

# Culture of Health Care in Urban Slums

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# **Culture of Health Care in Urban Slums:** A Comparative Study of Metropolitan Cities of Bangalore and Kolkata

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# Culture of Health Care in Urban Slums: A Comparative Study of Metropolitan Cities of Bangalore and Kolkata

#### DISSERTATION

to obtain the degree of Doctor at the Maastricht University, on the authority of the Rector Magnificus, Prof. dr. Pamela Habibović in accordance with the decision of the Board of Deans, to be defended in public on Monday, 28<sup>th</sup> of November 2022, at 10:00 hours

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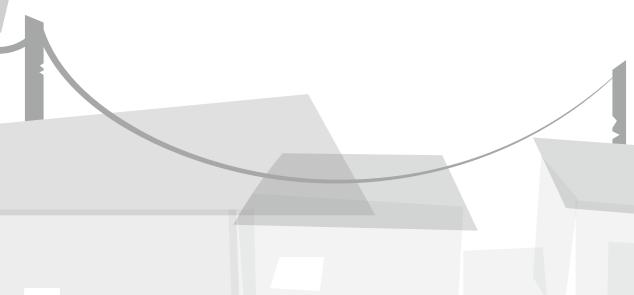
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# **Chapter 1** General Introduction



## **GENERAL INTRODUCTION**

This thesis investigates how health and illness are understood and manifested in the health demands, decision-making, and embodied activities of Indian urban slum dwellers. According to a prior UN-HABITAT (2006) assessment, urban slum dwellers' health often lags behind that of their counterparts in neighbouring cities and even rural areas. Despite rising public and private spending on healthcare, most emerging countries, including India, have poor consumption of basic health services (Sriram & Khan, 2020). The use of healthcare services relates to the availability and affordability of healthcare services for a household, particularly for impoverished households in urban slums. It has been shown that the use of health services is determined by people's health seeking behaviours within a community, which are influenced by a wide range of factors including physical, political, social and cultural ones (Challa, 2018). The prerequisite for changing human behaviour and improving health practices is an understanding of human behaviour, which includes attitudes, norms, and other variables; only with this understanding can healthcare be provided in an acceptable manner to the people who receive it (Hausmann- Muela et al., 2003). It is possible that people are encouraged to seek treatment because of certain enablers or discouraged because of barriers, or they could act or use health services in accordance with social expectations or standards (MacKian, 2003). The health system utilisation process examines the act of obtaining healthcare, whereas the illness response process examines the facilitators and barriers to seeking healthcare. There is more to health-seeking activity than merely a one-time event. It is a critical component of an individual's, family's, or community's identity, evolving as a result of a complex interaction of social, personal, cultural, and experiential factors (MacKian, 2003). A number of socio-cultural, economic, and physical factors (Lallet al., 2008) have been linked to the emergence of slums such as commuting costs (Alonso, 1964), access to local public goods (Tiebout, 1956), individual preferences for community or neighbourhood composition (Schelling, 1978), housing quality (Abramo, 2009) and social ties related to common culture, language and similar income-generating activities (Barnhardt et al., 2014; Kombe, 2005). In other words, any efforts to deal with problems related to slums must also take their surroundings and social systems into account.

### Towards an operational definition of slum

To begin building a more systematic approach to slum research, it is necessary to define slums. Slums do not have a broadly agreed definition. Slums are characterised variably according to their location, official and unofficial designations, or differences about the issues they address (e.g., temporary nature, land legality and health). Additionally, several cities (for example, Nairobi, Kenya, and Mexico City) lack a formal definition of slums, which adds another layer of subjectivity to the process of slum classification (UN-Habitat, 2003). The terms 'unplanned' illegal' squatter,'

'shanties' and 'ghetto' all have ambiguous meanings. Additionally, several places of the world have regionally distinct names, such as "favela", (Brazil) "barrid", (Latin America), "Mabanda", (Africa) "kampong", (Indonesia) and Jhuggi Jhompri (India) (Thomson, 2019). While these phrases are typically associated with certain sights and thoughts, quantifiable definitions are currently unavailable (Hofmann, 2015; Gevaert, 2019). Notified and non-notified slums are the two main types of urban settlements. "Notified slums" refer to communities created or renovated by government agencies or housing organisations that adhere to approved designs (Ishtiyag & Kumar, 2011). Apart from physical, social, and economic aspects, various other elements are taken into account when such colonies are established to guarantee that people live in conducive and comfortable conditions. Aside from environmental compatibility and economic viability, planners also place a high priority on the development of government-owned homes (Ishtiyaq & Kumar, 2011). Illegally or legally popped up settlements on government or private land are known as "Non-notified slums". Unplanned and in defiance of all official planning rules, they are. They have permanent, semi-permanent, and temporary structures that are located in and around the city along city drains, railway tracks, flood-prone areas, agricultural land, and green belts. They do not have access to adequate drinking water, reliable energy, sanitation, waste disposal, a road network, and parks. Additionally, the hallmarks of urban informal settlements such as acute poverty, inadequate housing, overcrowding, a lack of access to social services and adequate protection from crime and unemployment are also present (Ali, 2006; Vazsonyi, 2008). Since many neighbourhoods are both physically and socially dilapidated, it's practically impossible to lead a normal family life in many of them. In spite of the fact that some of these communities have been around for a long time, many of them still lack basic utilities and do not have the legal right to occupy. On the other hand, UN-HABITAT (2003) defines slums as urban areas where residents lack access to one or more of the following: permanent housing, suitable living space, easy access to safe water and adequate sanitation, and security of tenure. Slums come in a variety of sizes, shapes, patterns, and population densities (Taubenbock & Kraff, 2014). The labels "slum", "informal settlement", and others have been questioned qualitatively due to their typically negative implications (Thomson, 2019). As a result, they have been replaced in subsequent publications by more neutral terms such as "deprivation zones" (Wang, 2019).

