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Impact of Culture in Caregiving Experiences in the Context of Mental Illness: A Brief Review

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The scope of this paper is to provide a brief review of some Indian studies wherein 'culture' has been placed in the central position in researching caregiving in the context of mental health. Taking a biopsychosocial lens, an attempt has been made to explore the effect of explanatory models and mental health related beliefs on overall experience of caring. Another aim is to examine the scope of qualitative research in studying caregiving experiences. Thus, the reviewed studies in this paper are the one that have employed the qualitative methods or broadly speaking, alternative paradigmatic approach. In the final section, an argument is made on the need for more studies on care giving taking a biopsychosocial and qualitative research approach in Indian context.

Keywords: Care giving, Mental illness, Culture, Explanatory models, Health Beliefs, Indian Context

Research in the area of caregiving has focused on exploring and measuring the consequence of caregiving. Factors such as, caregiving burden, stress, effect on quality of life and well-being of the caregivers have been studied extensively. Research has also focused on coping patterns of caregivers, subjective wellbeing, and benefit finding through caring experiences.

The caregiving research in India in the context of mental illness has long been dominated by the positivist theoretical paradigm, where the focus of research has been to measure the caregiving burden, extent of burden, comparison of experiences in different mental illness, the quality of life of the caregivers, coping pattern, association between caregiving experiences and socio-demographic variables of caregivers, severity of psychopathology, social support and caring, association between expressed emotion of caregivers and quality of life of the patients, relationship between burden and coping and so on (e.g. Mubarak & Barber, 2003; Chadda, Singh, & Ganguly, 2007; Kalra, Nischal, Trivedi, Dalal, & Sinha, 2009; Aggarwal, Avasthi, Kumar, & Grover, 2009). All these studies have used different scales and measures as their tools, used statistical analysis methods and have been conducted using homogenous samples.

However, some studies have been done to explore the influence of culture in shaping the meaning of caregiving. Unlike the studies done using the quantitative method, studies using the qualitative approach have tried to uncover the contextual factors responsible for development of health related beliefs and practices. Also, these studies have focused on how these factors shape attitudes towards patients and illness. Thus, an alternate research trend is now visible in the area of caregiving in India. These new trends in mental health research demonstrate sensitivity towards community health care development and relevance to culture specific questions in mental health care.

As the nature of the research questions have become more culture centric, studies in mental health have started considering the importance of explanatory models (Kleinman, 1978), biopsychosocial framework (Engel, 1978) and qualitative approach (details about the biopsychosocial approach and explanatory models are discussed in the next section). Qualitative methods like ethnography, narrative inquiry, grounded theory, focus group discussion, unstructured in-depth interviews and observation have enabled the researchers to address some unattended and underexplored issues, which are important to understand health care related

issues. Moreover, the in-depth, flexible and self-reflexive nature of qualitative methods has opened up a new dimension in caregiving research in the Indian context. Studies related to explanatory models are not new in India. In fact, the Explanatory Model Interview Catalogue (EMIC; Weiss, 1997) was developed in India and is now widely used in exploring explanatory models in both mental as well as physical health context. Still, this area needs more attention as the number of studies, in which culture takes the central position in mental health context, is very less and most of these studies are based on a particular region of India.

The aim of the present paper is to provide a brief review of influence of culture in caregiving experiences in the context of mental illness. Attempt has been made to review the studies done in the Indian context that have used qualitative methods. The paper has three sections: the first section addresses how culture is related to mental health care; the second section aims to describe some of the relevant studies that have been done in Indian context; and the final section addresses the emerging issues and the future directions of caregiving research.

Culture and Mental Health Care

Culture signifies the set of common beliefs and practices, driven by certain norms and values, shared within a group or community, which is subject to change over time. It is regarded as the shared meaning shaped through learning at different societal level (Bhugra, 2006).

Culture structures the way people define what is abnormal and deviant, how illness is defined and how and where help is sought, as it is culture determines what resources are available for managing what kind of distress. The understanding of culture allows us to identify the precise role culture may play in individual's lifespan of illness. (Bhugra, 2006; p. 17-18)

Health care systems are cultural systems. Health, illness and health care are interrelated as their meanings are embedded in a particular cultural context (Kleinman, 1978). Culture plays an important role in understanding health and health related aspects, like the diagnosis of illness, management of illness, and promoting health related beliefs and behaviour (Kleinman, 1978; 1988; Liang, 2002; Bhugra, 2006).

