UNDERSTANDING THE EXPERIENTIAL WORLD OF THE DYING: LIMITS TO SOCIOLOGICAL RESEARCH

SUHITA CHOPRA CHATTERJEE
Indian Institute of Technology, Kharagpur

ABSTRACT
In recent years there has been a proliferation of literature on Sociology of Dying. However, sociologists often treat the experience of those who are critically ill as similar to those who are really dying. This article argues that the level of emotional experience of one who is facing death is different from one who is critically ill but can intellectually anticipate it as the end of one’s existence. In other words, dying though mostly contiguous with illness experience is not to be treated as synonymous with it. The article further shows how the complex issues related to the dying person’s world defy a systematic sociological enquiry. Many of the conventional methods of sociological research fail to gain access to the self of the dying. It concludes by suggesting the need for a thorough rejuvenation of sociological methods and theories to accommodate the dying phenomenon.

Can sociologists fathom the world of the dying? This query may appear seemingly out of place given the expansive literature on death and dying. Williams and Bendelow (1998) show how, in high modernity, death has become embodied in the words of the dying patient as a result of a shift from “interrogating the corpse” to interrogating the dying person. High modernity has also made it possible for the dying to engage in meaningful narratives and heroically affirm their self-identity in the face of life-threatening diseases. Despite proliferation of literature devoted to such thanatological issues, problems encountered in field research convince me that there are genuine limits to sociological understanding of the experiential world of the dying. And, the limitations may be more real in Asian societies where interrogation of the corpse and the dying both evoke a common deadly silence.
Although scholars have successfully theorized the complex death culture of our times—its sequestration (Giddens, 1991), extradition of the dead (Baudrillard, 1993), deconstruction of mortality and immortality (Bauman, 1992)—thinking about death and conceptualizing it is not the same as facing death. As the philosopher Solomon (1998) rightly points out, facing death is an emotional experience. Thinking about it is “curiously detached, abstracted, out of touch with the phenomenon it ponders” (p. 153). It also appears to me that gathering data from those who are dying is not the same as collecting information from the chronically or seriously ill. Dying, though at times contiguous with the illness experience, is not to be treated as synonymous with it, as most sociologists do. In other words, death may be a sequel to serious illness but the level of emotional experience of one who is facing death is different from one who can intellectually anticipate it as the end of one’s existence.

What does it mean to face death and to be dying? There are very few reflections on one’s journey into non-being, which could be useful in elaborating my point, but a few narratives of people looking death in the face show that dying is an intensely lonely journey. Although Solomon would like us to believe that dying has a social dimension—“death individuates insofar as it targets the vulnerability of intimate and significant relationships” (p. 176)—I feel the first person stance remains extremely powerful. As Solomon himself points out, dying engulfs one in morbid solipsism—a phenomenology of experience so steeped in “I” and “me” that it becomes difficult to appreciate that it could become a subject of sociological exploration at all. Compounding the problem is the fact that there is no mutually common world of experience between the world of the living (to which the sociologist belongs) and the world of the dying. The latter is wrought with pain and suffering. In the phenomenology of the pain sufferers, Schutz (1971) finds different features of common sense reality (like forms of experiencing self, sociality, time, consciousness, organization of social world in terms of intentional projects and suspension of concerns of mortality), getting deformed. A similar and a far more fundamental difference marks the world of the dying. While for the living the unity of life and the self is necessarily worked out in terms of particular locatedness and orientation within a spatial and temporal framework, the dying person does not have these familiar bases for experiencing reality—space, time, and the like. Horwitz (1998) writes of his journey into non-being, “I supposed that this is what death is—a realm without space, without time, without definition, without stimulation. In this realm there was no longer a sense of self, ego, consciousness, body” (p. 8). Dying involves a change in the entire perspective of the physical world.

Horwitz (1998) further states:

The world looked and felt more uniform, blended, undifferentiated, and much less substantial than it had before, and than it does now. People and
things had an air of impermanence or permeability. I felt as if I was looking through things as much as looking at things (p. 12).

It thus seems that, for the dying, there is not only a dissolution of space, time, and conventional notions of structure but also of body and self-identity itself—aspects which sociologists have suggested as possible ways of branching out into sociological theory to accommodate death and dying issues. Mellor (1993) for instance, feels that Sociology of Identity and Sociology of Body provide the theoretical perspectives that can enrich Sociology of Death (and dying, too?), since these are the aspects of existence which modernity has problematized/sequestrated from public visibility.

Field data impress on me the sheer distinctiveness of the world of the dying or the “death-world,” as we may term it. Here the relationship with the living seems to be replaced by those already deceased. Visions of one’s departed spouse, parents, and friends dominate the scene. While mortality is sequestrated from daily experience by the living, it becomes central to the concerns of those who are dying. I remember a woman who was so distressed and overcome by caregiver’s fatigue that she fervently prayed for her ailing mother’s death. However, death was still a distant relief; her mother did not yet see any visions of her deceased relatives. There was a family history of widows being recalled, as if it were, by their dead husbands, children by the parents . . . the death-world showed a remarkable solidarity with the deceased rather than with the living.