#### The impact of slums on health

Slum expansion is predicted to have a significant impact on both individuals and the environment, which are intimately linked. The literature on slums and health has demonstrated that structural and intermediary social variables interact to create complex and interconnected hazards, threats, exposures, risks, diseases, and mortality relationships (WHO Kobe Centre, 2005). Urban poverty in slums and informal settlements is the most significant structural factor of health, affecting

people of all ages and genders. Gender is also a prominent structural determinant that facilitate or impede people's ability to protect themselves from illness, and if sick, their access to quality healthcare. Women-headed households only form 30 percent or more of total households in slums (Baral et al., 2016) that structure hierarchical power relations and affect people's experience of being sick, their health outcomes, and the socioeconomic consequences of being ill (George, 2020). Women in slums are more likely than men to stay at home, increasing their exposure to health hazards and other risks associated with living in squalor. Their scant resources also force them to bear the task of obtaining water, securing food, and caring for other family members. Additionally, they are more susceptible to violence and criminality. They rely on public transportation, which compromises their security. Ethnicity is another critical structural factor in slums. Discrimination, intolerance, and stigma exacerbate health hurdles and worsen minority groups' susceptibility in slums and informal settlements. Low educational attainment, which results in low health literacy, is thus a structural factor of health in slums. Health literacy, defined as the cognitive and social skills necessary to obtain, comprehend, and use information in ways that promote and maintain good health (Nutbeam, 1998), is dependent on basic literacy and plays a critical role in increasing or decreasing individual vulnerability to health problems in slums and informal settlements.

Living conditions (for example, contaminated water, filthy conditions, substandard housing, overcrowding and excessive density, toxic locations, and exposure to temperature extremes) are intermediate determinants of health that are inextricably tied to poverty (Baral *et al.*, 2016). Newborns and young children, as well as the elderly, are more vulnerable to these determinants because of their age. Working conditions (particularly in slums and informal settlements where informal economic activity is concentrated) are also intermediate predictors of health for men, women, and children (i.e., child labourers, street children). Many of the advantages of city living are denied to people who live in slums or in informal settlements<sup>1</sup>. As important intermediary health determinants, stigma and social exclusion must be mentioned. Having no street address is just one of the many ways slum dwellers and informal settlers are denied "full citizenship" in cities<sup>2</sup>. Municipal census activities do not routinely include residents of shantytowns and other informal settlements. When looking for work or asking for permissions to run a small business, they may be excluded or discriminated against. They may be highly mobile, moving from city to

<sup>1</sup> UNDP states that these attributes are critical to full citizenship, though remain a monopoly of a privileged minority. They include: political voice, secure and good quality housing, safety and the rule of law, good education, affordable health services, decent transport, adequate incomes, and access to economic activity and credit

<sup>2</sup> United Nations Millennium Project. A Home in the City – Task Force on Improving the Lives of Slum Dwellers. Earthscan, United Kingdom, 2005.

city, undetected. The line between social and political exclusion gets blurred at some point. All of these factors deny slum people a 'political voice' and limit their ability to participate in decision-making processes impacting health determinants. Slum and informal settlement residents' health is strongly correlated with their ability to access quality healthcare. Children under five years old and women in reproductive age bear the brunt of healthcare service inaccessibility. Medical treatment and facilities in urban regions tend to be more advanced and complex, yet these areas are sometimes inaccessible to the people who need them. Living in constant fear for one's safety while being exposed to crime and violence leads to a high level of mistrust and a depletion of social capital. The stress of living in constant fear of one's safety, along with exposure to crime and violence, results in a high level of mistrust and a depleted social capital. This is a more intermediate component that has a greater impact on youth and adolescents who live in slums and informal settlements and eventually resort to hostile and aggressive behaviour in order to cope with their conditions. Transportation and its influence on the physical environment, as well as on individual behaviour and social interaction, can be considered as a secondary health determinant. Its influence on the physical environment, as well as on individual behaviour and social interaction, must be addressed. Access to social services, jobs, education, and child care is further hampered by a lack of appropriate, safe, and efficient mobility.