The health care system, as a cultural system provides a framework for illness related adaptations and structures the main functions related to health care. This includes six culture driven tasks - (a) meaning of illness shaped through social learning and certain socially practiced norms; (b) the choice of treatment and professionals are determined by the existing cultural systems. This also includes the appraisal of the treatment and its outcome; (c) the illness management as understood and communicated through available classification, labels and explanations at personal and social level; (d) the clinical intervention, health related care (biomedical care) along with other health care systems that are practiced within the cultural context constitute the healing activities; (e) health seeking behaviours (health enhancing /lowering behaviour) as shaped by existing cultural practices; and finally (f) The outcomes of handling the illness as shaped by the local culture (Kleinman, 1978).

The health related beliefs and perspective held by patients, families and the local culture are called explanatory models, which explains the "aetiology; onset of symptoms; pathophysiology; course of sickness (severity and type of sick role); and treatment" (Kleinman, 1978; 1988). The health-care relationship signifies the relationship between patient and family, and patient and professionals and can be understood as a give and take between different explanatory models of actors involved within a health care system. Also, these explanatory models interact with relevant "cognitive systems" and "social structural positions" within its context (Kleinman, 1978, p.88).

Generally, a health care system consists of multiple health care models- such a system is called a pluralistic system. According to Kleinman (1978) there are three social sectors of the existing health care system "within which sickness is experienced and reacted to": popular sector (care at individual, family, society and community level); folk sector (non-professional healer); and professional sector includes biomedical care, Ayurvedic, Unani etc.

(p.86). The perspective held by different sectors guide's people's attitude towards mental patients (Prabhu, Raghuram, Verma, & Maridass, 1984).

Nevertheless, the dominant discourse generally promotes a culture-free as well as context free health care system and practice (the biomedical model), the existence of pluralistic health care practice or biopsychosocial approach is documented (Engel, 1978; Kleinman, 1978; 1988; Muller & Steyn, 1999). The biopsychosocial model, unlike biomedical model in health care considers the psychosocial factors and cultural practices in health care system (Engel, 1978). As proposed by Engel (1978) a biopsychosocial model considers the patient, the socio-cultural context of patient, and other available medical systems (folk and indigenous health care system) to understand and determine the illness in a particular context. However, the biomedical model is not sensitive towards the existing socio-cultural context of illness and because of that it has been questioned and criticized (Engel, 1978). In South Asian countries, especially in India, biomedical system coexists with strong indigenous medical systems, like Ayurveda, Tibetian, Unani (Bhugra, 2006; Dalal & Misra, 2006; Patel, Sumathipala, Khan, Thapa, & Rahman, 2007) and traditional, religious healing (Campion & Bhugra, 1998; Raguram, et al. 2002; Shankar, Saravanan, & Jacob, 2006). The existence of pluralistic health care systems in India and other Asian countries makes it imperative to place culture in the central place to understand the caregiving practices in mental health context. The following section will discuss the research done in the Indian context where influence of culture on health related beliefs, treatment seeking behaviour and management of mental illness has been explored in mental health context.

Some Research Examples in the Indian Context

Studies in the Indian context mostly focused on finding and measuring the causal attribution of the metal illness. However, a shift is happening within contemporary research interests among researchers that are more focused on exploring the influence of culture in shaping health care practices. The shift is also happening in choosing the research paradigm. As the number of quantitative studies (mostly focused on measuring consequences of caregiving) has reached its saturation, contemporary researchers are showing interest in qualitative research. As a result of the paradigmatic shift in research interest, different interrelated areas, which were previously ignored in caregiving research in India, have emerged. Most of them were done taking biopsychosocial approach and used qualitative research techniques to explore the social reality. A number of studies were conducted to explore the explanatory models of patients, their family members and health care practitioners. Some studies also have been conducted to explore the subjective experiences of families and patients regarding needs and desirable treatment outcomes. A summary of the studies considered for review for the present paper are depicted in Table 1.

