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Living With "Man's Fate" Away From Home

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Abstract

Edward Nilges is a former software consultant who came from Chicago to Hong Kong in 2005, and has since worked as a teacher. Having been residing in Hong Kong for all these years, Edward fell ill with cancer and its complications. He choose to receive medical treatment in Hong Kong, where both the dominant culture and medical system were foreign to him. Here, he gives an account of his physical, psychological, social and existential experience, in quest of meaning away from home, while his physician discusses the clinician's perspective.

Keywords

palliative medicine, oncology, prostate cancer, patient experience

In the practice of oncology and palliative medicine within multicultural communities, it is important to effectively deliver health-care services that meet patients' social, cultural, and linguistic needs. Failure to do so affects patient outcome; a study in an English-speaking palliative care setting reported less optimal pain control and more mood disturbances in patients not fluent in the language (1).

Most medical literature focuses on the care of minority ethnic groups in western countries (2–4) and evaluates cultural factors with western models as the standard for comparison. There is however a paucity of data regarding health-related experience of expatriates living in Asia. This is of particular relevance as many Asian countries that once sent migrants abroad are now experiencing migrant inflows.

Although Hong Kong prides herself on being metropolitan and providing international standard medical services, expatriate patients with cancer may face unique challenges. Edward Nilges is one of them, a former software consultant who assisted John Nash at Princeton. Edwards comes from a medical family in the United States; his father was a neurosurgeon, his mother a nurse, and an uncle a personal physician for President Lyndon Johnson. Having been residing in Hong Kong for over 7 years, Edward falls ill with cancer. He chooses to receive medical treatment in Hong Kong, where both the dominant culture and medical system are foreign to him. Here, with his consent for publication, Edward gives an account of his experience, in quest of meaning away from home:

> "I do not have good news." My doctor's professionalism and my own preparation readied me for the bad news: stage IV prostate cancer.

Several months in and out of Queen Mary Hospital in Hong Kong ensued. In September 2012, my eldest son died suddenly. The flights back and forth between Hong Kong and Chicago, where he had lived, caused deep vein thrombosis.

Why didn't I go back to the United States for care being a US citizen albeit also a Hong Kong resident of many years? The problem is that at 63, I am in a dangerous "Medigap" zone wherein one does not qualify for Medicare but can get Medicaid if you hand over your bank account to your caregivers. "Too old for the ladies to care but too young for Medicare" as the saying goes.

Hong Kong's system is different from that of the United States. It's not as lavish as the National Health of its "mother country" (or former colonial oppressor if you prefer), but it nonetheless provides the basics at nominal cost: prescription drugs are mostly free and hospital stays 100.00 per night (US$13.00). Even this nominal fee is waived in my case insofar as I can prove no employment and no assets, which I can although my Chinese friends encourage me to go back to work.

But . . . there's a culture shock in a Hong Kong hospital. The wards include four or more people and the food is quite basic. For breakfast it's oatmeal or "congee," rice boiled to a mush. For lunch and dinner, it's a Mystery Meat plate relieved once

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or twice a week with an unnamed fish, a rice plate, and a greens plate; it takes a certain art to mix the three components together to be palatable, and I regard it as cheating to have a friend bring you extra black pepper, hot sauce, or pesto. It destroys the purity of the experience and the feeling of sharing it with Chinamen who in contrast to me are mostly older and poorer . . . ''Man's Fate'' in Malraux's words, in his novel about China in revolution; we even wear quilted Mao style jackets.

In Hong Kong, you get top-quality care because Hong Kong physicians read the same journals, attend the same conferences, and buy the same high-tech equipment as do the US and British doctors; Queen Mary Hospital, arguably the best teaching hospital in Asia, might be marginally less in overall quality than Memorial Sloan Kettering, but at some point, the attitude of the doctor and patient, their willingness to do what needs to be done, supersedes the technical gap.

In the United States as is well known, when you're discharged from the hospital you're given an enormous bill for a la carte things you never ordered (but which were needed all the same) each separately priced. If you have proven insurance already, you're good to go but for many of us this is where we turn into an over-obliging Jack Lemmon[a], smiling inappropriately as we wonder how we're going to pay the bill. Then you must go to the pharmacy and spend more money or make more insurance claims.

The US style of a la carte pricing falsely makes your stay in the hospital a restaurant meal, and you're considered a frivolous ne'er do well when you don't have insurance and cannot pay for things you never ordered. Nonetheless, in the New Yorker a few years ago, Atul Gawande recommended that a hospital be run as a quality midpriced restaurant like The Cheesecake Factory, minimizing its costs and maximizing the ''customer experience''[b].

Gawande does so in good faith. But this goes against the grain of most people, especially health-care professionals. It makes invisible my experience which is being equal to other men: eating communally the same food, sharing Man's Fate.

Hospital confronts the American with the reality of mortality in a society where we cannot stop for death:

Because I could not stop for death
He kindly stopped for me
—Emily Dickinson

According to some of the grimmest prognoses for stage IV cancers, I could have less than a year of life. I did quite a lot of inner work on this brute fact. I can reason life is short and pain cannot be easily denied, but then I am still free to make choices. Therefore, the plan is to work with the expert and compassionate team at Queen Mary as a patient. This is not an easy job. But I accept Man's Fate and I thank the team for their hard work.

Expatriate patients are often separated from their family by geographical distance, leading to a lesser degree of social support. Patients may also experience language barriers. Although locally there is little prejudice or hostility toward foreigners, interaction with non–Chinese-speaking patients may be avoided by some health-care providers or communication limited to exchange of simple information solely on the technical aspects of cancer care. This may become a major source of stress for both the patient and the medical team. As the patient's psychosocial and spiritual concerns cannot be well addressed, alienation and existential crises may ensue.

Health-care practices according to Chinese culture and values may not be applicable to expatriate patients. For instance, in medical decision-making, upholding family harmony is at least as important as patient autonomy for local patients and physicians. Moreover, issues regarding terminal illness and end of life are usually discussed in an implicit and subtle manner rather than openly. In contrast, Edward prefers detailed disclosure of diagnostic and prognostic information and makes his own informed decisions.

Practical aspects, such as financial concerns and hospital food as described in Edward's narrative, also contribute to an integral part of patients' experience of cancer care. Despite multiple adversities, Edward makes an effort to cope positively and accept Man's Fate. Our medical team supports him through a multidisciplinary approach. We recognize our own cultural assumptions while exploring Edward's concerns, while being attentive to nonverbal forms of communication. In particular, we support his reflective writing in his journey through the health-care system which tends nowadays to be technology driven and dehumanizing.

Our article highlights the potential burden of expatriate patients with cancer receiving medical care in Asian countries and illustrates their unique needs. It inspires greater awareness among the medical field to improve oncological and palliative care in this group of patients who are away from home.

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Notes

a. American actor and Academy Award winner in the postwar era, well-known for his comic interpretation of contemporary frustrations, reportedly with a tendency toward overacting.
b. Atul Gawande: ''Big Med'' in *The New Yorker*, 13 August 2012. In this article, the author emphasized quality control and system improvement in health care.

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Hilda Wong graduated from the Medical School of the University of Hong Kong and is currently a medical oncologist.

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