### ORIGINAL ARTICLE

# Social Constructionist Approach to Suffering and Healing: Juxtaposing Cassell, Gergen and Kleinman

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Received: 13 September 2011 / Accepted: 9 December 2011 / Published online: 18 January 2012 © National Academy of Psychology (NAOP) India 2012

**Abstract** To understand the experiences of suffering (overwhelming somatic pain or illness and its anticipation and other forms of severe distress arising in the socio-moral context) and facilitate healing (developing an enabling meaning and value for one's experiences when faced with suffering) have been the focus of medicine as a social institution throughout human history. However, the goals of Western biomedicine in the last few centuries shifted from taking care of these experiential concerns of the sufferers to predominantly the diagnosis and treatment of the symptoms of a disease. This article attempts to illustrate how the assumptions of the social constructionist paradigm (with its deconstructionist and reconstructionist facets highlighted in the writings of Kenneth J. Gergen) serve as a suitable metatheoretical framework to understand human experiences of suffering and healing. A critical review of the writings of Eric J. Cassell and Arthur Kleinman on endorsing and researching such experiences resulted in four themes that reaffirmed the utility of this new paradigm. These themes help comprehend that biomedicine's ontological claims may enhance human suffering, suffering and healing experiences are socio-historically contextualized, such experiences are performances within human interaction

This article is dedicated to my teacher, Girishwar Misra and Kenneth J. Gergen who introduced me to the huge potential of social constructionist paradigm of social inquiry for the welfare and growth of humankind. I also acknowledge the encouragement and inspiration provided to me by Vinay Kumar Srivastava, Ajit K. Dalal, Eric J. Cassell, Arthur Kleinman, Kathy Charmaz, Arthur Frank and Alan Radley toward making meaningful efforts to explore human suffering and healing through social science research.

K. R. Priya (⊠) Department of Humanities and Social Sciences, Indian Institute of Technology Kanpur, Kanpur, Uttar Pradesh, India e-mail: krp@iitk.ac.in and dialogic partnership between the researcher and the participant becomes a meaningful medium to study such experiences.

**Keywords** Social constructionism · Suffering · Healing · Eric J. Cassell · Kenneth J. Gergen · Arthur Kleinman

Mūnh ki bāt sūne har koi,
Dil ke dard ko jāne kaun?
Āwāzon ke bāzāron mein,
Khāmoshi Pahchāne kaun?
[Everyone can hear the spoken words,
But who understands heart's sorrow?
In the marketplace of sounds,
Who recognizes silence?]
-Nida Fazali, an Urdu poet

The test of a system of medicine should be its adequacy in the face of suffering . . . modern medicine fails this test.

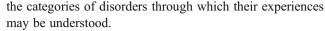
-Eric J. Cassell (2004, p. iii)

My reflections on the social constructionist research on suffering and healing take me back to three incidents in the past. The *first* is related to my field work among the survivors of an earthquake. In one of the semi-structured interviews with an elderly woman who lost her husband in the earthquake, I probed about whether she had difficulties in falling asleep after the earthquake. She shared with me her inability to go off to sleep at night because of recurring thoughts of her departed husband. But, as she shared, the problem that she was concerned about was her sorrow resulting from the frustrating thoughts about future that being a widow, she would not be allowed as per shared



Hindu religious norms in her village to participate in the marriages of her grand daughters (Priya 2007). The *second* incident was related to another field work in which I studied the Muslim children displaced as a result of a Hindu-Muslim communal riot. While sharing his difficulties of living in a 'colony of displaced', an 8 year old child expressed his tendencies to run off to his friends house to avoid whenever he was reminded of the violence. But, his immediate concern was about his missing his Hindu friends with whom he used to play before getting separated due to the riot (Priya 2012).

Cultural norms for widowhood in rural Hindu cultures and societal consequences of communal riots may be seen from the above two examples of ethnographic research as the socio-cultural contexts that shaped the experiences of suffering in the post-disaster period. Had I focussed only on the symptoms of posttraumatic disorder (PTSD) that are, reexperiencing, avoidance, numbing and hyperarousal among the disaster survivors, my understanding would not have been closer to their own concerns and experiences. My studies of suffering and healing among disaster survivors was possible because of a change in academic culture witnessed in social sciences globally and in India towards exploring experiential and not only symptom-based understanding of health and illness. This change in academic culture, however, is slow. The third incident that I am reminded of is about the academic culture within which the concept of suffering (and healing) is trying to create its legitimate space. I was listening to a narrative study of illness and suffering associated with spirit possession in an Indian temple that a young researcher was presenting at a seminar. Her study adopted the social constructionist epistemology through which she could highlight how participants' narrativization during the interviews was constitutive of their meanings of suffering. After the presentation was over, an immediate response of a senior psychologist was, "What do you mean when you say that the person was suffering? You should tell what the person was suffering from; anxiety, depression, hysteria or schizophrenia." The young researcher was able to respond to her with composure that a narrative study is done to co-construct participants' experiences from their own perspective rather than to dictate



Now that I look back at the three incidents, these indicate the potential of the social constructionist paradigm to help understand not only how the socio-historical contexts shape the experiences of suffering but also be critically aware of the discourse of 'natural science' (that claims to discover 'objective truth') prevailing within modern medicine as well as social science disciplines such as psychology; an awareness that may help understand the forces that often delegitimizes the experiences of an afflicted person, thereby increasing the possibility of enhancing his or her suffering.

In 1960s and 1970s, a period marked by an interpretive turn in social sciences, the seeds of such a paradigm shift in medicine and in the study of health and illness experiences in social sciences were sown by scholars such as Leon Eisenberg, Arthur Kleinman and George L. Engel. While Eisenberg (1977) focused on the need to study the socioculturally contextualized experiences of illness, Kleinman (1973) drew our attention to the need to "conceive of medical systems as existing within and themselves shaping a socially and culturally constructed space" (p. 160) in line with Berger and Luckmann's (1967) thesis of reality as social construction. During the same period, Engel (1977) proposed a biopsychosocial model as a viable alternative for the reductionist biomedical model. Engel contended that besides socio-culturally contextualized experiences of illness, 'suffering without symptoms' or problem of living would also be a subject matter of study in the new model. But, in his path-breaking article, Engel's focus was largely on diagnosing an individual for a disease by focusing on the contextual meanings of patient's by a skilled professional through interviews. His article doesn't provide much insight into how problems of living could also be conceptualized as suffering and how help would be provided to the needy person.