Health care pluralism has been observed in case of holding beliefs about causation of mental illness (supernatural origins like black magic, and evil spirits; Saravanan et al., 2008; Joel et al., 2003), in treatment seeking behaviour and practice (Campion & Bhugra, 1998; Saravanan, et al., 2005; Saravanan, et al., 2008; Raguram et al., 2002). A study by Shankar, Saravanan and Jacob (2006) conducted in rural South India (Tamil Nadu) to explore the explanatory models of traditional healers and their patients regarding Common Mental Illness (CMI) using a mixed method approach. The researchers conducted in-depth interviews and focus group discussion among traditional healers and faith healers while the patients were administered Tamil versions of the Revised Clinical Interview Schedule (CIS-R) and the Short Explanatory Model Interview (SEMI; Lloyd et al, 1998) in order to identify CMI and to understand explanatory models of illness. Schoonover, et al. (2014) conducted a qualitative study to explore the perception of folk healing and its effectiveness among the patients, family members, and other community members from a rural part of Gujarat (Western India). The study reported dissatisfaction over folk healing of the clients who consulted both biomedicine and folk. The study also reported that despite the feeling of dissatisfaction, folk healers played an integral part in rural areas of Gujarat.

Table 1. Indian studies related to cultural influence on health beliefs and practices in mental health context: A Summary

Author & Year	Aim/s	Target populations & Context	Methods	Findings
Campion & Bhugra (1998)	To ascertain the knowledge and management of mental illness of traditional and religious healers of India	Religious healers of different religious background , South India	Interviews and Observations	A pluralistic holistic approaches are used by religious healers
Srinivasan & Thara (2001)	To identify the causes to which the family members of patients with schizophrenia attribute illness in urban context	Family members of schizophrenia patients in Urban India, South India	Interview and list of causal attributes (based on earlier studies)	Mostly cited cause: Psychosocial stress unlike previous conception of black magic /supernatural causes.
Raguram, et al, (2002)	To understand the Clinical effectiveness of temple healing which may help with planning for community mental health services in underserved rural areas	Patients and family caregivers at the temple of Muthusamy, Velayutham-palayampudur, Dindugal District, Tamil Nadu, South India	Ethnographic inquiry	Observed improvement of symptoms
Joel et al, (2003)	To examine explanatory models of chronic psychosis among health workers of a rural community health programme	Rural community health workers, South India	The Short Explanatory Model Interview (SEMI) Lloyd et al, (1998)	A variety of indigenous beliefs (contradictory to biomedical model) were elicited; they believed that psychosis was caused by black magic, evil spirit and poverty.
Corin et al, (2005)	To explore the influence of culture throughout the narratives of patients' and their relatives through the convergence and divergence between narratives of relatives and patients	Patients and carers (schizophrenic patients), South India	Ethnography, open ended Turning Point / Period Interview (narratives)	A high degree of convergence at the level of symptoms and divergence in narrative construction were observed along with influence of culture

Padmavati et al, (2005)	To understand the reason behind seeking help from religious side by mentally ill patients and their caregivers in	Person with mental illness and their family members who were present at the religious site for help seeking, South India	In-depth Interviews (with a guideline questionnaire)	Causal attributions were based on culturally accepted reasons such as evil spirit, planetary position and sins of the past birth. These explained the nature of help seeking behaviour. Another important reasons behind taking religious help was advices from significant others.
Shankar et al. (2006)	To understand the emic perspective of Common Mental Disorder among traditional healer, their patients	Traditional healers and their patients, South India	Mixed method (both qualitative and quantitative methods), used Short Explanatory Model Interview (SEMI) Lloyd et al, 1998, Focus Group Discussion (FGD) and Interview with healers; interviews with patients	Findings suggest the long tradition of medical pluralism in this culture.
Saravanan et al. (2008)	To understand perception of psychosis , EM of caregivers , patients and member of general public	Patients (psychosis), caregivers, and general public, South India	Focus Group Discussion	Biomedical and Indigenous beliefs are simultaneously present
Jagannathan et al.,(2011)	To explore the needs of caregivers of inpatients with schizophrenia	Family members, Bangalore, South India	Focus Group Discussions (FGDs)	The main needs identified are regarding management related to: behaviour of patients; social-vocational problems; health issues of caregivers; education about schizophrenia; rehabilitation; and sexual marital problems of patients.

