

The Importance of Stories in Healthcare

A Importância das Histórias na Saúde

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Optimal healthcare is one of the main concerns of most societies and those dealing with human health and well-being, require unique knowledge, skills and behaviour. Physicians are constantly faced with the challenge of establishing an adequate balance between scientific and technological excellence and a more humanistic approach. The first step to promote patient centred care is acknowledging the importance of stories. Stories are an intricate part of each person's life since the day they are born and can be told in many ways, in books, poems, songs, paintings and films. The story of mankind binds us together sharing a common denominator, that one universal ending to all our stories, death. However, a multiplicity of feelings, experiences and journeys make each of our stories unique; a singular story that sets us apart from everyone else. Yuval Noah Harari begins his book, *21 Lessons for the 21st Century*, by emphasizing the importance of stories, "Humans think in stories rather than in facts, numbers or equations, and the simpler the story, the better."¹ In her book, *How to Stay Sane in an Age of Division*, Elif Shafak brilliantly points out that, "Stories bring us together, untold stories keep us apart. We are made of stories – those that have happened, those that are still happening at this moment in time and those that are shaped purely in our imagination through words, images, dreams and an endless sense of wonder about the world around us and how it works."²

When we place the patient at the centre of medical care, their story must always be the focus, as it is impossible to dissociate the person from their life journey. As Atul Gawande, the American surgeon, writer, and public health researcher, highlights in *Being Mortal: Illness, Medicine and What Matters in the End*, that "For human beings, life is meaningful because it is a story. A story has a sense of a whole, and its arc is determined by the significant moments, the ones where something happens."³ Rita Charon recognized the urgency to pay more attention to the stories of her patients and championed the concept of Narrative Medicine. Simple acts of reading and analysing literature have proven to promote the learning of narrative skills, beneficial to medical practice. Charon beautifully stated that, "the care of the sick is a work of art requiring all the creative powers of sight and discovery at my disposal."⁴ Literature and art have been useful in promoting skills for all aspects of medical practice. The ability to observe, analyse, compare and reflect upon literary texts and artworks, foster critical thinking and diagnostic skills. Observation skills are essential in Medicine and as Henry David Thoreau wrote in his book *Walden*, "it's not what you look at that matters, it's what you see."⁵

According to Arthur W. Frank in *The Wounded Storyteller*, "stories have to repair the damage that illness has done to the ill person's sense of where she is in life, and where she may be

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going.”⁶ Illness, especially serious illness, creates a state of chaos, where the ill person loses sense of time, priorities, and direction in life. According to Frank, “whether ill people want to tell stories or not, illness calls for stories.” Rita Charon defends that “the narrating of the patient’s story is a therapeutically central act, because to find the words to contain the disorder and its attendant worries, gives shape to and control over the chaos of illness.”⁷ Expressing the disease process through stories helps the patient and the physician to come to terms with the various dimensions of the illness. More importantly, it helps the patient better manage the impact of the illness on their life. Susan Sontag in her book, *Illness as Metaphor*, uses the metaphor of travel to describe illness, “Illness is the night-side of life, a more onerous citizenship. Everyone who is born hold dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.”⁸

Stories and books have important therapeutic properties for both physicians and patients alike. Brenda Walker, novelist and professor of literature, wrote the book *Reading by Moonlight: How Books Saved a Life*⁹ to illustrate the importance of reading during her ordeal with breast cancer. Walker describes the five stages of her treatment - surgery, chemotherapy, radiation, reconstruction, and survival. The story begins with the author trying to decide which book to take with her to the hospital. “The book will be the first thing I put my hand on when I arrive, when I’m taken to an empty room in an almost unimaginable place”. From the outset, the book is a central element in her tale. Walker considers that a story is “a release into the account of another’s life. A release in extended storytelling.” Regarding the title of her book, she explains that “When I tell myself that books can save a life, I don’t mean that books can postpone death. That is the job of medicine. I mean that certain books, by showing us the inner fullness of individual life, can rescue us from a limited view of ourselves and one another”. Narrative Medicine proposes that books enrich the reader, allowing them to comprehend life and illness with a broader perspective and within a deeper context.

Books and stories expand our horizons, humanize our views of life and those of others, and heighten our awareness of the frailty of the human condition - all essential requisites in medical care. Walker defends that books are a source of empathy, “empathy the way that we can place ourselves, imaginatively, in the position of another person, is at the heart of what we do as readers, as people striving for a generous understanding of one another.” Brenda Walker’s story is peppered with some of her favourite books, and each chapter makes a connection between literature and a specific moment of her illness. She cites the book, *The Hours* by Michael Cunningham¹⁰ and the

time when Clarissa tries to buy a book for her sick friend, “You want to give him the book of his own life, the book that will locate him, parent him, arm him for the changes.” That special time taken to choose the right book is a true ritual, resembling the moment Walker experienced before leaving for the hospital. The notion that there is a perfect story for moments in our lives, and that a book can guide, fix, and protect its reader, is quite an accomplishment. Brenda Walker states that as the reader, “I know that death can be a way of finishing a novel or beginning one; it can be central to the plot. But as a writer, I feel that storytelling is about staying alive. All narration holds the promise of further stories, and another dawn.” This passage underscores how stories permit introspection and allow physicians to recover their balance and renew their sense of purpose and self.

Stories can convey powerful meanings, not only for the reader but also for the storyteller. Paul Kalanithi a Stanford neurosurgical resident diagnosed with advanced-stage lung cancer wrote an opinion article in the New York Times in January 2014, *How Long Have I Got Left*¹¹ This powerful piece illustrates the difficult struggle of the ailing physician and the need to for the ill to share their stories, “but now that I had traversed the line from doctor to patient, I had the same yearning for the numbers all patients ask for”. As a patient, Paul Kalanithi began to comprehend the real needs of a patient, “What patients seek is not scientific knowledge doctors hide, but existential authenticity each must find on her own. Getting too deep into statistics is like trying to quench a thirst with salty water. The angst of facing mortality has no remedy in probability.”

Stories provide physicians with an escape from the toil of long hospital hours, treating and communicating with complex patients, as well as the bureaucracies of corporate medicine. Stories allow physicians to appreciate and value their patients, beyond the scientific foundations of disease and illness. Science and technology teach physicians how to diagnose and treat disease, but not how to assist patients living with chronic, debilitating illness, or more importantly how to face death. Physicians must recognize the necessity of treating their patients’ spiritual, emotional, and physical aspects. Stories help them to respond to the human needs of medical practice. While facing serious illness and eminent death, we must not forget the words of Maya Angelou, “There is no greater agony than bearing an untold story inside you.”¹²

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