THINK PIECES

The language of suffering
A commentary on Veena Das's 'How the Body Speaks'

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Abstract

The recently published book *Affliction* by Veena Das explores the meaning of normalcy, illness, suffering, and loss in the lives of the marginalized urban poor living in and around India's capital city of Delhi. The language that evolves in such communities to describe the afflictions of the body forms from an amalgamation of terms derived from medical, spiritual, and faith-based systems, resulting in a unique vocabulary that needs to be understood by the clinical service provider. This think piece is a psychiatrist's interpretation of an anthropological exploration of the understanding of various illness experiences. The commentary focuses primarily on the introductory chapter of the book, entitled 'How the Body Speaks', and discusses the various themes and theorizations offered by Das regarding communication about illness. The book and the chapter complement and broaden the biomedical understanding of what constitutes sickness and cure for the vulnerable and the disadvantaged.

Keywords

Affliction: Health, Disease, Poverty (Fordham University Press, 2015) by anthropologist Veena Das explores the meaning of normalcy, illness, suffering, and loss through the eyes of the marginalized urban poor living in and around India's capital city of Delhi. The book builds on the extensive fieldwork done by researchers at the Institute for Socio-Economic Research in Development and Democracy (ISERDD), an organization founded by Das and her colleagues to work with the urban underprivileged. The book strives to make sense of the chaos that guides the lives of these urban poor, though the insights, expositions, and theorizations of its author, which are often incisive in their clarity, but always humane and compassionate in their premise.

As psychiatrists working at the apex care center of the country (All India Institute of Medical Sciences), also located in Delhi, we provide services to the same group of people described by Das, when their trajectories of health seeking lead them to us. Though we often get a cross-sectional 'etic' (Harris 1976) view of their crises, their day-to-day 'quasi-events' (Povinelli 2011) – small, day-to-day happenings – are largely hidden from our clinical experiences. So when Bhrigupati Singh, a then visiting anthropologist from Brown University to the department, suggested we look into Das's work for a different perspective on the lives of our patients, this book became an obvious choice for our collective inquiry, and was chosen for the departmental journal club. Following our reading of the book, the department of psychiatry hosted an interaction session with Das, to help medical and psychology residents understand the underlying anthropological principles better. My commentary here, on one of the chapters of *Affliction*, is a psychiatrist's interpretation of an anthropological exposition.

The book's first chapter, titled 'How the Body Speaks', describes the archetypes and vocabulary through which the urban poor perceive and communicate their physical health and illness. In situations where malnourishment and ill hygiene are the normative way of life, sickness can also become an everyday event, with 'local lingo' about causes and cure evolving through complex and jumbled interactions among social, medical, indigenous, mystical, and faith-based systems. The chapter focuses on understanding and analyzing these experiences of illnesses in the lives of the urban poor.

The corpus of data that forms the basis for Das's arguments encompasses more than thirteen thousand interviews, in the form of weekly morbidity surveys spanning several years, which attempted to capture various transformations taking place in the lives of people living in Bhagwanpur Kheda, an urban slum of East Delhi. Between 2001 and 2003, researchers from ISERDD visited three hundred households (1,620 individuals) weekly for eighteen weeks, and then monthly for the rest of the two-year span, gathering extensive data on individual health and health care-seeking behavior. Additionally, twelve hundred interviews

were conducted with 291 care providers of various Western, traditional, and faith-based medical systems over the same time period to understand the services available. Demographically, most of the participants were young individuals, with little or no formal education and no fixed source of income. Brief recurrent episodes of illness were common in the community, but were often reported as variations of normal by the sufferers, rather than as illness. Such recurring episodes of ill health suggested the possibility of underdetected chronic disorders, masquerading as recurrent acute illnesses due to misdiagnosis or improper treatment. Treatment seeking for such ailments varied and often depended upon the amount of cash in hand. People frequently consulted practitioners, but most received only symptomatic relief without a diagnosis. Practitioners of indigenous and faith-based medicine provided the majority of primary care services, with visits to government hospitals accounting for less than 30 percent of treatment seeking. The treatment provided by indigenous and faith-based providers resulted from an amalgamation of sufferers' need for quick relief and the beliefs of the practitioners, along with an ignorance of diagnosis-based treatment on the part of both.

Based on her intimate experiences with such communities, Das debates the nature of normalcy and diseased states and explores the contextual factors that determine this distinction. When medical treatment is too costly to bear, diarrhea in a child might be described as a teething problem, arthritis might be labeled as the normal breakdown of the ageing body, and partially treated tuberculosis may be deemed 'mild TB'. The lexicon people living in such neighborhoods use to report illness borrows from available medical systems as well as from faith and the occult. Terms describing bodily sensations combine with prevailing social, political, and economic forces on health, illness, and treatment, thereby resulting in a narrative through which illness acquires a social existence. Das argues that perhaps no ontology exists that could effectively explain the movement of the disease from its abstraction in the textbook into the reality of the human body. In the absence of any firm epistemic understandings of why illness happens, new lexicons gradually develop, reflecting the societal, cultural, and economic forces at play.

A second theme of the chapter is the significance of illness narratives in understanding how people view and form concepts of their 'sickness'. Arthur Kleinman (1988), a psychiatrist turned medical anthropologist who pioneered the use of illness narratives, eloquently described it as the story the patient tells, and that significant others retell, to give coherence to the distinctive events and the long-term course of suffering. The personal narrative is not simply an explanation of symptoms but a process through which people become aware and make sense of their life situation. Over time, anthropologists have come to distinguish two types of illness narratives: those focusing on the literary quality of the illness narrative and those focusing on the political and economic conditions in which the illness develops (Hydén 1997). In this book, by providing the reader with multi-perspective narratives

collected from the patients as well as from their family members, Das explores both the details and the contexts in which illness occurs, analyzing the indexical and symbolic meanings of medical complaints.

