

Write Therapy: Patient As Narrator by Nandini Murali

□ What do Norman Cousins, Susan Sontag, Kat Duff, H, Christopher Reeve, Michael J Fox, Lata Mani, and Anup Kumar have in common? All of them are authors of books based on their lived experience of illness. "We hear from doctors about disease, and from a few of the formerly ill about their cures, but rarely from the sick about themselves," writes Duff, who explores the illness terrain in *The Alchemy of Illness*.

□ Illness is universal. Few of us have not been ill at some time in our lives. No one chooses to get sick. "Illness chooses us, instead, for its own inscrutable reasons, just as surely as the clouds catch up with the sun to cast a net of darkness upon the land," writes Kat Duff. According to her, illness is as closely intertwined with human lives as sexuality.

□ "Illness is the night side of life... Everyone who is born holds 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," writes Sontag in *Illness as Metaphor and AIDS and its Metaphors*.

□ Yet illness remains poorly understood. Novelist and essayist Virginia Woolf, a survivor of chronic depression, experienced the inadequacy of language to capture the lived experience of illness. "English, which can express the thoughts of Hamlet and the tragedy of King Lear, has no words for the shiver or the headache." When psychiatrist Carl Jung was recovering from a heart attack, the view from his window looked like "a painted curtain with black holes in it, or a tattered sheet of newspaper full of photographs that meant nothing." Illness shatters our illusion that we are in control of our bodies and selves.

□ Despite impressive clinical advances in the treatment and management of disease, little is known about the view from the other side – the psycho-social and spiritual impacts of the disease on patients, and their subjective processing of the disease. The Cartesian split in modern medicine between body and mind has perpetuated the myth of the body-mind dichotomy. Another parallel development was the reductionist paradigm in modern science that attempts to understand the whole by examining its constituent parts. This approach has led to tremendous insights into the nature of disease, predict its course, and plan treatments. Yet the scientific preoccupation with objectivity and scientific phenomena has led to a "flight from consciousness." It also led to the mainstream health care perception of "diseases as mechanical mishaps, stripped of their stories, the spiritual ramifications, and missing pieces of history that make meaning."

□ In the last 20 years, however, the increasing numbers of patients who chose to tell their illness narratives has led to a genre of writing – autopathography or autobiographical

medical narratives. Autopathography (a combination of autobiography and pathology) is a literary cousin of autobiography. Autopathography, also known as crisis or illness memoirs, are narratives inspired by or centred on a disease or disorder that affects the author.

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□ So we have Cousins' classic, *Anatomy of an Illness*, that deals with his successful recovery from ankylosing spondylitis (a degenerative disease of the spine), cancer survivor Sontag's profound *Illness as Metaphor* and *AIDS and its Metaphors*, described by Newsweek as "one of the most liberating books of its time," the poignant accounts of Reeve on life after traumatic quadriplegia (*Nothing is Impossible*), Michael J Fox's coming to terms with Parkinson's Disease (*Lucky Man*), the wrenching account by journalist Jean Dominique Bauby (*The Diving Bell and the Butterfly*), who dictated the book to a scribe through batting his eyelid, Duff's insightful analysis of the transformative potential of illness following her protracted engagement with Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS), in *The Alchemy of Illness*, Mani's exploration of societal constructs of illness following a freak car accident in *Interleaves*, Kumar's courageous account of life after cancer in *The Joy of Cancer*, and Wardell's empowering *ChildFree* after Infertility based on her personal engagements with infertility and her decision to be childfree.

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□ The original term for illness narratives was pathography. In 1853, Dunglison's *Medical Lexicon* defined it as description of disease, and later as "the study of any illness on the writer's life or art, or the effects of an artist's life and personality development on creative work."

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□ Whether we refer to medical narratives as autopathography, pathography, "medical confessionals," or plain "tales from the ill," these are told from the patient's point of view on how it feels to be the recipient of medical care.

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□ Why are patients increasingly telling their tales? Apparently, illness makes good copy. More importantly, people write about their illness because the experience of illness is isolating, and disrupts a person's life. Therefore, to seamlessly weave the threads of their lives, people choose to tell their 'stories'. The process of sublimating their personal pain through stories is obviously cathartic. Also, the very act of sharing their illness narratives is an inspiration for others who may find themselves in similar situations. Besides, such patient perspectives - often missing or glossed over in modern medicine - also educate and sensitise caregivers.

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□ Jerome Groopman, oncologist and professor of Medicine at Harvard Medical School, in his reflective book, *The Anatomy of Hope*, analyses the astonishing effects of hope or its absence on the outcomes of illness.

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□ "When you hope for something, we employ, to some degree, our cognition, marshalling information and data relevant to a desired future event. If you are suffering with a serious illness, and you hope for improvement, even for a cure, you have to generate a different vision of your condition in your mind. This picture is painted in part by assimilating information about the disease, and its potential treatments. But hope also involves affective forecasting - the comforting, energising, elevating feeling that you experience when you project in your mind, a positive future. This required the brain to generate a different affective or feeling state than the one you are currently in," reasons Groopman.

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□ In a very candid account, he writes that patient management trends in health care have witnessed several discernible shifts in the last few decades.

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□ In the 1980s, the practice of medicine became more patient centric. There was greater sensitivity to the needs and demands of patients. The 'patient empowerment process' included providing them access to relevant information about treatment, which was until then the prerogative of the physician/surgeon. Along with it, emerged the realisation that the patient's soul was neglected in the treatment process.