Among other social scientists and mental health professionals, Kenneth J. Gergen, Eric J. Cassell and Arthur Kleinman may be considered as the prominent ones to advocate a paradigm shift in the domain of medicine in the last few decades. While Gergen is better known for his contributions towards a paradigm shift in psychology and social sciences in general, Kleinman and Cassell have advocated and attempted to execute through their medical practice and research, a paradigm shift in the field of medicine. The research contributions of these three scholars of eminence to social sciences may be utilized to make sense of the paradigm shift in the domain of medicine and its impact on the study of human suffering and healing. Their contributions also help develop an integrated understanding of research on suffering and healing by renowned scholars of social studies of health and illness such as Kathy Charmaz, Arthur W. Frank and Alan Radley.



<sup>&</sup>lt;sup>1</sup> I was fortunate to have studied at the Department of Psychology at the University of Delhi that enhanced my understanding of human life through not only the positivist paradigm but also through other meaningful paradigms like social constructionism, critical theory and participatory inquiry. There were no such Masters or Doctoral programmes in Psychology in any other university in India in 1999; the year I joined the Masters programme. Besides Professor Girishwar Misra, a social constructionist, being my Ph.D. supervisor, I was also nurtured under the supervision of Professor Vinay Kumar Srivastava, a social anthropologist, who facilitated my understanding of ethnographic field work.

The basic assumptions of social constructionism<sup>2</sup> as an alternative paradigm within social sciences and medicine may be understood as (Cisneros-Puebla 2008; Gergen 1973, 1985, 1994, 1997, 2009; Misra and Gergen 1993; Sampson 1993): (a) Questioning or deconstructing the realist ontological claims that reality exists independent of the observer and universal and decontextualized theories represent its discovery through induction, (b) Reality is constructed through socio-historically situated interchanges amongst people, (c) The primary function of a talk or social interaction is to initiate or regulate some social action rather than to represent a discourse-independent reality, and (d) Understanding about human experiences may be coconstructed through dialogic partnership between a researcher and a participant where the worldview of none is privileged over the other.

With the help of a critical review of literature on the phenomena of human suffering and healing, this paper is an attempt to highlight how the assumptions of social constructionist paradigm provide a metatheoretical foundation for a meaningful understanding of such human experience in their socio-historical contexts. This paper illustrates this by elaborating on the following four themes:

- Deconstructing realist ontological claims of biomedicine and analyzing how such claims may enhance human suffering
- Human suffering and healing as socio-historically contextualized phenomena
- Suffering and healing as a performance constituted in the interactions of healers, doctors or researchers with the sufferer
- 4. Research on suffering and healing through dialogic partnership between a researcher and a participant

Before discussing these themes, how suffering and healing are conceptualized in social sciences and medicine must be looked into.

### Conceptualizing Suffering and Healing

Many a time in our lives, we face difficult life circumstances that may lead to a loss of an enabling meaning in our lives. Different cultures have different terms to understand how a person feels while going through such a phase of life. Although as Anderson and Bury (1988, cited in Charmaz 1999) point out that the British use of the term, 'suffering' refers to experiences of illness, it is important to note that it is social scientists or scholars who have invoked the terms,

suffering and healing to understand the complexity of human experiences in such difficult phases of life.<sup>3</sup> Charmaz (1999) points out, "Analyzing our subjects' tales and our collected stories of illness teaches us about suffering and how it affects the self" (p. 364).

A comprehensive definition of suffering according to Cassell (2004) is "the state of severe distress associated with events that threaten the intactness of person<sup>4</sup>" (p. 32, emphasis added). Cassell posits that personhood as a phenomenon is complex to understand but it is equally important to understand that different "aspects of personhood – the lived past, the family's lived past, culture and society, roles, the instrumental dimension, associations and relationships, the body, the unconsciousness mind, the political being, the secret life, the perceived future, and the transcendent-being dimension – are susceptible to damage and loss<sup>5</sup>" (p. 32). Healing, to Cassell, is restoring the intactness by reassembling parts or aspects of person in a new manner. Also, as we will observe throughout this article, suffering and healing are not two disjointed experiences. Despite experiencing distress or suffering, a humanizing space created by empathic witnessing of a listener may initiate a new enabling meaning and value for the afflicted person (Charmaz 1999, 2002; Kleinman 1973, 1988a; Morse and Carter 1996; Morse and Penrod 1999). Let us begin with exploring various facets of suffering first.

Research on suffering that has provided insights into its nature indicate that (a) suffering experiences are culturally constructed, (b) suffering associated with physical illness is the awareness of the psycho-social impact of having a disease and receiving treatment for it, and (c) suffering may not be associated a disease or a disorder.

<sup>&</sup>lt;sup>5</sup> For detailed examples see the chapter 3 of Cassell's (2004) book, *The nature of suffering and the goals of medicine.* 



<sup>&</sup>lt;sup>2</sup> It is also taken as a 'new paradigm' of social inquiry that has more similarities than differences with other new paradigms such as critical theory and participatory inquiry paradigms (Guba and Lincoln 2005).

<sup>&</sup>lt;sup>3</sup> It has also been reported that dealing with experiences of illness or 'suffering' is the concern of ill persons or their family members but paradoxically, the focus in modern medicine is on diagnosing the patient with a disease and providing treatment for that; something that usually does not address their concerns (Cassell 1975, 1991, 1999, 2004; Eisenberg 1977).

