Original Article

Re-examining the psychology of spinal cord injury: a meaning centered approach from a cultural perspective

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Objectives: To examine the impact of SCI from a non-Western cultural perspective.

Setting: India.

Methods: A philosophical approach.

Conclusion: Management of the individual with spinal cord injury needs to take in to account the individual's beliefs and cultural context.

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Introduction

The process of re-adjustment from SCI requires substantial coping by the patient and their carers. They experience a significant burden especially in the social role and functioning of the individual and adjustment to the disability.^{1,2} This burden, if excessive, may lead to emotional break-down among people with SCI. Despite the last few decades having witnessed an increase in literature regarding psychological reaction to people with SCI^{3,4} and their carers^{5–7} there is a paucity of studies on individual conceptions of the experience of SCI. However, the few studies that address these individual conceptions of the experience of SCI are based on Western European perspective.^{8,9} This study attempts to address the psychology of SCI from a non-Western cultural perspective.

Stage theory – is it a psychological imagination?

Theoretical approaches to the understanding of psychological adjustment to SCI have recently experienced a re-examination, which seriously questions the traditional 'stage theory' of adjustment. Stage theory represent the process of psychological adaptation which involves an initial period of shock and denial, anger, depression, self pity and slowly moves to acceptance of this 'personal tragedy' in order to achieve effective adjustment. Despite limited empirical validation at best, the stage theory has not only

enjoyed an unchallenged popularity amongst rehabilitation professionals but also amongst research personnel who have tended to over-estimate depression, anxiety, and social discomfort while under-estimating the optimism of their SCI people and their carers.^{10,11} How good is this, is a matter of debate. The question here is: Are we the less insensitive rehabilitation professionals who can go beyond this labelling process?

The incorporation of this 'personal tragedy' into their (people with SCI) ongoing life world is a process of rebuilding of a new self in a life world. This process focuses less on the personal reactions of someone's loss and more on the readjustment to the social arena.¹² For example: What it is to be a wheelchair user, to be a person with disability, and how do I carry on? These are fundamental questions of human life. Although the emotional response or 'stage theory' gazes at an ever-receding present as it moves further and further into the past, from our perspective, stage theory has failed to capture the complex problems of people with SCI who perceive themselves as ordinary people coping with extraordinary circumstances.

The interaction between culture, human subjectivity and SCI: basic assumptions

The fact that different cultures may give a different content to orientations of the self and provide different meanings and emphases about the self and its behavioural objects and environment, is not controversial. What is at issue involves whether, as a result of internalising different systems of meaning, individuals

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perceive the world differently, conceptualise differently and emote differently. In a basic way, the self is a by-product of a cultural meaning system. Put another way, cultural meaning system represents the world, directs oneself to do something and evokes certain feelings. Given this as background, human subjectivity cannot be viewed as similar cross-culturally.

Recent developments in this field of anthropology will also have a direct bearing on studies of the psychology of SCI cross-culturally. Although the psychological dimension, particularly self-perception and self-acceptance has been considered by some authors^{8,9,13} to be the most crucial indicator of achievement of rehabilitation goals, this has been greatly influenced by Western European knowledge and experience. Even researchers who insist on individual explanations regarding the experience of SCI, ground their criticisms in notions of 'rediscovery of self' and 'redefining disability'.^{8,13} They neglect to consider that sadness, anger and distress vary across cultures.

Recent advances in cross-cultural research have begun to address these issues.¹⁴ Evidence from a number of sources propose that social and cultural factors are important in the conceptualization of illness and seeking help.^{15–17} Though there are very few studies in this area,^{18–20} evidence seems to be emerging that social and cultural factors are important in rehabilitation research. The studies that have explored the cross-cultural issues in disability and intervention have demonstrated cross-cultural variations in beliefs and attributes and insisted on culture-based interventions.^{21–24}

It appears, therefore, that more emphasis should be given to the role of cultural knowledge in the personal experiences and concerns of non-Western people. In our view, the understanding of the human subjectivity or the self from a cultural perspective is central to an understanding of the psychology of people with SCI.

Depression in people with SCI – from a cultural perspective

Cultural beliefs and practices affect nearly all aspects of mental disorders – assessment and diagnosis, illness behaviour and help seeking, expectations of patients and health professionals and the acceptance of appropriate therapies. The ways in which subjects of a particular culture express, experience and cope with feelings of distress are called 'idioms of distress'.^{15–17} Culture also has an important role in defining norms and influences how particular behaviours are judged. What may be abnormal and psychopathological in Western culture may be considered culturally acceptable in a non-Western society and vice versa.