These qualities combine to create "high ecological stress" for communities living in slums and informal settlements, which manifest itself in a variety of ways affecting physical, mental, and social health, well-being, and quality of life. As a result, poor health and early mortality are caused by a complex web of causation that includes individual behaviour, family, neighbourhood, and community, access to health facilities and services and the physical environment.

Lilford *et al.* (2019) have proposed in a study that space should be taken into account in health research. When looking at the incidence of ill health in urban slums, urban geography is crucial because 'neighbourhood impacts' may be caused by variables that are geographically linked (Zerbo *et al.*, 2020). Factors that affect health at the community level but are unrelated to individual home circumstances such as poverty/ deprivation levels are referred to as neighbourhood effects. They cover a wide range of consequences that affect everyone and everything. These neighbourhood effects are more likely to occur in densely populated slum areas, where the physical environment is shared and where one person's behaviour affects another's (Ezeh *et al.*, 2017). So, lack of basic sanitation, inadequate nutrition and other factors including behavioural issues and overcrowding all contribute to the high rate of child mortality in slums (George*et al.*, 2019). Residents of low–income neighbourhoods are more likely than those in higher–income neighbourhoods to engage in risky behaviours when it comes to their health (Algren *et al.*, 2017). Diez & Mair (2010) summarised in a review that neighbourhoods' social environments can influence residents' health through features such as safety/violence, social connections/ cohesion, local institutions, normative attitudes toward health behaviour, norms and social support. The authors also showed that the built environment, aesthetic qualities/natural areas, services, and housing quality can influence health behaviour.

### Neighbourhood traits and their role in shaping health behaviours

Because of the stress of living in a low-income area, inhabitants may resort to unhealthy coping behaviours like smoking, drinking, and overeating to help them cope (e.g., inadequate housing and overcrowding) (Algren et al., 2017; Olstad et al., 2016). Furthermore, pressures can deter people from engaging in good preventative health practises (Stimpson et al., 2007). Individuals with a low socioeconomic status (SES) lack the material and financial means essential to obtain the basic goods and services necessary for a healthy existence, such as adequate housing and healthcare (Macintyre, 1997). Inadequate financial resources, for example, may impair an individual's ability to get high-quality treatment and prevention (Kabia et al., 2019). According to the behavioural theory, health inequalities occur as a result of the concentration of health-harming behaviours among lower socioeconomic groups. The higher risk of disease has been connected to behaviours such as smoking, sugar snacking, low fruit and vegetable consumption, poor hygiene habits, and intermittent clinical attendance, all of which are more common in those of lower socioeconomic class (Sanders, 2005; Singh et al., 2013). Furthermore, the social environment is becoming increasingly recognised as having a substantial impact on human behaviour.

Disadvantaged neighbourhoods may have standards about health-related behaviour established through social ties, or residents may lack the confidence in their own abilities to maintain healthy habits (Stimpson et al., 2007). According to the theory of normative social behaviour (TNSB) (Rimal and Real, 2005), both descriptive norms (perceptions of the prevalence of a behaviour) and injunctive norms (perceptions of social pressures to conform) influence behaviour (Cialdini, 1990). The presence of injunctive norms is one of the circumstances that regulate the influence of descriptive norms on behaviour. Many studies highlighted that an individual's proclivity to engage in a behaviour is determined by their perceptions of others' behaviours (descriptive norms), social sanctions for noncompliance (injunctive norms), and the interaction of these two factors, with the highest compliance occurring when individuals believe they will face consequences for not engaging in a popular behaviour. For example, smoking may be more socially acceptable or less of a problem in disadvantaged communities than in non-deprived neighbourhoods, owing to deprived neighbourhoods' higher smoking prevalence (Paul, et al.2010). A number of studies have shown that African-American men in particular are less likely than other groups to seek treatment or preventive healthcare services (Beia *et al.*, 2021; Heise *et al.*, 2017). Griffith *et al.*, (2011) discovered that African American men are hesitant to seek medical assistance due to existing African American cultural norms. Williams (2003) makes the following observation regarding men in general: The deep-rooted cultural ideas about masculinity and manhood influence men's conduct in ways that have an impact on their health. Men are conditioned to avoid showing emotion or vulnerability that could be interpreted as weakness. In the literature on family planning methods, scientists are increasingly emphasising the critical role of social norms at both the individual (Sebastian *et al.*, 2010; Iacovou & Tavares, 2011) and at community levels (Store & Kaggwa, 2009). Modern family planning or seeking care in reproductive health clinics are hindered by numerous social and cultural traditions at the household and community levels (Stephensopn & Tsui, 2002; Rutenberg & Watkins, 1997; Daniel *et al.*, 2008).

