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Culture of Health Care in Urban Slums

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Summary

SUMMARY

In India, several health care initiatives targeted at enhancing the health of the slum population have been adopted and implemented in recent decades. Consistently, however, the poor health status of urban slum populations has been observed. Even if health services of reasonable quality are available, the poor do not necessarily utilise them. In earlier research, poor usage of health care services has been identified as a contributor to the poor health conditions of the slum population. It is common for care services to be underutilised since slum inhabitants do not always reveal and seek treatment for their illnesses, resulting in insufficient utilisation of health care. In India, the majority of health issues are typically addressed within familial and societal contexts. In the lay realm, decisions regarding when to seek healthcare and whom to consult are made based on the lay understanding and management of illness. However, decisions are not just made regarding the time of treatment seeking and selection. Decisions also pertain to the manner in which illnesses are disclosed, including to whom, when, and how illnesses are to be communicated. Infrastructure and socioeconomic variables peculiar to slum regions have various effects on the meaning-making of health and the aetiologies of disease, presenting differently and necessitating different approaches to health promotion and management. The physical, social, and psychological suffering of urban slum inhabitants is frequently compounded by the poor's underestimation of their health needs, which are defined by the community's volume of social, cultural and economic capital. Therefore, within these contexts, health meanings, health values, health attitudes, and health practises become localised. In the setting of India's urban slums, there is a dearth of data that illuminates the body of lay conceptions, practises, and meanings that constitute lay theorising about health and health-related behaviour. As it is founded on people's personal experiences and a complex web of culture, internal environment, social structure, family and social interactions that all interact in the process of constructing such an explanatory framework, such information could be both powerful and useful for practise. The need to tap into the richness, complexity, and diversity of the urban slum dwellers' experiences will reveal the lay structures of thought that underpin everyday health-relevant behaviour, leading to interventions for health promotion where practise and application of lay theory can illuminate the cognitive meanings, settings, and socio-cultural contexts that influence health-related behaviour.

The overall objective of this study was to explore the impact of the quantity of resources available in the forms of economic, social and cultural capitals of the place in shaping lay understanding of health and structuring health care choices for comprehensive illness among the urban slum dwellers in India. Several specific objectives and research questions followed from this overall objective:

1. To provide a more nuanced understanding driven by culture-centered approach of the diverse components of knowledge, neighbourhood, material culture and symbolic drivers of a place that interweave in shaping the urban slum dwellers patterned way of valuing health and managing in practice, a narrative study was conducted guided by the following research questions:
   - *When it comes to their health and well-being, how do slum dwellers as lay people view health and wellness as a whole? (Chapter 2)*
   - *What are the external and/or uncontrollable factors impinging on health, and the place health occupies in slum dwellers lives? (Chapter 2)*
   - *How have images of health, the socio-cultural context of behaviour and the constraints of daily life provided the background to health-relevant behaviour? (Chapter 2)*

2. Assuming that slum dwellers' future plan of action completely relies on the lay discussion phase, it is crucial to understand the disclosure pattern during that stage in order to improve estimates of future healthcare demands and patterns of healthcare utilisation. To gain deeper insight into the many facets that encapsulate the manner in which the slum dwellers articulate their sentiments about being ill, the confidantes they pick, and the helpful and disconfirming social and cultural exchanges to which they are subjected before seeking and selecting healthcare services the following research questions were developed:
   - *To whom and to what extent do slum dwellers decide to disclose their illnesses? (Chapter 3)*
   - *What are the reasons not to disclose illness? (Chapter 3)*
   - *What are the reasons underpinning a delay in disclosing illness and the reasons underpinning prompt disclosure of illness? (Chapter 3)*

3. To gain insights into the enabling, restricting, and discriminating nature of habitus in connection to health shaped by the composition of the neighbourhood capital (such as financial assets or social networks and cultural norms and skills) that produces distinctions in poor neighbourhoods' complicated concepts of healthy behaviours or lifestyles, the following research questions were developed:
   - *Does the amount of accumulated economic, social and cultural capitals embodied in a habitus vary by neighbourhood to the extent that their combination causes the choice of necessity that is reflected in their healthcare behaviours positively or negatively? (Chapter 4)*
   - *How does the set of preferences and choices made by urban slum residents across a spectrum of abilities and impairments (the capital) shape their perceived healthcare needs and the type of care sought? (Chapter 4)*

4. When it comes to treatment preferences, to better understand how women and men are exposed to a wide range of different circumstances in their daily interactions with society that can have a profound impact on how well and how different, what types of health services men and women in urban slums looked for and how often they looked for them, the following questions were formulated:
    - *Do gender preferences exist in making choices among the different available therapies in India's urban slum settings? (Chapter 5)*
    - *If yes, what kinds of therapies are used by men and women in slum areas? (Chapter 5) How do complex gender interactions function in slum settings and influence the therapeutic behaviour of men and women? (Chapter 5)*

The research objective described above and the research questions outlined formed the basis of this thesis.