<sup>&</sup>lt;sup>4</sup> Cassell (2004) prefers to use of the term, 'person' to 'self' to avoid the general limiting meaning of 'self-awareness' associated with self. By invoking the term, 'person', he asserts that there are parts of oneself known only to others. To him, "self is that aspect of person concerned primarily with relations with oneself. Other parts of the person involve relations with others and the surrounding world" (p. 33). It is important here to note that Paranjpe's (1998) notions of self that its boundaries are uncertain and socially constructed and Baumeister's (1997) and Misra's (2010) conceptualization of self as a socially constructed phenomenon are close to Cassell's (2004) meanings of person in that self pivotally involves relations with others and the surrounding world and is not only synonymous with self-awareness. Therefore, in this paper, 'self' and 'person' are used interchangeably incorporating aspects of oneself that may be known only to others.

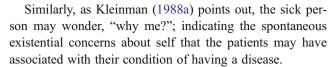
### Suffering as a Culturally Constructed Experience

Along with other aspects of personhood, relational, cultural and socio-political dimensions have been the focus of the researchers of suffering (Kleinman 1987, 1988a; Lewis-Fernandez and Kleinman 1994). In the first incident mentioned in the beginning of this paper, as she felt that the cultural norms for widowhood in her rural Hindu culture would disallow her from participating in her granddaughter's marriage, the suffering of the widow may be understood as moral distress (Kleinman 1988a). In the second incident, societal consequences of communal riots led to suffering marked by the child's anguish that he could not play with his erstwhile Hindu friends. Here, the child's suffering may be understood as socio-politically induced 'disaggregation of relationship' (Lewis-Fernandez and Kleinman 1994). Suffering is inherently subjective, local and pluralistic in nature (Cassell 1991, 1999, 2004; Charmaz 1999; Kleinman 1988a; Kleinman et al. 1998; Radley 2004; Young 1998).

### Suffering as an Illness Experience

It is important to note that since it is the *person* who suffers, suffering is not only limited to physiological symptoms or pain of a disease or a disorder. Suffering associated with a physical illness is often about an experience of being overwhelmed by the symptoms and their treatment. As Young (1998) explicates, ". . . suffering is associated with somatic pain and the moments of consciousness that accompany or anticipate this pain. To experience such suffering, an organism requires only a nervous system evolved to a point where we can say that it is conscious of its pain" (p. 245). But even in those moments of being overwhelmed, one's meanings of self or life may not remain untouched. Charmaz (1999) explicates this,

Joan Sorani is 68 years old. She has chronic bronchitis, emphysema, bronchiectisis, osteoporosis, and a history of lifelong severe asthma and undetected tuberculosis, which was later estimated to have been contracted at age 5 or 6. She often experiences a lack of oxygen because of emphysema and sometimes feels crazy when on high dosages of steroids. During these episodes, Joan feels out of sorts and out of self, as if watching someone else live in her body. Body and self seem separate. Joan remarked, "My brain sometimes gets addled because I can't remember. I think it's because of the loss of oxygen to the brain [laughs]. It's kind of strange that you can't remember all these things that you're supposed to be doing." Even severe physical suffering does not always overpower concerns about self. (p. 364)



Suffering associated with physical illness, thus, is about the 'spiraling consequences' (Charmaz 1999) of having a disease, that is, becoming aware of its impact; an impact that is also understood as an experience of 'demoralization' (loss of self-esteem or self-worth in a socio-moral context; Kleinman 1988a). Charmaz (1999) mentions the suffering of Christine Danforth, a 43-year-old receptionist who was diagnosed with lupus erythematosus, Sjogren's syndrome, and chronic pain from old back injuries. Besides bearing severe pain of treatment and hardships and humiliation in getting herself admitted to a hospital, as Charmaz points out,

"Christine has few resources – economic, social, or personal. Yet she perseveres in her struggle to remain independent and employed. She believes that if she lost her current job she would never get another one. Her recent weight gain adds one more reason for the shame she feels about her body. . . . Her physical distress, her anger and frustration about her life, her sadness, her shame, and her uncertainty all cause her to suffer. Christine talks some about pain and much about how difficult disability and lack of money make her life" (p. 364).

Besides the experience of being overwhelmed by pain, symptoms and their treatment and the awareness of being impacted by the spiralling psycho-social consequences of the disease, suffering may also be a distressing experience arising out of events such as political violence or forced migration that may devastate a person's social world or relationship that provided meaning to his or life. Such an experience of suffering is not associated with a disease or a psychiatric disorder.

### Suffering in the Absence of a Disease

Cassell (2004) asserts, "People can suffer from what they have lost of themselves in relation to the world of objects,



<sup>&</sup>lt;sup>6</sup> Michael Bury (1982) and Kathy Charmaz (1983) have used the terms 'biographical disruption' and 'loss of self' respectively to describe such spiraling consequences of having a chronic disease. For Bury, biographic disruption included the disruption of common sense boundaries of taken-for-granted assumptions and behaviour related with health and illness, rethinking of person's biography and self-concept in terms of emerging disability and uncertainty related with illness and the disruption of social relationships affecting the person's ability to mobilize much needed support or resources. For Charmaz, loss of self meant living restricted lives, experiencing social isolation, developing discrediting definitions of self (due to stigmatized identities and decreased participation of the ill person in the normal world) and burdening others.

events, and relationships. Such suffering occurs because our intactness as persons, our coherence and integrity, come not only from intactness of the body but also from the wholeness of the web of relationships with self and others." For example, as Lewis-Fernandez and Kleinman (1994) illustrate, "A collective reality such as a political upheaval like the Cultural Revolution in China, may . . . erupt in the family by disaggregating previously coordinated relationship" (p. 68), thereby causes suffering. Similarly, as Lofland (1982, cited in Charmaz and Milligan 2006) has noted, loss of a related person (due to death or severing of relationship) may mean loss of a source of affirmation and trust besides other facets of shared experiences.

It must be noted here that the person may suffer due to devastation of social world or coordinated relationship and not necessarily from neurasthenia or major depression that these authors contend might also be caused by the political upheaval. Furthermore, even if the person is diagnosed as having these disorders, these clearly do not exist "just in the interior of the body-self but equally at several social levels" (p. 68). Suffering of the widow due to moral distress in the *first* incident mentioned in the beginning of this article and that of the child due to disaggregation of relationship in the *second* also were not associated with any symptoms of PTSD.