Recent research underlines the crucial function of social networks in giving options for good social assistance (Sanders *et al.*, 2006). Additionally, it informs that health inequities are a result of differences in psychological distress experienced by socioeconomic groups (Sisson, 2007). Psychological distress can have a direct effect on health via neurobiological mechanisms, such as financial difficulties, a lack of social support, or traumatic life events (Sabbah *et al.*, 2009). Information, health literacy, and social norms all may also harm in indirect ways people's ability and attention to maintain good health and can increase the chance of poor health habits and episodic medical care use (Saah *et al.*, 2021).

Underprivileged neighbourhoods are more likely to have fewer interactions with the healthcare system due to socioeconomic factors such as poverty, poor hygiene, poor nutrition, and poor access to healthcare (Liburd *et al.*, 2007). Few studies on urban slum health explore the intricacies of social impact beyond the fact that it is provided by family, friends, and significant others, in spite of evidence that socioeconomic characteristics affect health seeking behaviour (Cheatham *et al.*, 2008). To capitalise on social effects that promote healthy behaviour, researchers need to better understand the mechanisms and repercussions of these types of social ties on urban slum dwellers' health (Berkman, 1995).

# Factors influencing health-seeking behaviour and utilization of health services among the urban slums

The link between poverty and poor health has been consistently highlighted in both academic and popular discourse. According to research, people who live in low-income households are more likely to get sick, have a higher rate of neonatal mortality, have disabilities, have a shorter lifespan, and have fewer options for healthcare (Raifman & Raifman, 2020; Besnier *et al.*, 2019). More than a few sociological studies have explored health and sickness from the perspectives of social policy and inequality, leaving the genuine health experiences of the poor

generally unresearched. Poverty and ill health are linked, according to national and international reports, and measures are being implemented to help reduce poverty while also improving health indicators. For instance, the OECD and WHO (2003) advocate for a pro-poor health policy in order to improve the poor's health and avert the spiral from illness to poverty. Poverty and health are inextricably linked, as Health Poverty Action (2017) has just revealed. In the pursuit of quantitative indicators, the poor are reduced to numbers rather than agents or subjects with social ties, experiences, viewpoints, or coping methods, and are treated as passive objects of ill-health indicators. There is a dearth of study on how the poor define and perceive health, the factors and experiences that form their perspectives, and the patterns underlying these perceptions. There are major lay studies that investigate how health and sickness are classified, notably in terms of occupational class, ethnic origin, age, and gender (Currer & Stacey, 2021; Hiebert et al., 2018; Blaxter, 1990; Keyes et al., 2020; Kikuzawa et al., 2019; Williams, 1983). The sociological study of health and illness in Indian urban slums is, nevertheless, lacking. To date, the majority of research on poverty in India has relied solely on quantitative representations of poor people's disadvantages – which coincidentally include health – while ignoring the poor's human viewpoints.

There are illnesses that are particularly laden with societal meaning, which dictates how society responds to those who are unwell and moulds the illness experience, meaning that is not derived directly from the nature of the illness. All illnesses are socially created at the experiential level, based on how individuals learn to understand and live with their illness. In order to shed light on this issue, a new approach is to see if social norms have an impact on gender differences in illness reporting behaviours in urban slums. Research on gender and patterns of self–reported illness in India's urban slums is lacking (Bora & Saikia, 2015), although the body of literature on specific diseases is rising rapidly (Vlassoff, 2007; Goswami, 2014). Self–reported health status or reporting of illness can be an important predictor for understanding how gender interacts with the effects of health and illness and for defining their threshold for seeking care. The research can also spur much–needed work on gender differences and the development of interventions that take social norms into account, helping to keep people in urban slums healthy and lessen their suffering.

Healthcare-seeking behaviour, also known as health- or help-seeking behaviour in the literature, is a perplexing term. Cornally *et al.* (2011) define help-seeking behaviour as "a goal-directed, planned behaviour that involves interpersonal connection with a specific health-care provider" when a health problem requires assistance. Healthcare consumption decisions are influenced by a variety of factors that affect both people and healthcare. Numerous factors influence healthcare use, including physical, socioeconomic, cultural, and political concerns. The gender difference in healthcare utilisation is one of the most significant determinants of healthcare utilisation. Men and women may take a different attitude to healthcare decisions. Many theories have been advanced to explain why women are using healthcare services at higher rates. One of them is the fact that women's greater need is approximated by their worse health (greater morbidity, poorer perception of well-being as well as a lower health-related quality of life) and the different social construction of disease (roles, attitudes and behaviours of men when they are sick or worried about their health), which results in different processes for seeking healthcare and differences between men and women (UN Women, 2018; Verbrugge, 1985; Gomez Gomez, 2002).