HOW TO AUDIT EMPATHETICALLY?

With no common basis for experiencing and ordering realities between the world of the living and the dying it becomes difficult to audit other’s experiences and to gain access to the world of the dying person. While sociologists do use empathy for understanding different misfortunes and deprivations of others, death is not a deprivation of this or that; it is a deprivation of the entire life project itself. It goes without saying that it is far more difficult to imagine oneself in a state of non-being in order to understand the dying person, since the ability to put oneself in the other’s place is arguably dependent on having some degree of mutuality of experience of the thing one studies.

The limitations of sociological methodology are also evident in understanding pain and suffering of the dying person. Understanding pain has been one of the most important challenges in social science research. Pain is a greatly complex knot of bodily, psychological, social, and philosophical conundrums. Understanding the physical experience of pain requires an embodied approach—one that combines the physical, affective, and social dimensions in a web of lived experiences. Various factors—personal, social, and cultural—shape the meaning of and responses to pain. For instance, complex processes transform painful relationships into chest pain and vice versa transform chest pain into a
painful world (see Good et al., 1992). Some categories of pain, particularly chronic pain, remains often undiagnosed and escapes successful cultural construction (Hilbert, 1984). It is not adequately appreciated with the help of linguistic terms and cultural categories. It is an inner experience and even those closest to the patient cannot truly observe its progress or share its suffering. In the epilogue to his book, Good, 1994, p. 199) writes that the experience of chronic pain resists incorporation even into ethnographic reporting and social science analysis.

Suffering is a still more expansive concept than pain. It encompasses the anguish, terror, and hopelessness the dying patients experience. Symptoms or feelings become suffering when people perceive it as a threat not only to their existence but also integrity as a person. Although suffering involves an intersubjective process and is shared by patients, families, and caregivers, it remains an intensely personal matter (Casel, 1991). Both pain and suffering are influenced by deep social and cultural factors (Kleinman, 1998). And understanding these involves an appreciation of how history and social relations are inscribed on the body. In order to successfully study these processes, sociologists have to do away with the dualistic legacies of Western thought which they have nurtured for a long time in the form of neat looking distinctions like mind–body, nature–culture, reason–emotion, public–private, etc. And second, sociologists have to bring corporeal concerns at the heart of the sociological enterprise. For a long time, sociologists had a nagging fear of reductionism and did not look at the bodily basis of social order and action. They emphasized on social systems, their problems and their interrelationships, rather than on the ontological status of human beings. In recent years, although there has been a growing concern with the body and an embodied sociology (see Turner, 1984, 1992; Shilling, 1993; Falk, 1994), a theoretical framework that satisfactorily addresses the broad range of ontological and epistemological questions surrounding the body and its relationship to the socio-cultural and historical order has not yet developed. We are theorizing about the bodies in a largely disembodied way rather than theorizing from live bodies (Williams & Bendelow, 1998, p. 17). Given these limitations, can sociologists hope to explore the ethnography of the experience of suffering? Can they incorporate the dying person’s emotional dismay into scholarly discourses? It would not be too harsh to suggest that sociology, with its modest beginning in interpretative framework, can hardly hope to compare favorably with other disciplines like medical anthropology which has enjoyed a fairly long history of studying how micro-contexts mediate the relationship between societal and personal processes. Anthropology’s ability to deal with both culture and embodied experience favorably predisposes it to the study of end-of-life issues wherein intimate relationships between biology and culture exist. Using ethnography as genre, anthropologists can represent more appropriately those aspects of suffering which resist the positivism, the reductionism which sociology for instance privileges. Sociologists, therefore, have to be more realistic in laying claims to new frontiers of study. This may actually involve a more thorough rejuvenation
of the field by way of a radical dismantling of boundaries between sociology and allied field of social sciences—particularly anthropology and psychology.

END OF ALL NARRATIVES

It is considered in some quarters (see Frank, 1995; Hyden, 1997) that narrative is one of the most powerful forms for expressing suffering and experiences related to suffering. Qualitative research-oriented sociologists have found the nature of pain experience can be inferred from the narratives told by the patients. It is considered an important way of understanding human life from “outside” (Mishler, 1986). But we must be clear that through narratives one only listens to factual accounts, not to facts themselves. Moreover, while this methodology does keep the researcher close to the experience of the participants who are ill, I have serious doubt as to its efficacy in accessing the world of the dying persons. As mentioned earlier, dying, though mostly contiguous with the experience of falling seriously ill, is not to be treated as synonymous with it, and as generating the same type of experiences. Those who are chronically or seriously ill may not have yet anticipated or imagined the end of their potentiality for being. They are in the midst of their illness experience—attempting to make sense of it—and, hence, the narratives are not complete or finished although they may be terminated abruptly by illness. They are, as Ricoeur (1981) says, told from the blind complexity of the present as it is experienced. The actors are engaged in a striving, in a quest for cure. Being in the midst of a story they are telling, such persons are committed to portraying a “subjunctive” world—one in which healing is an open possibility (see Good, 1994). The remaking of their life world is therefore a process which phenomenologically-oriented sociologists have tried to analyze. But the life world of the dying is strikingly different. Not only are the subjunctivizing elements lost, but being deeply conscious of the fact that their life’s ending is close or almost reached, the consciousness itself signals the end of all stories. Rather, there is no need to recount it as such. Indeed, my attempts to make the dying patients speak only resulted in a silence broken by intermittent sobs. While narratives of the ill are important for the sociologists insofar as they project activities and experiences into the future, directing desires and strategies toward some end, for those who are dying there is no future, no desire but an end to all life projects.