Just as we saw that suffering may not be associated with a disease or a disorder, a person may not suffer despite having a disease. (Cassell 2004) illustrates,

I remember a man with polycystic kidney disease who was quite proud of his ultimately fatal disease because he was finally "one of them", like his mother and sister. . . . one of my patients dying of cancer of lung, literally shrugged his shoulders over his impending death from the disease that killed his father and two brothers. His children suffered at his bedside. He was fulfilling his destiny while they were losing a father. (p. 37–38)

### Healing as a Culturally Constructed Experience

Returning to the conceptualization of healing, according to Kleinman (1988a) and Frank (2000) healing is the experience of remoralization. Remoralization, according to Kleinman (1988a) is understood as "building of an illness narrative that will make sense of and give value to the experience" (p. 54). He points out that remoralization or healing is facilitated within an experiential space for a sufferer through empathic witnessing by another person. What also facilitates remoralization are the cultural beliefs, symbols and rituals that help rebuild meaning and value for the person through "culturally authorized interpretations" (Kleinman 1988b, p. 134). The section, "Theme Two: Suffering and Healing as Socio-

Historically Contextualized Phenomena' will provide illustrative examples of suffering and healing culturally constructed experiences.

After going through the definitional issues, let move on by refocusing on how the social constructionist paradigm my initiate a meaningful understanding of suffering and healing. We will do this by elaborating on the four themes mentioned earlier.

### Theme One: How Biomedicine's Ontological Claims may Enhance Suffering

Social constructionist orientation calls for an analysis of how biomedical model under the aegis of positivism relegates the experiences of misery or suffering whether or not associated with having a disease to be a non-matter for a scientific study (Cassell 1986, 2004; Gergen 1994; Kleinman 1988a). Through such a process of exclusion, biomedicine produces human suffering in the forms of 'community erosion' and 'self-enfeeblement' (Gergen 1994, chap. 6) besides causing demoralization because of, as seen above, the clinician's focus on the patient rather than on the person (with a disease). Let us begin with analyzing the former.

### Critiquing Ontological Claims of Biomedicine

It would be difficult for anyone to believe that doctors or psychiatrists are not concerned about the misery of patients in hospitals or victims or disasters, socio-political afflictions and violence. Indeed, like any other human being, they too are concerned. But, when the actual help is provided or attempted, the focus of the professional help turns primarily to addressing the symptoms of the disease. However important the meanings that a human sufferer attaches to his or her crisis situation, these are rendered untouched and delegitimized due to the clinicians' lens of biomedicine that is apathetic towards studying cultural contextualization of illness experiences (Kleinman 1985). Kleinman (1988a) points out, "The biomedical system replaces this "soft," therefore devalued, psychological concern with meanings with the scientifically "hard," therefore overvalued, technical quest for the control of symptoms" (p. 9). Cassell (2004) is of the view that there is a growing recognition of human suffering situated within the person since 1920s but the progress in medicine as a social institution would require "rethinking the fundamental principle on which it was based" (p. xviii). Gergen (1994) points out that the attempts the mental health professionals make to reduce the dehumanization biomedicine causes to the afflicted persons "remains lodged, for the most part, in the realist view of mental events and the belief that there can be objectively correct accounts of the interior world" (p. 162). Similarly,



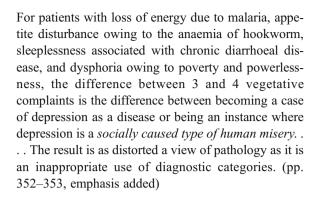
Cassell (2004) reflects, "Nineteenth-century scientific thinking as it had been incorporated into medical science, and the philosophical positivism that supported it, was the worldview underlying my training and current scientific medicine. This way of looking at the world, however, seemed inadequate to the problem of suffering and the care of the sick – medicine's basic task" (p. xviii).

Biomedicine has taken a shape of dogma. However, a historical look at the systems of medicine throughout human civilization tells us that the phenomenon of 'disease' (or analogous terms used in diverse cultures) involves "a person-centered, harmful, and undesirable deviation or discontinuity . . . associated with impairment and discomfort" (Fabrega 1972, quoted in Engel 1977, p. 130) and corrective actions are based on culturally derived belief systems constitutive of "socially adaptive devices to resolve, for the individual as well as for the society in which the sick person lives, the crises and uncertainties surrounding disease" (Fabrega 1975, quoted in Engel 1977, p. 130). To Engel (1977), Fabrega (1972, 1975) and Kleinman (1973, 1988b) then, the historical meanings of disease or illness are not confined to biological or behavioural symptoms and the social institution called medicine has been aware of the role of addressing experience of sickness or suffering located in the cultural context.

It follows from above that reality of suffering has been recognized in every historical era of human civilization. However, biomedicine, a product of Western culture, relegated experiences of suffering not to be good enough as a subject of enquiry.

### The Dehumanizing Impact of Biomedicine

Gergen (1994) contends that the use of language to describe mental states like 'attitude', anxiety', or 'feelings' in a referential or reificationist manner (presuming that language represents mental states existing 'out there' within the individual independent of the language) can mislead us towards what he called 'fallacy of misplaced concreteness'. The universalistic diagnostic categories of psychiatric disorders that are often uncritically used in biomedicine in reificationist manner may produce reliable but invalid results if applied across human population living in diverse cultural and socio-political contexts. Kleinman (1977, 1987) termed such an imposition of one culture's diagnostic categories onto some other culture (where these may be found to be reliable but invalid) as 'category fallacy'. As Kleinman (1987) points out a category fallacy that result from being blind to cultures different from the one in which the diagnostic category was founded based on its members' experiences may also lead to medicalization of social problems. For example, as Kleinman (1987) points out,



Not attending to medicalization of social problems leads to blaming the person for having the disorder while the appropriateness of diagnostic system remains unexamined (Gergen 1994).