Numerous studies have shown that men delay treatment for a wide range of health issues and use fewer preventative healthcare services than women (Courtenay, 2000a; Vaidya *et al.*, 2012). As a result of common ideas regarding traditional male gender roles, men may be reluctant or unwilling to seek medical attention for their problems (Staiger et al., 2020; Farrimond, 2012). A variety of masculine standards influence male behaviour in different ways depending on the situation or variables, such as social class, occupation (Wenger, 2011), race or ethnic differences (Garfield *et al.*, 2008) or age (Peak & Gast, 2014), according to social constructionists.

Women are more likely than men to seek medical attention for both physical and psychological reasons (Liddon et al., 2018, Wright & McLeod, 2016). They are more receptive to alternative medicine than men are, and they are also more inclined to conduct their own research prior to contacting a physician. Despite the fact that women have distinct healthcare demands (such as pregnancy and the care that goes along with it), research shows that women visit their family doctors more frequently and spend more time in consultation than men (Nabalamba, 2007). The gender disparity in health reporting has been attributed in part to differing health attitudes between genders. According to Kessler et al. (1981), women are more prone to interpret symptoms associated with low well-being as indicators of emotional distress and seek care. This shows that women perceive symptoms differently than men do, and hence seek out more healthcare. According to Hibbard and Pope (1983), women likewise express a greater interest in and worry about health than males do. This is supported by Verbrugge (1989), who discovers that health issues are more salient among women, that they value health more than men, and that they have a greater burden of caring for unwell family members. These findings support the notion that women place a higher premium on health than men do. Additionally, Hibbard and Pope (1986) discover that the largest disparities in health symptoms reported by women and men exist in categories that represent milder morbidities and those that allow for a great deal of discretion in defining sickness and/or the need for care. As a result, the authors conclude that gender differences reflect differences in how men and women perceive themselves as "sick."

In urban slums, poor healthcare seeking behaviour is common (van der Heijden, 2019). Numerous studies have shown that the healthcare system in India has major gender disparities (Canudas- Romo, 2015). Health-seeking behaviour is an important indicator of how successfully and frequently men and women living in urban slums get healthcare. It is critical to investigate these characteristics in order to have a better knowledge of how health services are used, avert difficulties, and improve overall quality of life. The existing literature suggests that healthcare use is determined solely by perceived need for care (Goodwin and Andersen, 2002; Parslow et al., 2004) such as whether people recognise their need for care; desire to receive care, and ability to acquire care. Slum residents are generally aware of their own healthcare needs and make use of the diverse array of available healthcare services (George. et al., 2019). They prioritise and seek out specific healthcare treatments based on their socioeconomic status, provider knowledge, and treatment plans' cultural expectations. Prior research indicated that Indian slum inhabitants got a combination of private and public aid (Islam et al, 2006; Banerjee et al., 2012; Gupta and Guin, 2015; Essendi et al 2011). Certain individuals appear to be circumventing the healthcare system by obtaining medications directly from pharmacies, consulting unlicensed medical practitioners, or engaging traditional healers who provide a range of medical services (Paterson and Britten, 1999; Suarez and Reese, 2000). Patients and their families seek personalised treatment when they lose faith in clinical care or when they no longer obtain aid with their recovery as a result of indifferent or excessively expensive care (EP et al, 2021).

Neighborhood characteristics have a critical role in explaining the link between perceived healthcare need and utilisation (Law *et al.*, 2005). Locality has an effect on people's health that extends well beyond its demographic composition. In addition to living in a low-income neighbourhood, urban slum dwellers face a number of additional challenges that contribute to their poor health, such as limited access to nutritious food (Donkin *et al.*, 1999; Stafford *et al.*, 2007), crime and lack of safety that restrict their mobility (Burgoyne *et al.*, 2008), difficulty finding work because of the negative connotations associated with their community's reputation (Lobo and Das, 2001), and inadequate services and infrastructure (Cummins *et al.*, 2007). A lack of study on the association between neighbourhood and healthcare consumption among refugees and migrants is currently evident in India.

# **RESEARCHABLE ISSUES**

An urban slum is a synthesis of many characteristics, including numerous religions, culture, language, and urban life styles and habits. As a result of this assimilation, odd views, attitudes, habits, and psychological behaviours evolve among slum inhabitants that are incompatible with their native environment. Health meanings, such as how community members conceptualise health and illness, are ingrained

in cultural ideas, values, and behaviours. Additionally, these beliefs, attitudes, and behaviours are contextual in nature. Context encompasses both the characteristics of the local community and the day-to-day daily experiences of community members. As a result, health meanings, attitudes, beliefs, and practises get framed within these contexts. Ignoring the marginalised community's local cultural context might be viewed as a barrier to health communication between provider and user. As a result, the slum's health services are underutilised. As a corollary, a culturalcentric approach (CCA) (Dutta, 2008) that emphasises an understanding of one's cultural context may be useful in developing policies that benefit one's health and well-being. Because the cultural context has an effect on the health seeking behaviours and perceptions of community members regarding health, illness, and healing, addressing the health problems of slum dwellers from their perspectives is an effective way to identify resources that would facilitate the development of culturally meaningful health solutions.