Balaji et al. (2012)	To explore and explain the desirable outcomes in schizophrenia among the patients and their primary caregivers (family members)	Patients and their primary caregivers (family members), Goa (Western India)	In-depth interviews, thematic and content analysis	Eleven desirable outcomes expressed by patients and family members: symptom control; employment/ education; social functioning; activity; fulfilment of duties and responsibilities; independent functioning; cognitive ability; management without medication; reduced side-effects; self-care; and self-determination.
Schoonover et al. (2014)	To understand the perception of patients, families, and other community members regarding faith healing and its effectiveness.	Patients, families, and other community members, in rural parts of Gujarat	Grounded Theory, Interviews	Dissatisfaction among clients who consulted folk healers. However, folk healers and healing appeared to be an integral part of rural areas of Gujarat.

In an earlier study, Campion and Bhugra (1998) interviewed ten religious healers from different religions (Hindu, Muslim, and Christian) in South India, to know their explanatory models. This study reported that these traditional and religious healers use a holistic and pluralistic approach in curing mental illness. The study also revealed that some of the indigenous healers could diagnose specific psychiatric problems and referred the patients to a psychiatrist, whereas others preferred to deal with it themselves. Other than health care pluralism, the study also argued that these alternative treatments were affordable and religious denomination does not come between the help seeking behaviour. Similar argument was made by Raguram and his colleagues (2002). They conducted an ethnographic study at a well-known South India based healing (Hindu) temple for three months. To elicit their explanatory models of patients and their family members (caregivers) they used locally adopted semi structured cultural epidemiological interviews. In this study, they discussed how limited availability of health services in rural South India lead people to seek for various alternative health care practices.

The association between socio-demographic variables and nature of causal attribution has also been studied. The differences of mental health related beliefs are documented among urban and rural population (Srinivasan & Thara, 2001; Saravanan et al, 2008; Joel et al, 2003). Srinivasan and Thara (2001) observed that the relatives of schizophrenic patients in urban context mostly cited the psychological causes followed by personality defects in adjustment, heredity, brain dysfunctions for the illness than the previously stereotyped beliefs about supernatural causes.

Padmavati, Thara, and Corin (2005) reported why people in South India seek religious help in curing mental illness. In-depth interviews were conducted among patients and their caregivers on a religious site (temple). The study revealed that causal attributions were based on culturally accepted reasons such as evil spirit, planetary position and sins of the past birth. These findings justified the nature of help seeking behaviour among caregivers and care receivers of the

particular context. The study also reported that advices from significant others also influence the specific health seeking behaviours. Another study, which has been done in rural South India, reported the existence of commonly held indigenous beliefs about mental illness among rural health workers (Joel et al. 2003). By using the SEMI (Lloyd et al, 1998) as a guideline for interviews, this study reported variety of indigenous beliefs regarding causation of mental illness among community health workers. The majority of them did not recognize psychosis as a disease condition. Instead, they explained the state as a result of black magic, evil spirit, and poverty, and expressed that doctors could not help in recovery.

Other socio demographic variables like, education, gender, duration of illness and relation with the patient were also observed to be responsible for differences in causal attributions. Srinivasan and Thara (2001) observed that the causal attribution by family members changes according to the gender of the patients. While the causal attribution for male patients' were more often reported as "cause not known"; heredity was more often cited as cause for mental illness in female patients. The attribution to heredity has also been observed when the illness was of longer duration; while personality defect was often cited when the duration was shorter. On the other hand, psychological cause was more often reported by relatives who had higher education level. Parents were observed to cite multiple causes more often than other relatives. However, other than causal attributions and explanatory models, the relationship patterns between patients and their relatives has also got attention. Corin, Thara, and Padmavati (2005) studied the dilemmas faced by patients and their relatives, how they deal with their dilemmas together, and how patients and relatives related to culture in similar ways. By doing an ethnographic study they examined a high degree of convergence at the level of symptoms, and divergence in narrative constructions among patients and their relatives. Application of the ethnographic method enabled the authors to explore and understand the subjectivity of the experience of psychosis among the patients and their caregivers in their cultural context.