Depression after SCI is a near universal phenomena – this sort of sweeping statement offers a superficial means of approaching a person with SCI. In the past, the methodological issues in assessing depression in people with SCI were rigorously reviewed and possible alternatives were discussed.²⁵ However, the data

produced even in this form failed to explain in a compelling way how individuals from diverse communities conceptualise personal experience, rationality, irrationality, emotions of sadness and depression?

The Western European perspective on SCI rehabilitation has focused on rediscovering self, identifying individual needs and differences.^{8,9,13} However, all of these notions about the nature of self and others are necessary aspects of what is understood by culture. Different cultures may give a different content to orientations of the self and possible different meanings. So, what is universal and what is culture specific is a controversial issue. The question here is: Do non-Western varieties of human subjectivity exist? If so, how do we understand those experiences and make that experience available to rehabilitation professionals if research cannot tell us about it – the research defined in terms of the 'gold standard'? Do we have an answer for these queries? From our perspective, we do. For this, first we must simply listen to what these people would tell us; individually as clients; and as research participants. One of our research participants (part of our ongoing qualitative study) told us:

'Doctor ... initially (after SCI) we lose ourselves ... then we search ourselves ... at last we find ourselves ... we don't know whether this is what we are searching for ... but to live through this fully aware of it all the time is a real struggle ... I don't know whether you have understood ... but this is what the truth is.'

Few people have this capacity to look at one-self and can express the pain and struggle that they go through. Although this may be labelled as depression, this happens to people with the same cares, concerns, and anxieties as the rest of us. Over time, this depression will melt into the commonplace tribulations of life. However, rehabilitation professionals should not forget that these people are usually an elite as far as education and ambitions are concerned, and do not necessarily represent the needs of poor people with SCI living in rural areas of developing nations. When we administered our in-depth interview one person said:

'I believe that this came from *karma*. I do not know what does that mean. My *naattu vaidyar* (native healer) spoke a lot about the influence of deeds in the past; I thought that must have caused it.'

Such themes are common among poor people with SCI living in rural India. Non-Western perspective (for instance, Indian religiosity) have long focused on passivity and external locus of control, inferred from beliefs in fate and karma. Anthropological research of karma in popular Hinduism emphasizes 'moral responsibility and destiny' as well as the 'unpredictability of human fortune in the short run'.²⁶ Although karma specifies ideas of cause and effect in the context

of moral economy, the context in which these people generally mention it seemed to emphasise the unpredictability of events. The way these people emphasise karma looked as if it is a cultural idiom meaning 'I don't have any idea, so it must be karma'. While such ideas may be associated with the failure to make use of available help, a closer look from this cultural background however, suggests that these persons with SCI and their carers in fact bear the weight of moral responsibility as well, akin to guilt, which increases their psychological distress.^{26,27}

Although Islam rejects the concept of karma or rebirth, diseases in Islamic psychology are of four types: spiritual (severe mental disorders), functional (personality and coping styles), structural (organ involvement), superficial (skin diseases).²⁸ In addition, treatment in Islamic psychology insists more on religious practices as the most effective intervention in the process of health promotion.²⁹ Although Islamic psychology gives a lot of importance to logic and imagination, when it comes to physical, psychological and social diseases Muslim scientists explain more in terms of moral principles. These cultural models of sadness, anger, and pain, for instance, explains how people use these terms – when, under what circumstances, why, and with what consequences. In this cultural framework, selfhood cannot be viewed as similar cross culturally, and in so far as SCI disturbs the integrity of self, individual experiences can be expected to bear the impact of distinctive cultural influences on the self.

We do not have rigorous research evidence to substantiate these culturally specific ethno-theories (native people's assumptions, premises, concepts about an area of concern). However, ethnographic and clinical interviews, conducting focus groups and listening to our clients provided something like a window into the kinds of alternative conceptualisations of the experience of SCI. In non-Western cultures' norms, collective needs, collective self-definitions, and values are often more important.³⁰ Emotions of sadness and depression in people with SCI vary across culture. Understanding this will broaden our service delivery, with attention to diversity based on the needs of individuals within the context of their respective cultures.

Conclusion

Future research in this area has to focus on cultural and clinical context to identify locally meaningful categories, elaborating insider's point of view (the *emic* approach), careful observation and description of the interaction between linguistic and nonlinguistic behaviour in settings of cultural importance and the selected use of native people's assumptions and beliefs about SCI. This meaning centered approach will help us to reexamine the psychology of SCI, application of this may facilitate a more client centered approach to rehabilitation practice.

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