It is important to note that adequate health service delivery in slums does not always translate to better health outcomes. This leads to poor health-seeking behaviour and under-use of current resources. A major knowledge gap for Indian policymakers and practitioners is how slum dwellers express their illness-related emotions, who they confide in, and how they interact with helpful and unsupportive social and cultural interactions. The expression of illness is significantly influenced by the socio-cultural context (Ladak *et al.*, 2020). It is during this stage that a definite plan of action is defined (whether to keep quiet, see a specific doctor, go to a clinic, start self-medication, or wait for more symptoms to arise). Exploring how slum dwellers report symptoms and transform them into actions (seeking care or avoiding) may help improve health policy formulation. Slum dwellers' illness reporting habits can assist predict future clinical treatment and resource demands, preventing underutilization of healthcare.

Understanding what drives this spatial variance in utilisation is critical for developing policies that benefit the urban poor in India. Weak family support network that cannot promote well-being; living environment prone to epidemic and can affect the poor the most; health programs and systematic efforts of urban health programming focused on slum dwellers have been limited to few cities (Agarwal *et al.*, 2007, Kumar and Mohanty, 2011). Existing researches in India have identified the elements contributing to the poor's public-private health care utilisation contradiction (Verma *et al.*, 2018; Rout *et al.*, 2021). Despite formal care, the impoverished seek out other local healthcare providers (Priya *et al.* 2019). But few have addressed the growing disparities in formal and non-formal healthcare consumption (Priya *et al.*, 2019). There is also no research on the inter–urban disparities in slum health care utilisation.

Despite the abundance of research on gender differences in treatment seeking behaviour, it is important to examine these correlations in diverse cultural settings, given the importance of the socio-cultural environment underpinning these differences. Also, due to cultural heterogeneity and acculturation, urban slums in India are different from other populations (Martinez and Lee, 2000). They are also renowned for the contextual aspect of gendered health-seeking behaviours including visiting other local healthcare services (Yesudian, 1999). To design appropriate policies that promote and provide proper treatment options for both women and men, understanding gender variations in therapeutic choices in the slum milieu is critical.

To sum up the study addresses the following research questions:

- 1. 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)
- 2. What are the external and/or uncontrollable factors impinging on health, and the place health occupies in slum dwellers lives? (Chapter 2)
- 3. How images of health, the socio-cultural context of behaviour and the constraints of daily life provided the background to health-relevant behaviour? (Chapter 2)
- 4. To whom and to what extent do slum dwellers decide to disclose their illnesses? (Chapter 3)
- 5. What are the reasons not to disclose illness? (Chapter 3)
- 6. What are the reasons underpinning a delay in disclosing illness and the reasons underpinning prompt disclosure of illness? (Chapter 3)
- 7. Does the amount of capital vary by location to the extent that their combination causes the choice of necessity that is reflected in their healthcare behaviours positively or negatively? (Chapter 4)
- 8. 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)
- 9. 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)
- 11. How do complex gender interactions function in slum settings and influence the therapeutic behaviour of men and women? (Chapter 5)

# SETTINGS

Kolkata, West Bengal's capital, and Bangalore, Karnataka's capital, were used for this study's primary research locations. For the second time, a mix of core and periphery slums was purposefully selected from each city to demonstrate how the core-periphery neighbourhood dynamic and local uniqueness might be expressed (Klimczuk and Klimczuk-Kochaska, 2019). Motijheel Basti (core) and SahidSmriti Colony (periphery) are located in Kolkata, respectively, while NakkaleBande Slum (central) and UllaluUpanagar Slum (periphery) are located in Bangalore.

Due to their advantageous location, the core slum population is expected to have better communication, transportation, and healthcare facilities than the periurban slum population, which is in a state of transition, adopting urban lifestyles and facilities while maintaining their traditional means of subsistence (Banerjee *et al.*, 2009).

The UN Habitat Prosperity Index components, which examine living conditions and quality of life differences, led to the selection of Kolkata and Bangalore (Belliapa, 2011; Sivaramakrishnan et al., 2020). To put it another way, they're a good representation of northern and southern India, which many scholars have described as culturally distinct (Karve, 1965; Sopher, 1980a; Miller, 1981; Dyson and Moore, 1983). With pre-independence slum development in Kolkata, Bangalore is the second-fastest-growing major metropolis in India and is home to large numbers of slum dwellers (Nagendra et al., 2012). Eventually, in Kolkata, the manufacturing industry stalled due to a variety of factors, most notably when compared to other areas (Chandrasekhar and Ghosh, 2008). A variety of public-sector-heavy sectors have evolved in Bangalore, making it a major economic and medical hub, as well as a booming centre for information technology. As a result, Bangalore's migration is expanding. According to the 2011 census, Kolkata has an 8.3 lakh migrant population out of a total population of 44.9 lakh, while Bangalore has a population of 96.2 lakh, with an incredible 44.3 lakh classed as migrants. Approximately every ten years, the urban agglomeration of Kolkata sees a decline in growth. More than half of medium and small towns saw negative or extremely poor growth (Yadav and Bhagat, 2014). On the other hand, Bangalore has developed into a rapidly rising metropolis in southern India, ranking as the sixth largest metropolitan agglomeration in the country (Census, 2011, Verma et al., 2017).