THEORETICAL FRAMEWORK

Arthur Kleinman's Explanatory Model of Illness (EMIs) was used to guide the study's investigation into how urban slum dwellers understand and make sense of comprehensive health, as well as how they act when they are sick in urban Indian settings. The original idea behind the explanatory models is based on categories that are typical of biomedical explanations. But the model has been used in different ways in studies about how people feel when they are sick. The explanatory model framework works well for biomedical explanations, but we wanted to know how well it works for categorising slum dwellers' social and moral order, inner experience, habitus negotiating and constructing choices, feelings, and aesthetic experiences, and how it could be used to find out about these things. The categories of meaning and explanation that were not biomedical were more important to understand the relationship between the explanatory models of people living with illness and their status quo as marginalised, as well as the relationship between their explanations and their influence on the built environment, treatment and self-care decision making, including medication adherence. This model is helpful for exploring different points of view and explanations because it uses a specific interview method to reconstruct, in a systematic way, slum dwellers' ideas about health and illness and how to deal with them. These ideas build the belief systems that are organised around the idea of causes. The idea of EMIs was used to make the topic guides that were used to help with data collection and the analysis that followed. To help understand how habitus and capital affect people's health-seeking behaviour, we used the culture-centred approach, Bourdieu's concept of habitus, and forms of capital were used, which eased also the conceptualization of emerging concepts.

STUDY DESIGN, DATA COLLECTION AND ANALYSIS

The study employed a methodological trajectory of merging lay perspectives, narrative and phenomenological knowledge, and theoretically informed data collection procedures. The study was based on the acquisition of original data. Kolkata, the capital of West Bengal, and Bangalore, the capital of Karnataka, were the two cities in India where primary data was collected. To highlight the dynamics and local variation of the core-periphery neighbourhood, a mix of core and periphery slums from each city was chosen. MotijheelBasti (central) and SahidSmriti Colony (periphery) are the places in Kolkata, whereas NakkaleBande Slum (central) and UllaluUpanagar Slum (periphery) are the locations in Bangalore. Maximum variation purposive sampling was used to choose the study regions in order to capture the largest possible diversity of wide geographic dispersion and built environment, in order to identify crucial shared patterns across a heterogeneous participant population. The selection criteria of the participants were left open in order to identify a diverse group of participants, including slum dwellers of various genders, ethnicities, and religions, who have resided in the study areas for more than five years (as people residing for less than five years do not connect with the social dimensions of the host communities due to their short-term presence). The data collection team consisted of the researcher and a bilingual interviewer with a linguistic background and experience collecting qualitative data in the healthcare domain. The data collection operations included two rounds of in-depth face-to-face interviews: the first round was conducted between July 2011 and September 2011, and the second round was conducted between June 2012 and September 2012. Thematic analysis was used to produce inductive and abductive codes for data analysis. Various theoretical concepts, such as the concept of explanatory models of illness, the culture-centred approach, and Bourdieu's concept of habitus and forms of capital, were used to enhance data interpretation during the data analysis.

KEY FINDINGS

This section highlights the study's principal findings. These findings are provided in accordance with the chapter order of the dissertation and the order of the research questions.

Results of primary research into urban slum dwellers' understanding of holistic health and illness are presented in chapter two *(research questions 1, 2, & 3)*. Research shows that slum dwellers' health is encoded by a persistent threat to their survival in an uncertain environment, which is framed in terms of limiting resources. The slum dwellers' perceptions of their lives' susceptibility and severity were thought to be informed by existential uncertainty due to the constantly shifting surroundings. The expanding understanding of the connection between health meanings, including

illness, and uncertainty management feeds the human desire to make sense of their existence by protecting and defending themselves from the hazards they confront. It takes a team effort to deal with this kind of existential dilemma. In the face of existential uncertainty, individuals frequently seek solace in cultural and religious worldviews when they realise that their mental, physical, and spiritual well-being is in jeopardy, when they are uncertain as to the availability of a relationship essential to their psychological well-being, or when faced with the practical uncertainty that comes with a limited lifetime. Slum dwellers will continue to rely on their body's language until they learn how it reacts to illness, how much of a schedule they can keep before getting tired, and how long they think they can complete tasks before their body stops performing as effectively as they wish. As shown by their preventative and healing methods, people who live in slums are aware of how important it is to make their bodies work better.