Understanding the illness narratives of such vulnerable individuals can be challenging. Das begins with an open acknowledgment that it is difficult to theorize the ordinary suffering of everyday life, which is not dramatic enough to compel attention. She supports Povinelli's (2011, 132) definition of suffering as 'ordinary, chronic and cruddy rather than catastrophic, crisis-laden and sublime', and shares her view that there is no categorical separation between health and suffering, rather a slow flux of movement between the two, highlighting the vulnerability and fragility of everyday life. According to Povinelli (2011, 13), while events have a certain objective certainty, quasi-events never are afforded such importance; they 'neither happen nor not happen'. However, such quasi-events have enough power to cause slow, imperceptible movements in a person's life that take him from one state to the other (Povinelli 2011). Das describes illness as an example of such quasi-events in everyday routines. The meaning of illness for the sufferer can range from being a simple deviation in daily habits to being the consequence of changes of season or normal transitions in the life cycle; for example, getting a sore throat can be due to cold weather or aches and pain due to old age. However, for the urban poor devoid of social security, economic stability, and financial reserves, small everyday events can suddenly turn into life-threatening catastrophes capable of rupturing the affairs and relations of the sufferer. Das's expositions here are similar to Kleinman's (1988) concept of 'sickness', defined as the understanding of a disorder in its generic sense across a population in relation to macrosocial (economic, political, institutional) forces.

The third theme of the chapter lies in understanding health-seeking behavior and following the trajectories and pathways of care for a range of illnesses that the urban poor risk suffering. Indian sufferers frequently struggle with the multitude of choices available for seeking relief and, in absence of guidance, often do not get proper treatment (Chadda et al. 2001). Such choices include pharmacists; self-prescribed medicines and home remedies; allopathic practitioners; traditional medicine practitioners; private or public hospitals; untrained, self-taught, self-proclaimed purveyors of medicines and cures; and religious and faith-based healers.

Research from our institute has shown that people make treatment choices based on a few common reasons: the ease of access, a good reputation, availability for consultation, belief in a particular system of healing, and recommendation by someone known to the patients or their family (Mishra et al. 2011). Additionally, Das shows that the choice of treatment often depended upon cash flow and the employment situation of the person or family. Thus for a

daily wage labourer, treatment from a untrained local practitioner (*jhola-chaap daktar*), who would give medications for symptomatic relief for the next two to three days for around 20 to 30 rupees, is economically more feasible than going to a private health care facility, which would cost at least twenty times more, or going to the government health care facility and missing a day's wage in waiting. In such situations, a person may not consider themselves ill until they are unable to work and earn their daily wages. In the author's words, 'The intersecting temporalities of work, cash flows, and the therapeutic practices of local practitioners created certain ways of dealing with illness that emphasized immediacy and the short term rather than investment in proper diagnosis and cure' (Das 2015, 45). In the long term, these temporary measures create a recurrence of illness or push the sufferer over the brink of crisis. Helen Sheehan (2009) has similarly described India's existing medical pluralism as a 'forced pluralism' resulting from the gross lack of access to qualified health care providers, especially in poorer neighborhoods where people don't have much choice but to explore cheaper and easily accessible avenues for relief.

Using a vignette describing a women's struggle with tuberculosis (TB), Das explores various barriers to treatment. Despite taking multiple full courses of treatment from the government-run DOTS (directly observed treatment, short-course) center, and being declared as cured at the end of each such course, the woman suffers from repeated TB infections and finally succumbs to the disease. The apathy of the government system that never looks for the cause of recurrence – but stigmatizes the sufferer for her failure to get cured – leaves a mark in the minds of the reader. Das refers to Foucault's concept of 'letting die' in which the sovereign determines whose lives are enhanced and whose lives are not worth preserving. In the eyes of society the lives of the urban poor are evidently expendable.

Das further touches on contradictions that highlight the inadequacies in our understanding of the concepts of culture, illness, and normality. People seeking traditional Ayurvedic treatment from local practitioners feel assured if the practitioner uses a stethoscope and prescribes modern tests. The classical understanding that religion determines the healer is questioned, as Hindus and Muslims often seek help from healers of the other religion. Traditional and modern techniques are blended in centers that provide tomography scans and treatment for possession under the same roof. The failing of the family can be offset by the 'silent kindness' of neighbors, while the apathy of the system is counterbalanced by the 'everyday ethics' of the common man. Such pearls of insight make the book shine, as it describes a world that pulsates with life both in its suffering and its vigor, in its tenacity and its fragility.

Das's book suggests that for the urban poor, illness represents an incoherence, unamenable to elegant theorization. As clinical practitioners of psychiatry catering to the urban poor through our community clinics, we could not agree more. While we do perceive patterns and

flows through which our patients move in and out of illness and health, we are also aware of the fragility of the threads that draw these patterns. A significant effort in community psychiatry training therefore goes into understanding and learning how to stabilize acute crises in vulnerable families using any and all available resources. Even simple gestures, like seeing a daily-wage patient ahead of other patients, as doing so might enable him to go to work and provide food for the family, are pursued as ways of averting crises.

Such anthropological work complements and broadens our clinical and research-based understanding of marginalized populations. While our clinical experiences and research into pathways of care help us understand how our patients eventually reach us, such in-community studies help us understand what happens to the people who do not reach us. This chapter illuminates the pathways that do not lead to care, of which we clinicians often unfortunately remain oblivious. Finally, as clinicians working in resource-constrained settings, we are painfully aware of the phenomenon of patients falling out of service safety nets, and cross-discipline dialogues such as these help us understand how to bridge treatment gaps and reach out to the needy.

Acknowledgements

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