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□ "A glaring deficiency in medical education with regard to a patient's spirit had at last come to the foreground. The pressure on the medical establishment to address the spiritual dimensions of the disease came not only from patients. Physicians faced growing competition from alternative healers as patients flocked to them. Beyond the herbs and acupuncture was the time they spent with patients enquiring deeply into their emotional state... At Harvard Medical School, for example, the curriculum was overhauled to create what was termed a 'new pathway'. It emphasised the patient's experience of illness, not just the biology of the disease."

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□ I first stumbled on autopathography when I was negotiating multiple spine surgeries. As a novice reader, I was inspired by the triumph over adversity writing that accounts for most of the popular appeal of books in this genre. Later, as my personal growth spiked, I began to veer towards narratives that viewed illness as a movement from fragmentation to integration – of the body, mind and spirit. Among the books that have influenced me most are Mani's *Interleaves*, Sontag's *Illness as Metaphor* and *AIDS and its Metaphors*, and Duff's *Alchemy of Illness*.

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□ A hallmark of illness narratives is that such catastrophic life changes have an inherent transformative potential. However, an efficiency driven, achievement-centred modern society places a premium on health and well-being. Any deviation from this idealised image is perceived as an attestation of one's helplessness, dependency, and disempowerment.

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□ Why is it that we equate 'well-being' with an able bodied life? Despite society's apparent compassion for those in pain, why do we still hold on to entrenched prejudices regarding the possibilities of "differently abled" people leading lives as fulfilling as those not circumscribed by disability or illness, wonders Mani as she explores societal constructs of illness in her prose poetry narrative, *Interleaves*. Adolf Guggenbuhl Craig describes such a tendency to accept people only when they get better, heal, or want to heal as "wholeness moralism".

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□ In 1993, a freak automobile collision changed Mani's life forever. A historian, poet, and cultural critic, Mani sustained a closed head injury – an internal brain injury, from which she admits, she is yet to recover completely. "I could not return to my job as a teacher, researcher, and writer, and I was forced to embark on a different kind of journey," recalls Mani.

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□ "When life as you know is abruptly transformed, you are brought face to face with questions about the purpose, meaning, and value of existence. I cannot say I consciously set out to find the answers to these questions. In the depth of cognitive disarray, I sensed the loving presence of Devi, the Divine Mother, inviting me to journey within," writes Mani. *Interleaves* weaves two interconnected strands in its narrative – Mani's illness, and that of spiritual awakening.

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□ "I would like all of us to reconsider how we, in our day, tend to think of illness as a negative thing, never as an opportunity. *Interleaves* does not in any way glorify pain and

suffering. But one must distinguish between the physical sensation of pain and suffering, and our response to pain. I refer here not just to the response of the individual in pain, but even more to that of society towards the chronically ill, disabled or dying. The experiences of such people are not seen to be inherently valuable, and indeed, may often provoke fear and discomfort. No wonder that those who are ill often experience loneliness and a sense of worthlessness. Illness has as much potential to teach as wellness," writes Mani.

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□Duff, a practising counsellor, sketches a similar liberating and empowering view of illness in *Alchemy of Illness*. Like Mani, Duff's sudden encounter with the incurable (as yet) Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) was a turning point.

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□Duff recalls that in the initial years of her illness, it was impossible for her to find reflective accounts of illness based on a patient-centric perspective. She uses the metaphor of alchemy to describe the transformative processes that occur during illness. Duff cites tribal and Shamanic traditions that regard ill health as "healing crisis" that are part of the ongoing life cycle - "manifestations of the body's inherent wisdom, processes of physical and psychic transformation that cleanse us of bad habits we have accumulated, the everyday neurosis of ordinary consciousness that bind us to suffering, and interfere with spiritual growth."

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□Carl Jung revitalised the principle of the ancient science of alchemy, and extended its applications to develop a holistic model of illness by outlining the various stages of spiritual transformation that accompanies illness. Based on one of the central principles of alchemy that physical decay is the gateway to higher consciousness or the beginning of a "Great Work", illness is a spiritual transformation.

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□Paracelsus, the 16th century alchemist and healer, believed, "Decay is the beginning of all birth... the midwife of all things." In his view, healing grows out of illness because each disease "bears its own remedy within itself... Health must grow from the same root as disease." Such a concept is best exemplified in many illness narratives in which patients realised that the source of healing springs from their innermost recesses. Like the alchemists who transmuted base metals to gold by keeping them in a closed container until they broke down to their original state, the limitations and isolation of illness facilitate a similar transformative process. "The walled space of illness, like therapy, intensifies the brooding, and incubates the egg, simply because there is no way out," writes Duff.

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□Novelist and essayist Sontag, a cancer survivor herself, demystifies illness, and sweeps away the cobwebs of stereotypes that surround it. For instance, she suggests refraining from the use of militaristic metaphors to describe cancer, such as "invasion", "attack", the "arsenal" of drugs that "control" or "bombard the cells". She also points out the need to steer clear of blaming the person with cancer as "having a cancer personality" or the metaphors of dread and fatality that surround cancer and AIDS. Instead, she speaks of "disease-producing lifestyles" that highlight what cancer really is - a disease, and not a punishment.

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□For many of us who were forced to migrate into the land of illness, and who are now repatriated into the land of wellness, illness narratives help us to order and reorient the wheel of our lives upturned by illness. Illness, then, is a journey within that helps us to seek, discover, and reclaim our selves. "Like an alpine meadow or coral reef, it may play an important, even necessary role, in the ecology of the whole."