The third chapter describes how engaging in selective disclosure influences the meaning given to a larger system of practises and institutions that implies social dangers such as family and community breakup *(research questions 4, 5 & 6)*. It turns out, according to the research, that slum dwellers suffer disclosure restrictions that have a negative impact on how individuals think and communicate about their illnesses, their coping mechanisms, and their overall psychological well-being. This shows how important stigma beliefs are as a common cultural phenomenon that affects how people choose and use health services. Disclosure is tied to slum dwellers' social lives, daily routines, and experiences with their health conditions. These different roles affect how they see themselves and how others see them. Additionally, men and women reveal to different audiences in different ways, ranging from not disclosing at all to selective or partial disclosure based on the reactions of others. There are many possible sanctions for coming forward as disadvantages of disclosure, such as fear of job loss, fewer social contacts, and social rejection. As a result, low self-esteem, anxiety about being institutionalised, fear of being judged, apprehension about the future, and feelings of shame are rampant. Due to their tendency to keep their feelings bottled up, males have a smaller pool of confidantes. This is because men are more concerned with their jobs and income, maintaining their masculinity in the family or society, and living a regular life for as long as possible. Timely reporting is closely associated with men's ability to both prevent and deal with biological challenges that they have already encountered. At different stages of illness, women look for different people to talk to, which may be influenced by different cultural support systems. Some of the reasons for delaying or not coming forward are: not knowing enough about the illness; fear of stigmatisation or emotional loss due to social exclusion and identity crises; financial problems related to health care costs; and problems dealing with the bad conditions in the slum. Early disclosure is associated with providing women with therapeutic experiences of disclosing ailments; boosting their confidence in facing unknown

physical issues; minimising negative repercussions resulting from delay or non-reporting; and avoiding future social sanctions.

Chapter four shows how the amount and type of capital in a slum neighbourhood affected how slum dwellers thought about when to get curative and preventative primary care, as well as how they behaved while getting care *(research questions 7 & 8)*. In the research, whether it's the quality of housing or access to health care, or community cohesion or crime rates, these factors all play a role in highlighting the enabling, restraining, and discriminating nature of habitus in relation to health in poor neighbourhoods. Fixing the problems caused by an inadequate physical environment had a significant impact on how urban slum dwellers prioritised their needs and the benefits they saw from doing so. Health concerns are often put on the back burner due to the constant and inescapable struggle with infrastructure, which forces people to prioritise their daily woes over their health. A person's "choice of necessity" is to accept the circumstances of his or her life when confronted with a choice between alternatives. As a result, the need to invest in imagined health may appear inapplicable, if not ludicrous, as has become the public idea in terms of health behaviours.

The fifth chapter presents findings on gender-based treatment choices as influenced by cultural norms and expectations *(research questions 9, 10, & 11)*. Every day, women and men are exposed to a wide range of situations that can have a large impact on their well-being, both in a good and bad way. One of the most important things that helped figure out how well and how differently men and women in urban slums looked for health services and how often they looked for them was how they went about finding them. There is a greater demand for a wider range of healthcare services among women due to the traditional socialisation of women who are more prone to engage in nurturing, caregiving, and self-treatment activities (including both clinical and alternative treatments). However, women had to set up channels and ensure that the treatment approach they wanted and the standards they followed coincided in order to ensure that norms were followed. When men are stressed out, they are more likely to avoid or not be able to do things that are good for their health. Regarding health care, men have fairly limited options. Men like to use over-the-counter medicines for minor symptoms that do not get in the way of their daily lives. However, they prefer to see a doctor for more serious problems that need immediate care.

CONCLUSION

This study contributes to a thorough understanding of the components influencing the meanings of health and sickness and consequent health-seeking behaviour with regard to holistic health and illness situations in India's urban slums. This information

is useful for policymakers, public health professionals, and those interested in enhancing the quality of life for slum dwellers in the Indian context, and it can contribute to the creation of interventions that facilitate treatment choices based on accurate information. Reiterating the importance of looking beyond economic factors and considering immaterial and socio-cultural factors when examining access to healthcare, the findings of this study could help develop context-specific interventions to strengthen slum dwellers' health-related decision-making in relation to their "choice of necessity" in daily life; build on existing social networks to serve as role models for healthy behaviours in peer groups; come up with ways to reduce stigma and aversion to normative behaviour so that slum dwellers can talk about their health and take care of it; provide comprehensive, low-cost multi-sectoral therapies to make sure that slum dwellers get the essential health benefits they need to take care of their own and their families' health; and advocate for gender equality. In showing how important it is to help people make sense of their lives as a way to improve their health and well-being in different slum environments, the study's findings also make important contributions to future research and policy making.