There are other faces of dehumanization due to such a use of diagnostic categories in a reificationist manner. Gergen (1994) pointed out 'community erosion' and 'self-enfeeblement' of people diagnosed with a disorder. Diagnosis reifies the problem within the person and he or she needs standardized clinical treatment in a different set of relationship than the ones in which he or she lived before getting diagnosed. Gergen refers to this as community erosion. He illustrates this with an example from his childhood experiences with an older man, Kibby, who used to exhibit behaviour atypical of his age. He had no job and he sometimes used to play with kids. He often used to speak in gibberish. Gergen used to talk about him with his mother and she used to tell him to be nice to Kibby but not to play with him alone. The neighbours were aware of and concerned about Kibby but despite showing unusual behaviour, he was a part of the community. But as Gergen explains, in today's times, the fate of Kibby might have been different:

"At that time we had no vocabulary of "mental illness," no frightening stereotypes from movies and television, and no professionals to name and treat the "illness." Kibby was simply odd, but we all managed to get along in the neighbourhood. Today I suspect that Kibby would either be sedated in front of his television or locked in an appropriate institution, no longer a participating member of community life." (p. 150)

Gergen directs our attention to the development of self-doubt in a person diagnosed with a psychiatric disorder. He critiques the knowledge received from the textbooks of psychiatry that the afflicted person carries the deficit or disorder in all situations as it is not limited in time and space. A disorder is also taken as not limited to a specific domain of one's life and will inevitably manifest itself. Gergen illustrates this by citing an example,

At 17, Marcia Lovejoy, a woman now working to rehabilitate schizophrenics, was herself diagnosed as



a schizophrenic. Her doctors informed her at the time that because of her illness, she would never work, finish school, or be able to maintain satisfactory relationship with others. The situation they said was hopeless. Lovejoy compared this diagnosis with being told one has cancer. "What would it be like if nobody who got cancer got better, and they were called by their illness? If people said, 'What should we do with these cancers?' Isn't it too bad. Let's send these cancers to the hospital since we can't cure them" (Turkington 1985, p. 52). To be labelled by mental deficit terminology is thus to face a potential lifetime of self-doubt. (pp. 151–152)

Let us now move on and analyze how social constructionism helps understand the experiences of suffering and healing through its focus on socio-historical contextualization.

### Theme Two: Suffering and Healing as Socio-Historically Contextualized Phenomana

The social constructionist paradigm provides the legitimate ontological status to experiences of suffering as healing as socio-historically contextualized phenomena associated with physical illness (Charmaz 1999; Kleinman 1988a), emotional or psychological disturbances (Lewis-Fernandez and Kleinman 1994; Kleinman 1988b), and difficult life circumstances without any presence of a diagnosable physical or psychiatric illness (Cassell 2004; Bracken et al. 1995). Let us first examine the role of culture in shaping the experience of suffering.

### Role of Culture in Shaping Suffering

How culture shapes suffering becomes lucid through Lewis-Fernandez and Kleinman's (1994) definition of culture "as value commitments and moral orientations more akin to faith that are embodied in, and experienced by, individuals as what is at stake in specific, local setting" (p. 68). Then, as per Cassell's (2004) definition of suffering, a person may suffer if he or she is not able to meet the socio-moral demands in the local moral worlds. Lewis-Fernandez and Kleinman's (1994) have illustrated such a socio-moral basis of human suffering in the Chinese communities,

As renqing (favor based on human feelings and moral sensibility), emotion is a resource that can be exchanged, owed, or given as a gift along networks of social connections (quanxi) that bind participants in rules of reciprocity (bao; Hwang 1987). The appropriate exchange of favor energizes the social net with qi (vital force), which results in healthy individual

minds, bodies, and communities. Favor connects with face (*mianzi*, *lianzi*), an embodiment of social power that represents one's moral capital and one's prestige in the interpersonal field. To lose face is to lose one's ability to engage in reciprocal affective relationships guided by moral norms involving *renqing*; it is to be demoralized, bereft of *qi*. (p. 69).

Kirmayer (1989) too observes that distress in different ethnomedical systems is expressed in the form of disrupted social and moral order. Studies conducted among people affected by war, atrocity or violence have indicated that they suffer not necessarily from PTSD but due to the devastation of their social world or web of relationship resulting in debarring the person to exercise his or her socio-moral commitments (Bracken et al. 1995; Summerfield 1999; Young 1998). Bracken et al. (1995) illustrate this citing the case of one of the woman survivors of the government's counter-insurgency operation in 1980s in Uganda in which hundreds of thousands of civilians were killed,

A 28 year old woman who witnessed her husband being killed by the army was unable to bury his body as she was forced to flee the area immediately with her children, for fear that she herself, would be killed. When she was able to return 6 months later his body could not be traced. When she was seen by members of our team some 5 years later she was still haunted by nightmares and feelings of shame because she had not been able to bury her husband according to traditional rites. It was this aspect of her loss that she spoke most about when interviewed and which seemed to cause her most distress. (p. 1077)

Culture and cultural norms are not uncontested sites. As Gergen (1985) mentions, realities like cultural norms are not only culturally constituted but are also contested by different stakeholders within the culture. Therefore, adhering to the norms may not always result in a humanizing experience such as *qi* (vital force) experienced in the Chinese culture mentioned above. Cultural norms may suffocate or deny an experiential space to a person as observed in the *first* incident mentioned in the beginning of the article. Furthermore, moral distress may also be associated with disaggregation of relationships. For example, the case of a woman presented in their study of the impact of civil war in Uganda by Bracken et al. (1995) illustrates this point:

A 34 year old woman with five children had been rejected by her husband because of the fact that she had been raped by two soldiers 5 years prior to her interview with us. He had turned her off the small holding which she had cultivated. As the rest of her own family had perished or been dispersed in the war, she had to survive on what she could find in the bush



until ultimately she found her way to the home of some distant relatives who took her in. unable to explain what had happened to her because of the shame she felt regarding her circumstances and the fear of further rejection if her plight was known, she relinquished any rights she had to the land and to her children and remained in the position of a servant in her relatives' home. Five years late she was still suffering terrible grief over the loss of he children and had had no other relationship during that period. The lack of support because of social attitudes towards rape and the political position of women at that time in Uganda prevented her from asserting any rights she may have had regarding the custody of her younger children. (p. 1079)

Returning to suffering due to spiralling impact of chronic illness, not being able to execute one's role or commitments (that are culturally valued) due to the disability caused by physical illness may lead to sense of worthlessness or what Kleinman (1988a) calls demoralization. This leads us to another aspect of suffering due to chronic illness in the socio-historical context.