## **OUTLINE OF THE THESIS**

With Aurthur Kleinman's "Explanatory Model of Illness" (EMs), the questionnaire framework was developed to better understand how urban slum dwellers conceptualise health and make sense of their illness by assigning meaning to symptoms, evolving causal attributions and communicating appropriate treatment expectations (Kleinman *et al.*, 1978). The explanatory model took five factors into account: the identification of the illness, the time line, the causes and attributions, the consequences, and the control and treatment. These factors are shaped by and have an effect on social expectations on the role of the sick, individual disease

behaviour, and assistance seeking. As a starting point, we looked at the many different facets of health and the significance of illness for both the individual and their family. This helped us gain a better grasp of their world views as a whole, which helped us tell the stories of urban slum inhabitants in narrative form.

Health is not a single or homogeneous term; it encompasses a variety of dimensions related to many aspects of life and lifestyles (Blaxter, 2010; Davey & Zhao, 2018). While documenting health, it is impossible to convey the diverse views on health held by different ethnic groups simply by focusing on health experts (Airhihenbuwa, 1995; Dutta-Bergman, 2005). Thus, a dialogic idea of culture-centric approach is essential to develop localised health concepts that reflect the diversity of various cultural populations. Indeed, a culture-centric method has already been used to investigate the health beliefs prevalent among many ethnic groups beyond India (Yehya & Dutta, 2010; Kandula & Baker, 2012; Basnyat & Dutta, 2012; Jamil & Dutta, 2012). However, in the Indian context, this approach has been limited to examining tribal groups' perceptions of health (Dutta-Bregman, 2004; Dutta & Basu, 2007). However, no research examining how health is prioritised among low-income populations such as slum residents have been identified thus far. Thus, understanding slum dwellers' health-related perspectives from a cultural perspective may assist add value to the existing material. Additionally, it may aid in the development of suitable health policies targeted at lowering adverse health outcomes among them. Chapter two provides through a cultural lens the subjective component of health-related perception prevalent among society's excluded groups. Lay meaning of health as discussed with participants reveal that the fundamental concept of health is rooted in physical components of daily life, such as a conscious interpretation of bodily symptoms. Thus, 'health' refers to an examination of one's self-concept in terms of its physical dimensions, features, and processes. Phenomenologically, chapter two demonstrates how health is constructed and negotiated among slum residents within the constraints of their precarious living conditions. The area's structural characteristics, adherence to both traditional and modern city cultures, fatalism, and deteriorating quality of life all contribute to the health construct among slum dwellers. Despite a variety of health and well-being concerns, they maintain a sense of optimism for survival. Additionally, they anticipate being actively involved in the administrators' aim to improve slum conditions. This can be accomplished by taking their perspectives into account while developing various health policies for them and by boosting their morale through the provision of adequate food, shelter, quality health care, job prospects, and education, among other things.

Researching how slum dwellers report symptoms and translate them into active behaviours (either seeking care or abstaining) may contribute in the development of more effective health policies. Insights on the illness reporting behaviours of slum residents will benefit in projecting future clinical care and healthcare resource

demands, as well as preventing underutilization of healthcare. Chapter three presents an in-depth investigation of illness disclosure patterns. It exhibits how causes affecting men and women in the study slums are equivalent, yet men and women commonly reported distinct explanations for their disclosure pattern restriction to the same factors. Chapter three offers an explanation as how regardless of whether participants believe illness poses a danger to themselves or others, disclosure is a coping strategy employed by them to deal with any unpleasant conditions linked with it. The option to delay, not to delay, or to avoid illness disclosure is determined not by an individual's recognition of illness, but by the interaction of their agency, the consequences of disclosure, and the socio-cultural context. It further describes that decision to postpone, not to delay, or to avoid disease disclosure is not driven by the recognition of illness, but rather by the interaction of human agency, the consequences of disclosure, and the socio-cultural context. Because the sociocultural environment is so important for varying health-seeking behaviours, despite the large body of research on gender disparities in treatment seeking, it is vital to study these relationships across a variety of cultural settings. The complex social structure of Indian urban slums is a product of ethnic variety and acculturation, making them distinct from other groups (Martinez and Lee, 2000). At the same time, they are acknowledged for the contextual aspect of gendered health-seeking behaviours, such as addressing other available healthcare options in a specific location (Yesudian, 1999). This knowledge is essential for developing policies that promote and offer women and men with suitable treatment alternatives, resulting in increased use of healthcare facilities.