Under conditions of such stark differences between the world of the living and the dying, between the world of the seriously ill and those who are really dying, production of meanings in narratives become difficult and the intersubjective quality of narratives also suffers. We know that the reader response theorists have given special attention to the phenomenology of the act of following a narrative. It follows from their logic that in order to constitute a narrative, a reader or the audience must “appropriate” the story (see Ricoeur, 1981). My contention is that it is this very process of appropriation of meanings related to the deathworld, which becomes difficult for the sociologist.
UNDERSTANDING SILENCE BEFORE DEATH

It also appears to me that while scholars have acknowledged wide variations in illness narratives due to their structuring in cultural terms, there has been little attempt to explore the importance and scope of narrativization per se in different cultures, and its role in the life world of the natives. Although phenomenologists like Schutz and later literary critics like Scarry (1985) have successfully uncovered the world of patients in chronic pain and with life-threatening illnesses (despite Scarry’s own submission that pain is beyond language), I presume their subjects were expressive, i.e., took solace in communicating, narrating their experiences to others. However, telling of illness stories is not culturally sanctioned outside the American-European social context. Although scholars have rightly noted the dearth of studies on pain experiences across cultures and the need for a more thorough understanding of the “phenomenologies of bodily modes of experiences” (Good et al., 1992; Kleinman, 1986), the important question for sociologists is how to interpret experiences in cultures where silence rather than narrative is important.

In many Asian societies like India, suffering in silence is highly valued. Narratives are not easy to come by since there is no attempt to relieve suffering through descriptions. Indeed, there are very strong social expectations of what constitutes a dignified acceptance of death. To be verbose is to approach end of life with trepidation, while an uncomplaining silence marks the ability of the dying not only to accept pain and suffering as an inevitable component of the decaying body, but also the ability to dissociate oneself from bodily concerns altogether.

Death in the Indian classical tradition leads to a perfection—i.e., emancipation and liberation. Before physical death is reached, renunciation of the world is a necessary condition for achieving this state and many religious texts are designed to help people achieve a state of meditation. Renunciation cultivates a peaceful silence. There is no place for speech or narration in the soul’s search for harmony. In fact, the soteriological world of the spiritually inclined shows a remarkable capacity to achieving such a state of silence by transcending bodily pain and this-worldly suffering. This results from a continuous striving to interfuse life and death, see death as a constant companion and complement to life. The result is a philosophical detachment from the body altogether. It is said of the saint Sri Ramakrishna (spiritual leader of Swami Vivekananda), that even when diagnosed with cancer, he maintained a joyful posture, for the cancer struck his body and not the soul (Gupta, 1985). What is valued here is the denial of the body as the chief source of and the ultimate medium of experience of the phenomenal world. So highly valued is this particular philosophical stance that it often becomes embarrassing for a researcher in an Indian setting to engage a dying person in conversation. It shatters the peaceful world of the dying person, the intense striving for detachment, and negates the salutary effects of death itself. This is but one example of how meanings of dying vary in different cultures. We
may ask: how do these cultural meanings translate into individual and social experiences, and how does the researcher fathom the experiences? These experiences and meanings can neither be interpreted nor observed. They are in the domain of silence. Understanding silence in many non-Western cultures becomes all the more difficult because silence doesn’t necessarily result from breakdown of meanings; it results from a striving to achieve a new state of consciousness that can hardly be communicated to others.

CONCLUSION

This article has tried to bring out some of the vexing issues involved in the sociological enquiry into the experiential world of the dying. As dying becomes more and more prolonged with advances in medicine and technology, the distinctions among the different phases in the illness experience—in facing one’s mortality—need to be conceptually demarcated and understood. It has been argued in this article that understanding the world of those who are face-to-face with death is an especially daunting task for sociologists. Most of the conventional sociological methods of enquiry fail to gain access to the world of the dying. In order to accommodate the dying phenomenon, sociologists would therefore need to bring about a radical rejuvenation of not only sociological theories and methods, but also take a critical look at the academic boundaries between sociology and other fields of social sciences.

REFERENCES


Direct reprint requests to:

Suhita Chopra Chatterjee
Dept. of Humanities and Social Sciences
Indian Institute of Technology, Kharagpur
Kharagpur, India 721302
e-mail: suhitacc@yahoo.co.in