Suffering Due to Chronic Illness as Low Moral Status

Charmaz (1999) posits that in the beginning, suffering may present opportunities to perform the myth of a hero emerging from a battle. But, time my gradually erode high moral status as suffering implies work for chronically ill, caregivers and coworkers. Charmaz explicates this,

A professor in an understaffed department suffered a rapid decline that resulted in his colleagues taking over his classes. Although they said they did so willingly, he sensed how burdened they were and felt that he had let them down. Meanwhile, his colleagues banged at the dean's door, saying, "How can we get him out of here?" Moral claims of suffering seldom long preserve a person's public status. (p. 369)

If illness leads to low moral status, stories of ill persons may resist a mention of their suffering to avoid moral judgement. This brings us to another aspect of suffering in the socio-historical context and it may be termed as silent or silenced suffering.

### Silent and Silenced Suffering

Charmaz (2002) points out, "Ill people intentionally remain silent when they believe that (a) other people can not comprehend their situations, (b) their views would hurt a significant person, (c) voicing them would prove too costly, and/ or (d) no one wants to hear the story" (p. 309). She reports

the case of Ron, a young man, who faced multiple sclerosis and was bedridden due paralysis,

As his body failed, his world narrowed, and his autonomy shrank. His main contacts dwindled to the male caregiver in whose home he lived and a young church volunteer. After being stuck in a nursing home for months against his will, he appreciated living in a "real" home and savored his volunteer's visits. However, his inability to do any bodily self-care, much less anything else, left him feeling useless. He wanted to die. But he could not voice his feelings. Talk of wanting to die or commit suicide had kept him in a nursing home for months before, and anyone without money who required so much physical care was hard to place in the community. His caregiver told me that Ron knew he was pledged to report any death or suicide talk. For Ron, that meant being sent back into a nursing home, a fate he saw as worse than death. He also knew that such talk would hurt his mother and his volunteer. Thus, he chose not to burden them with his feelings. (p. 309)

Ron became silent about his suffering to avoid moral judgements in case he broke his pledge and to avoid hurting the feelings of people who were important in his life. In her study on suffering associated with multiple sclerosis among patients and their family members, Anand (2010) found that one of the participants rationalized her daughter's emotional distancing by commenting that she was not available as a mother when her daughter needed one and hence it was wrong to be angry about the daughter's behavior.

Furthermore, on some occasions when an ill person has to face expressions of value judgements and acts of resistance directed at him or her, the ill person's suffering is both aggravated and silenced from being told further. We may recall the plight of the ill professor mentioned above by Charmaz (1999). Similarly, being faced with a *researcher's or health professional's insistence to extract explanations of illness experiences* (rather than the researchers' sensible response of being an empathic witness to the overwhelming experiences of illness) is another condition when the experiences of suffering are silenced. Radley (2004) explains, ". . . the failure to acknowledge the 'uselessness' of total suffering – and with that, the inability to provide relief or make it sensible – is actually to banish it further by 'speaking over it'" (p. 38).

### Role of Culture in Shaping Healing

As mentioned earlier while conceptualizing suffering and healing, healing may be understood as process of remoralization in which a sufferer may, within a humanizing space created by a clinician, family member, healer or a



researcher, develop an enabling meaning and value for his or her experiences (Kleinman 1988a; Frank 2000). However, as Kleinman (1988b) has illustrated, this "transformation is created out of the *effective enactment of culturally authorized interpretations* (p. 134, emphasis added).

Kleinman provide examples from two diverse cultures to illustrate how culturally authorized interpretations may lead to healing or the development of a new meaning and value for his experiences. He first presents a case from a non-Western culture:

A threatened and demoralized Taiwanese patient, for example, who fundamentally questions his sense of self-efficacy, accepts a shaman's master myth of a calm, reassuring, effective spirit commanding his consciousness. During the ritual treatment he enters trance and is possessed by the guiding spirit, during which time he expresses his fears in a crescendo of cathartic release authorized in the ritual setting. . . . Through this powerful therapeutic experience, the patient reverses his negative cognitions, lessens anxiety and depression, and begins to transform his personality. As a member of the healing cult, moreover, his status is elevated and practical difficulties is his social life (e.g., too few clients for his woodworking business, and the absence of close friends to whom he can explain his fears of business failure and from whom he can receive affective support and practical advice) are overcome through his new social network. (p. 135).

In another example, Kleinman illustrates the role of such culturally authorized interpretations of experiences in Western culture:

A deeply demoralized middle-class North American housewife accepts a cognitive behavioral model of her problem as a matter of the personally destructive effects of ideas of self-inefficacy which can be changed through a relationship with a therapist who applies an authorized protocol of behavioral interventions. The positive cognitions, like those of her Taiwanese counterpart, only here sanctioned by behaviorism's epistemology and experienced through the mediating symbolic meanings of the cognitive therapy, alter the patient's self-image and that endocrine and autonomic nervous system activity experienced a decreased dysphoria, improved sleep and energy, and diminution in pain, weakness and other symptoms. (pp. 135–136)

Importantly, Kirmayer (2004) has indicated about the possibility clinicians have to combine healing practices of diverse cultures to help utilize their efficacy for the afflicted person, his or her family and community. Such an innovation may help facilitate healing of people living under a flux

or change of culture often forced by historical events such as migration and globalization.

We have noted in Kleinman's (1988a) conceptualization of healing or remoralization that a humanizing space created through empathic witnessing by the listener may initiate it. Let us look at this process closely through a social constructionist orientation.

### Theme Three: Suffering and Healing as a Performance within Human Interaction

The premise in social constrctionism that social interaction initiates or regulates some social action rather than representing a discourse independent reality highlights the potential the researchers and professionals in the interdisciplinary domain of health have to provide legitimate space to suffering and facilitate healing while attempting to empathically understand experiences of the sufferer (Kleinman 1988a, b; Frank 2000; Charmaz 1999, 2002). Let us see how compassionate responses that are premised on empathic understanding of experiences serve the function of validating the experiences of suffering and initiating the process of healing.