Other than exploring the explanatory models and health related beliefs and practices some qualitative studies have been conducted to identify desirable outcomes of treatment and needs of the caregivers to understand the subjectivity of the client's experiences. For example, Balaji et al. (2012) conducted in-depth interviews with patients and family members in Goa and identified a total of 11 desirable outcomes using thematic and content analysis. The desired outcomes expressed by patients and family members were - symptom control, employment/education, social functioning, activity, fulfilment of duties and responsibilities, independent functioning, cognitive ability, management without medication, reduced side-effects, self-care, and self-determination. Jagannathan et al. (2011) conducted focus group discussions with the family members from an inpatient unit of a psychiatric hospital in Bangalore regarding the needs of the caregivers. The authors observed that the caregivers' needs were related to the management regarding the behaviour of patients, the social-vocational problems, the health issues of caregivers, the education about schizophrenia, rehabilitation, and the sexual marital problems of the patients.

The studies reviewed in this section provide an understanding of cultural beliefs and explanatory models in shaping caring experiences and experiences with mental illness in Indian context. The review also highlighted the efficacy of qualitative methods in exploring subjective experiences such as needs of the caregivers and desired outcomes of mental illness treatments among patients and family members in the Indian context. In addition to this, an attempt was made to identify research issues and future direction.

Identified Issues and Future Direction

The paper finally attempts to give some suggestions for future research by identifying some issues based on the review. They are as follows-

The numbers of studies taking biopsychosocial perspective of mental illness are less in the Indian context. Studies related to caregivers mostly intend to measure burden or related concepts. Therefore, more in-depth

studies are needed to understand caregivers' experiences, which would help in developing culture specific care for the family caregivers.

The research interest in caregiving studies is tilted towards finding negative consequences like burden, stress, etc. but caregiving experience can have some positive consequences life benefit finding, satisfaction, resilience, and finding meaning (Hunt, 2003). These areas are under researched in Indian context.

There are two types of caregivers; formal or paid caregivers and informal or family caregivers. More studies are required to get a clear picture of divergence and convergence of experiences of different type of caregivers, coping pattern, explanatory models and meaning making.

The notion of selfhood differs across culture (Lewis-Fernandez & Kleinman, 1994) and that too influences the experience of a person. On that basis a suggestion can be made to explore the notion of selfhood of caregivers, which is less represented in Indian research of caregiving. This exploration may introduce a new dimension in caregiving research.

Most studies have focused on only primary caregivers. Studies with multiple caregivers could introduce a clearer picture of the family dynamics and caregiving experiences.

Participation of family members in caregiving activities in Indian context is one of the common phenomena. However, while dealing with families the research attention should focus on studying the family dynamics and interaction among family members and the patients.

Caregiving experience can also differ according to socio economic status, education and location (urban and rural). This can influence the perspectives about illness and illness related behaviour. More studies are needed to get an in-depth understanding of these concepts in Indian context.

The self-reflexive nature of qualitative approaches would be a contributory factor in empowerment of the family caregivers and developing self-help group. This could also help spreading health related awareness and practices. On the other hand, ethnographic research and narrative approach could be useful in capturing the unique perspective of caregiving experience. Thus, qualitative exploration is required in the context of mental illness care.

India is known for diversity of culture. Different regions or states differ in their language, customs and practices. Though there exist similarities in values, ideals and some customs. It has been noticed that most culture-centered studies are done in the context of Southern India, which does not represent India as a whole, or do the findings of studies conducted in this part can be generalised (Patel, 2001). Thus, to get the whole picture more studies need be done in other parts of India.

Finally, cross sectional studies can only provide a mere glimpse of the picture. Whereas longitudinal studies or follow-up studies can capture the temporal aspects of a phenomena and that would contribute in understanding caregiving experiences.

Conclusion

A major paradigm shift is happening in mental health research in Indian context. Despite the fact that health care pluralism is not a new phenomenon in India, the acknowledgement of its practice is underrepresented in research literature. Perhaps, the 'shift' from traditional approach (bio medical approach) to biopsychosocial approach in recent research practices is a positive and effective change that would have contribution in understanding caregiving experiences and could also help in developing culture specific care for caregivers in the Indian context.

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