[14] Wilson's recently reported study of suffering in patients with advanced cancer found that there was a dominant physical component in those with significant suffering (especially pain, malaise, functional loss, weakness and inability to eat).[13] The major non-physical sources were grouped around the dimensions of social-relational concerns (especially dependence, isolation, concerns for others), psychological morbidity (especially anxiety, depression, hopelessness, loss of pleasure) and existential worries (especially loss of dignity, loss of resilience, loss of control, spiritual crisis).[13]

Problem of suffering for clinicians

Despite the universal expectation that healthcare professionals have a central (core) role in relieving suffering, it is acknowledged that healthcare professionals are poorly trained and unprepared to diagnose, assess and manage patient suffering, even though pain management, psychological issues and psychiatric diagnoses are often covered.[15] Since suffering frequently has an existential component, related to a shattering of meaning, purpose and hope, physicians cannot rely solely on theory, knowledge and skills that address physiologic dysfunction. Rather, as Coulehan suggests, "we must learn to engage the patient at an existential level".[2]

Therapeutic use of self: a wholly communion

The starting point in attempting to engage with the suffering of our patients stems from our readiness to develop a deep awareness of illness, its meaning and symbolism to our patients and to recognise both mute and expressive phases of the suffering which may result from illness.[16] 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.[17] As Sassall says, the good doctor "must come close enough to recognise the patient fully".[18]

To be physically present during another's personal illness and distress is important. Our training 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. 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".[10] It is important for our patients to know that we are witness to their suffering and that they are not abandoned.[19] 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.[2]

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".[17] However, as health professionals we tend to be in a state of preoccupation with emphasis on diagnosing, investigating and curing the physical aspects of disease; "curers of disease" rather than "healers of the sick".[20] Nouwen continues: "Every time we pay attention we become emptier and the more empty we are the more healing space we have to offer".[17]

Dobkin and Stewart emphasise the importance that physicians develop 'mindfulness' as an initial step in fostering healing in their patients,[21,22] and many commentators stress the need for physicians to better understand their own beliefs, feelings, attitudes and response patterns.[23] Mindfulness is characterised by learned mental habits, such as attentive observation of self, patient and context - critical curiosity, a fresh mind and presence ('being there').[23,24] 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.[24] It has been recommended that mindfulness be introduced early in medical education, recognising the need to broaden training such that curing and caring are equally valued.[23] Mental preparation in order to fully exercise compassion is a prominent teaching in Buddhism,[24,25] as well as other followings.[17]

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 to be the outcomes. My essential self is sufficient.[24]

The recent interest in teaching communication skills to healthcare professionals is both encouraging and overdue.[26,27] However, the communication techniques which are taught do not necessarily guarantee connection and better communication. 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 who will come to this meeting not bearing any kind of technique, be it therapeutic, pastoral or evangelistic, but just as another person".[10] 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".[27]

The importance of connecting with patients and becoming aware of the therapeutic use of ourselves is usually not taught formally in medical schools.[28] Instead, many aspiring young doctors might see that to be 'professional' also means becoming detached.[2,25] Providing a listening ear may risk opening up our own vulnerabilities. There has been an unwritten caveat that getting too close to patients can be dangerous, both personally and professionally, because so

much perceived pain, negativity, fear and loneliness can prove to be overwhelming and may lead to emotional exhaustion and compromise good sound clinical decision-making and on the job learning. As Shlim describes it: "The only way they (doctors) feel they can care more for patients is by not caring too much".[25] Remen has contrasted the important clinical roles that doctors have in fixing, helping and serving patients.[29] In discussing the clinical role of service, Remen suggests that "we can only serve that to which we are profoundly connected, that which we are willing to touch".[29]

In the beginning was the word, then came the stories

While 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 Allen's opinion that "a human being is nothing but a story with skin around it".[30]

Our own stories define who we are. Human experience is framed and interpreted in terms of our life stories. Amato has said that "with no story to tell, we are no people at all".[31] It has been said that we live in stories not in statistics; 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".[5] Stories help us to make sense of the insensible, 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. Suffering arises from the meaning ascribed to events and is commonly expressed as a personal narrative - 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 wrote: "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".[32] Stories, according to Mount et al, are one conduit through which "healing connections" may be created, so that patients may be able to move from suffering to a sense of wellbeing.[33]

How can we as health care professionals assess and relieve suffering of our patients and their families?

In the health system, there are a large number of parameters and outcomes which are assessed – outcomes such as length of stay, infection rates, waiting times, responses to treatment, survival times and treatment-related toxicity. However, if it is accepted that a core activity of the health care 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 argued that physicians do, in fact, have a professional responsibility to understand and to treat suffering at an existential level.[1] 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.[34,35] There is no agony like bearing an untold story inside of you; health care 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. The cartoonist Leunig encourages "teach us to embrace sadness lest it turn to despair".[36] 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. 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 recommendations for the implementation of a spiritual history and spiritual care in patients with life threatening illness.[37]

To be a witness to a person's story is a validating and re-personalising 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 suggested, "the doctor ought to bleed the patient of talk".[38] The physician-healer, according to Egnew, 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".[35] As observed by Frankl, "suffering ceases to be suffering in some way at the moment it finds a meaning".[39]

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. 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 (see Wal's story).

Wal's story

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 eight 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 VB stubbies. 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 11.30am 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 six 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 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".[40]

Finally, stories may represent a patient's quest for 'immortality', and they remain a legacy for others.[34] Our patients may therefore say, as if in the words of Byron: "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".[41]

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.

In his letter of 1549, Michaelangelo Buonarotti suggested that sculpting is a process of 'taking away', in contrast to painting which was seen as 'adding on'.[42] It is up to the sculptor to reveal the soul imprisoned within the stone. Michaelangelo 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, though unfinished; whole, though imperfect.

Conclusion

In conclusion, three recommendations appear appropriate. Firstly, understand and appreciate suffering. As a result, you will learn more about yourself. Secondly, understand and appreciate the stories that your patients need to tell you. As a result, you may become healers. Finally, never underestimate the therapeutic potential of who you are, whether student, intern or senior consultant. In the words of Remen, "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".[43]

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