Role of Compassion in Shaping Suffering and Healing

Experiences of suffering that may be overwhelming can often not be verbalized. Furthermore, as Radley (2004) posits, such an intense experience of suffering has no intrinsic form that can be further revealed through inquiry and explanation. Such experiences of suffering may remain unavailable to the knower but not to the person in him or her. But what is of utmost importance to the sufferer is that his or her experience is not delegitimized or denied a space. As noted earlier, deliberate attempts to seek meanings and explanations of suffering may be entirely fruitless or it may also result in silenced suffering. Radley argues, ". . . the recognition of suffering in the other is seen here as less an explanation (of suffering) than as being the condition for, what we might term, its legitimated presence" (p. 38).

Compassion is the form of engagement through which a knower may recognize suffering while simultaneously providing a humanizing space for it. Radley explains, "Other's suffering recognized in my own experience is that which provides not an explanation but a demand for a response that

<sup>&</sup>lt;sup>7</sup> Besides, through the social constructionist orientation, as we saw above in the section, 'Theme One: How Biomedicine's Ontological Claims may Enhance Suffering', we may understand the economic and political (creating the dichotomy of 'deficient other' and 'service-provider'; Sampson 1993) purpose for self-enhancement that scientific biomedical model might serve to the scientists and professional who implicitly or explicitly follow positivist paradigm.



in its immediacy is termed compassionate" (p. 35). Thus compassion that involves empathic understanding may give shape to suffering (that has no intrinsic form in the sufferer who is overwhelmed with experience) by endorsing it.

Ellingson's (1998) interest in the research on health communication in a cancer research hospital was intensely related to her own past experiences as a bone cancer survivor. During her research, she could empathize with her participants,

When I weep for Evelyn Anderson, I weep for myself. And when I sit alone with my journal and grieve my pain, I also grieve the collective pain of cancer survivors. (p. 507)

The compassionate responses that she could give to her participants endorsed their suffering besides enabling her develop an empathic understanding of their experiences. She reflects on her interactions with a participant,

Sitting with Evelyn Anderson, I felt very involved and very much part of the setting. I was deeply moved by her plight, and *I felt like a staff member caring for her needs. At the same time, I could empathize with Ms. Anderson's perspective.* To use the parable of the blind men and the elephant, I shifted between feeling the tail, the trunk, and the leg. This dynamic perspective enables me to describe the setting and the participants in a manner that reflects the complexity of the setting. (p. 506, emphasis added)

Also, the acts of imagination and reflection as a person, rather than a professional or a researcher, may help empathize with and endorse the experiences of suffering. Radley (2004) illustrates this with an example of a patient who he wanted to interview in his research on illness experiences but he had to wait until the surgery that she had to undergo in a hospital was successful. Later, while shopping in a supermarket, he could reflect on the difference in his current preoccupations and the plight of the patient and her husband. He shares,

Suddenly, in the act of reaching for some trivial item, our seemingly limitless scope of action made their suffering tangible for me for the first time, in a way it had not been when I spoke to them in the hospital. I reflected on our relative situation; to be able to move about the shop (*versus* not to be trapped in a side room on a hospital ward), to be able to plan one's own eating for the evening (not to denied food in preparation for surgery), for my wife and I to plan together the next 24 hours (not to have that time sense, perhaps ever again). . . . I knew the couple's suffering through its implied absence (as an active emptiness) in the fullness

of the presence of the world enjoyed by me and my wife at that time. (p. 39)

Compassion or empathic witnessing may also facilitate the process of remoralization or healing (Charmaz 1999, 2002; Frank 2000, 2001; Kleinman 1988a). I was reminded of my childhood crisis (of being told by my family members about the uncertainty of my mother's recovery from meningitis) the day I interviewed a widow in her mid-40s in a post-earthquake setting (Priya 2010). She began to weep before me after she shared only this about her daily routine, "kain . . kain karun chhun" ("something"). It was indeed difficult for me to bear the minutes of silence that followed. Before taking leave and promising to meet her again, she insisted that I should take tea that she made and served quietly. Before leaving the field after completing my field work, I asked her whether she felt bad about or wanted to avoid my interactions with her about her suffering. She said, "Tame prem thi puchu chho, tyare bikh nathi laagto" ("You interact with compassion; therefore, I do not feel sad talking to you about he incident" p. 486). The compassion that she noticed in my way of interacting during the interviews with her perhaps also created an experiential space in which she could gain meaning and value for her experience. She shared in one such interview with her how the cultural belief in karma (internalized duties toward self, family, community, and nature) shaped her meaning in life then,

"My two nephews stay with me. Sending them to school, looking after them, offering my services at the ashram of Mansingh Das Baba [a Hindu priest of the village], and doing satsang there keeps me engaged the entire day. My work, satsang, and devotion to God are everything for me." (p. 486)

If compassion may help a researcher to empathically understand suffering (besides endorsing it) and facilitate healing, it may help clinicians also to attempt to achieve the same. Let us see how this may be possible.

### Redefining the Roles of Helpers

Cassell (1973, 2004) is of the view that knowledge of medical science or the art of medicine in itself does not relieve suffering. A compassionate person in the clinicians does that. Cassell (2004) explains,

The patient and the illness are not merely experienced, they are experienced by this particular physician. The problem is that experiential knowledge is tinged with emotion and passion—it cannot be otherwise. Centuries of trying to disengage the person from knowledge born of experience through science or other means have not been successful. The solution to the problem lies in remembering that only another person can



empathetically experience the experience of a person. In medicine the triad is inseparable—patient, experience, physician. It must finally be accepted that there can be no substitute for the physician as a person. (p. ix)

He recognizes that the clinician as a person would be exposed to unavoidable uncertainty and overwhelming subjectivity associated with chronic illness and suffering but he is optimistic that with help of suitable education and methods it is possible "that these dangers are converted into therapeutic power" (p.ix).

