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How we endure

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The art of medicine

How we endure

When I began my health research in Taiwan in 1969, many Chinese people explained to me that the most important lesson in Chinese history and in their own lives was that people had to learn how to endure. This was not surprising to hear from people who had either personally endured the great 20th-century turmoil in China—the fall of the Qing Dynasty, the chaos of the Warlord period, the long and brutal war with Japan (1937–45), the civil war between the Communist and Nationalist parties, the tumultuous era of radical Maoism, or in Taiwan the oppressive colonial experience under Japanese, and later Nationalist, rule. World War 2 alone had resulted in some 20 million Chinese dead and 250 million people uprooted. But it also gave further credence to old folk wisdom among ordinary Chinese people who for millennia lived amid the enormous upheavals of historical and natural disasters, exposing them to deep poverty, famine, disease epidemics, floods, earthquakes, war, and revolution. Survival itself was viewed as the principal success in living that individuals and their families could aspire for. And this was conveyed in multiple ways and contexts both in Taiwan and China to generations of children such that it became a core cultural wisdom.

Of course, much of this past has changed over recent decades of rising prosperity. In China the new generations of singletons have come to expect much more from life than bare existence. Indeed, that is the global cultural understanding of our era: that life offers many possibilities, that individuals can strive for success, wealth, and happiness, and that to merely get by is aspirationally unacceptable. This has been the main American cultural message for the seven decades of my life.

Yet, for billions of poor people in our world, enduring pain, misery, and suffering is not only a description of their everyday reality but the moral message that they share with their children. And this is true as well of many people in rich societies who must endure seriously debilitating illnesses, disabling accidents, terminal organ failure, end-stage neurodegenerative conditions, and the final days of dying. While the media constantly conveys hopeful messages that cures are around the corner, and that even where treatment is futile people can still be “happy”, families and individuals struggle to come to terms with the genuine reality of enduring the unendurable. The acceptance of mortality, loss, and minds which are afflicted without the means of repair may be part of the wisdom of a career in medicine, but it doesn't fit well with the upbeat media messages of the contemporary culture of consumer desire, personal social ambition, and technological ascendancy over pain and suffering.

Poverty, joblessness, migration, and other social realities of our era, along with the experience of major natural disasters, nonetheless revivify for many the importance of striving to endure. For professionals who complain of burn-out and for family caregivers who exhaust their own inner resources, for those involved in humanitarian assistance, and for many other people faced with unrelenting hardship, and physical and emotional burdens, it might prove useful to reconsider the value of enduring in human experience. Instead of asking why patients, caregivers, physicians, aid workers, and other health professionals burn out, suppose we ask how they endure? And I mean by endure withstand, live through,

put up with, and suffer. I do not mean the currently fashionable and superficially optimistic idea of “resilience” as denoting a return to robust health and happiness. Those who have struggled in the darkness of their own pain or loss, or that of patients and loved ones, know that these experiences, even when left behind, leave traces that may be only remembered viscerally but shape their lives beyond.

When I was a medical student at Stanford University during the early 1960s, I was given the responsibility of holding the hand and trying to calm a young girl who had been severely burned and had to go through the daily horror of debridement of her wounds in a whirlpool bath. She was in great agony, screaming with pain and fear. It was my assigned task to calm her and control her wild thrashing. Day after miserable day, I tried to do some good, to help her, but completely failed. Her suffering was an assault on my sense of agency and harrowing to watch. So I asked the little girl how she endured the fearsome procedure, because as I admitted I could barely endure accompanying her. She looked at me and to my complete surprise told me what she was experiencing while grasping my hand harder. She went on each day to tell me more about what her experience was like, and in the process became calmer and easier for the staff to work with. She endured because she had to endure in order to go on living. And she helped me endure what had become a devastating clinical role. Neither of us was resilient, in the contemporary meaning of the term; she withstood and kept me going as well. She taught me more in those moments than any book or clinical mentor could have done.

In caring for his wife during her experience of the ravages of Alzheimer’s disease, the late writer E S Goldman explained that he endured because the caregiving was there to do, it had to be done. The commitment to the other person was fundamental. That is how I felt about caring for my own wife who suffered from the same destructive disease; and I have heard many family caregivers of relatives with progressive and terminal conditions voice the same moral sentiment. Of course, there are also many members of family and friendship networks who choose not to endure the burdens of caregiving or become psychically exhausted and cannot go on and either drop out or cede the role to others or to institutions.

Patients endure greatly debilitating and painful disorders and some of the most trying therapeutic interventions with the hope of getting better. But many don’t. Still they go on. They struggle to survive; and to do as much as they can, because this is their only viable alternative. Some individuals give in and give up, but even then they must endure a state of hopelessness with the realisation that they have no alternative. Suicide is not an option for most people. They must go on. In the tragic view of life that many hold, this is what they expect. Religion, ethics, and aesthetics help many to rework what enduring is so that it can be emotionally sustained, and made morally meaningful. They provide the “why” that makes the “how” to endure supportable. The anthropologist-writer-existentialist Michael Jackson observes in *Life Within Limits*, his ethnographic return to rural Sierra-Leonese friends who have endured poverty, isolation, and the trauma of a horrific civil war, that their everyday strategies of enduring include a place, albeit limited, for love, happiness, and appreciation of beauty alongside all the suffering. This may be what makes their suffering bearable. The sinologist Michael Puett describes an ancient Chinese tradition that teaches that no matter how arduous we work at building human purpose and value in our lives, we are always ultimately defeated by all the negative

things in the world. Nonetheless, our task is still to cultivate what is most human and domesticate what we can in the face of failure.

Professionals also go on, despite clinical futility and failure, caring for those who don't get better, assisting some to make an end, and carrying on in practices that are financially under-resourced, bureaucratically burdened, and chronically frustrating. What keeps doctors, nurses, home health aides, and other health professionals going? Financial and career rewards, plans for retirement, the lack of viable alternatives—all must play a part. And yet, the many professionals with whom I have spoken point to other reasons as well: such as moral commitment to help their patients technically and emotionally; assisting them and also their families when they cannot be cured to achieve an adequate, if not necessarily a good, life (and death); the same religious, ethical, and aesthetic activities that bring significance to the lives of their patients; and for many, an abiding passion to bring value into their world by doing good. They go on, not just out of necessity but because they find satisfaction and self-worth in giving comfort and care, even when hope is eclipsed by the inevitability of an early death or their own resources, physical or emotional, are depleted.

Assisting family and professional caregivers as well as patients to endure may not be assessed today as a measure of the cost-effectiveness of health-care systems, and yet it is at the very core of what human experience is about and what caregiving should be about. Our cultural images today seem blinded to life's limits and dangers. While emphasising human flourishing and celebrating happy outcomes, they obscure the reality of human conditions. Physicians can work hard at achieving the best outcomes, while still acknowledging that their patients, like they themselves, must prepare for lives lived under some degree of constraint. This means that each of us at some point must learn how to endure: the act of going on and giving what we have. And we need, on occasion, to step outside ourselves and look in as if an observer on our endeavours and our relationships—personal and professional—to acknowledge the strength, compassion, courage, and humanity with which we ourselves endure or help to make bearable the hard journeys of others. These are the qualities that make acceptance and striving, if not noble, then certainly deeply human—worthy of respect of ourselves and those whose journeys we share.

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