Kleinman (1988a, 1992) has recommended the use of mini-ethnography and a brief life history as methods that may gain insights into illness experiences. He also emphasizes that once a clinician recognizes the significance of his or her involvement as a person within the professional relationship with the ill person, it may facilitate healing. According to him (Kleinman 1988a),

Whatever else it is, psychotherapy is a deeply moral relationship. The practitioner attempts to be with the patient in the ambit of suffering. The patient actively opens his life world to their conjoint exploration. Practitioner becomes a moral witness, neither a judge nor a manipulator. Patient becomes an active colleague, not a passive recipient. Both learn and change from the experience. . . . When the tasks of support, attention to emotional needs, and negotiation of an authentic relationship are accomplished in a caring fashion the question of how to do medical psychotherapy vanishes. That is psychotherapy. (p. 246)

We now move on to the methodological challenges associated with the study of suffering and healing that carry forward the message of the probable use of compassion in the research interactions.

## Theme Four: Research on Suffering and Healing through Dialogic Partnership

The social constructionist paradigm invites researchers to utilize qualitative research such as ethnography, interviews and action research to create dialogic partnership with the participants by providing legitimate space to their worldviews or perspectives (Charmaz 2004; Denzin and Lincoln 2005; Sampson 1993). This new methodological focus may be utilized to gain meaningful insights into the contextualized experiences of suffering and healing (Kleinman 1988a, 1992).

Research that tends to understand subjective experiences of suffering and healing is gradually entering into medicine. Cassell (2004) asserts, "With a few exceptions, the

worldview, knowledge, and disciplines trying to gain entrance to medicine and parity in the curriculum are based on the subjective" (p. xiv). Marsella (1998) emphasizes that qualitative research approaches are suited to study of subjective experiences as he mentions, "qualitative research openly acknowledges the interpretive influence of the researcher in arriving at conclusion; in doing so, it legitimizes and endorses subjective research approaches" (p. 1287). Gergen in his interview with Cisneros-Puebla (2008) takes the growth of qualitative research as a healthy sign as it provides a space to the voice of the participants. Gergen contends,

And I am an enthusiastic supporter of the qualitative movement. In my view, all methods of research come with values and ideology attached. Thus, as we expand the range of research methods, we also expand the range of voices participating in the molding of the future. There are other reasons as well, but I am most pleased with the development of action research, narrative methods, ethnography, auto-ethnography, performance, and more. (¶ 56)

We have already observed in the previous section ('Theme Three: Suffering and Healing as a Performance within Human Interaction') that the use of ethnography (Ellingson 1998) and interviews in ethnography (Priya 2010) in understanding through empathy and co-construction the meanings of suffering and healing. Kleinman (1992) illustrates the ways ethnography can be used for this purpose.

The ethnographic approach to illness and care clarifies the social course of illness and the social construction of clinical work, and it opens for study a range of novel if vexed questions concerning the interplay between social, psychological, and physiological factors in health and sickness. It also gives access to aspects of suffering that are obscured and distorted by standard biomedical and epidemiological studies. I have in mind the particular instances of the delegitimation experience of chronic pain and chronic fatigue syndrome patients whose experiences are unauthorized by practitioners, and also the liberating insight that come when we get to see at least some examples of noncompliance, as chronically ill persons resist the dominating definitions, records, and commands of their caregivers. Yet other examples abound in which the ethnographic focus, which decenters critical attention away from individual pathology and sick persons and toward aspects of the interpersonal context, opens new directions that powerfully illuminate suffering and its care. (pp. 131–132)

As evident from above, ethnography among other methods endorses the spirit of dialogic partnership that advocates



researcher being co-authors with the participants where, as Sampson (1993) emphasizes, "A genuine dialogue requires a meeting among variously positioned standpoints, among persons who have an equal say in the discursive processes out of which their joint realities are constructed" (p. 1227).

### **Concluding Comments**

With the help of this article, I attempted to highlight how the hopes of bringing about a paradigm shift in medicine through research on suffering and healing have been partly fulfilled. As reflected in the article, the three eminent social scientists have outlined the ways in which the promise of this paradigm shift may be realized. What is of particular interest is the fact that ethnography and other types of qualitative research are increasingly providing critical and culture-sensitive understanding of human problems and their interpretation through the concepts of suffering and healing (Kleinman 1992). Besides this, there are indications of a growing realization among medical practitioners and researchers of health and illness experiences that a social constructionist paradigm may be more appropriate for medicine (Wilson 2000), ideas and clinical approaches of Western biomedicine and non-Western systems of medicine may by synthesized to achieve a more meaningful model of psychiatry (Lake 2007) and medicine's primary focus should be a person-centred approaches to care and healing (Harris 2009; Stange 2009).

While the meaningful outcomes of a paradigm shift in medicine through an emphasis on care and healing is being increasingly realized, a note of caution is also warranted. According to Gergen (1994, 1997), social constructionist paradigm inherently reminds of the danger of reifying its co-constructed research findings as the reflection of the true reality out there and the paradigm itself as the way to discover reality. Gergen in his interview with Cisneros-Puebla (2008) comments on this issue,

There is a danger in championing constructionist ideas so strongly that they take on the character of "is true." So, I have to say to myself, "be careful that you do not become so engaged in these ideas, that you cannot see them as a construction." To do so would be to give up one of their major sources of hope for the future. (¶ 78).

Similar to this, Frank (2001) among other researchers of chronic illness alerts us about the dangers of reifying understanding of the experiences of suffering and healing by using forced narrativization and fitting experiences into extralocal categories,

Research is always caught between the imperative to speak, which risks reinscribing the local under some extralocal category, and the equal imperative to recognize but remain silent. Yet silence, however respectful, risks abandoning the field to the standpoint of extralocal discourse. The censoring of what does not fit remains unchallenged. (p. 361)

It becomes important then to emphasize that a researcher of suffering and healing processes who adopts interdisciplinary approaches of new paradigms should understand the importance of compassion in shaping them as Frank (2001) contends, "Qualitative researchers pride themselves on their personal encounter with ill people. Remember, how you touch them affects their healing, and your own healing too" (p. 361). This is not to reify compassion as *the* technique because as seen earlier, Radley (2004) along with Kleinman (1988a, 1992) reminds us that there may be other meaningful methodologies to study human experiences of suffering and healing.

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