A more complete theoretical framework for understanding the interactions between various types of capital and their role in slum population health creation appears to be missing in India's urban slum public health and health promotion studies. In the context of Indian urban slums, a sociological understanding of the neighbourhood effect has been largely disregarded in health research (measured in terms of the volume and shape of each capital's habitat/field) (Patra & Ghosh, 2020). Using Bourdieu's concepts of habitus and capital (Bourdieu, 1986), we suggest that slum dwellers' responses to diverse neighbourhood characteristics might help us understand how they perceive and act on their health requirements and healthcare use across environments. When it comes to capital theories, what sets Bourdieu's theory apart is how it encompasses not only economic capital but also other forms of capital (social and cultural), as shown by lifestyle indicators such as educational attainment and the symbolic components of class connections such as social ties. As a result of this method, specific projections can be made based on the presence of different types of capital. While Bourdieu's theories place health behaviours in the context of family and social structure, they also emphasise how a person's capital structure, such as their economic, cultural, and social resources, may all have a complicated influence on their health habits at the same time. Chapter four

reaffirms the necessity of using Bourdieu's capital-based method to explain health behaviour discrepancies. Chapter four also focuses on Bourdieu's habitus and capital in order to obtain a better understanding of how slum dwellers connect with a variety of social spheres, collecting and deploying capital instinctively and occasionally consciously, according to their habitus. It illuminates how neighbourhood's amount and type of capital effects respondent's perceptions of when to seek curative and preventative primary care, as well as their embodied actions when seeking treatment. It reflects cultural attitudes and tastes for social necessity. It also reflects conflicts and investments in health and well-being. This study can assist academics and policymakers in increasing the effectiveness of community health promotion programmes by identifying various neighbourhood and its impact on general health.

The fifth chapter examined the treatment seeking behaviour of men and women living in an urban slum in Kolkata, India, by delving into the underlying perceptions that shape their therapy selections. Men's choice for traditional healthcare and women's preference for complementary and alternative medicine were previously found to be gender discrepancies (Al–Krenawi and Graham, 1999; Vlassof, 1994). In contrast, the current study reveals that men and women both engage in formal and informal care simultaneously. Nonetheless, the key finding of the study indicates that they do so in separate ways and with distinct goals. The study throws insights on gendered societal prescriptions, financial stressors, socio–cultural constraints, social capital that positively or negatively endorses health seeking behaviour, among men and women in the urban slums.

Finally, we will discuss the main findings of the thesis, provide theoretical and methodological reflection of the study, explain the scientific and practical ramifications for urban slum inhabitants' healthcare interventions and promotion, and suggest directions for additional research in Chapter six.

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#### Chapter 1

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General Introduction



# **CHAPTER 2**

Understanding self-construction of health among the slum dwellers of India: a culture-centered approach

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## ABSTRACT

Disembarking from a traditional approach of narrow hazardous environmental and structural conditions in understanding urban slums' health problems and moving towards a new notion of what constitutes health for slum dwellers will open a new avenue to recognise whether and how health is being prioritised in disadvantaged settings. Drawing on in-depth semi-structured interviews with a total of 67 men and 68 women from Kolkata slums and 62 men and 48 women from Bangalore slums, this study explored how knowledge, social realities, material and symbolic drivers of a place interweave in shaping slum-dwellers' patterned way of understanding health, and the ways health and illnesses are managed. The current study adds to the growing evidence that ordinary members of the urban slums can articulate critical linkages between their everyday sociocultural realities and health conditions, which can support the design and delivery of interventions to promote wellbeing. The concept of health is not confined to an abstract idea but manifested in slumdwellers' sporadic practices of preventive and curative care as well as everyday living arrangements, where a complex arrangement of physical, psychological, financial, sociocultural and environmental dimensions condition their body and wellbeing.

Keywords: culture, health, perception, urban slum, well-being/ill-being

## INTRODUCTION

Although health conditions and illness play a pivotal role in poor health outcomes of urban slums, knowledge is still very scant about the subjective dimension of health, which is inextricably linked to poor health occurrence (Garcia 2006, Marshall & McKeon, 1996). Health is shaped not only by biological risk factors but is also conditioned by the human-built external environment such as social learning, cultural norms, ethnic traditions and interactions in which it takes place (Blaxter, 1990; Bury, 1997). The emphasis, therefore, should be on phenomena that build up through dealings in a social milieu rather than on meanings of phenomena that do not essentially exist in the phenomena themselves (Airhihenbuwa, 1995; Berger & Luckmann, 1991). For instance, Dutta-Bergman (2004), in their study, showed that Santal tribes of West Bengal located healthy life not in illness but primarily in the realm of their access to food. Sen (2002) observes that spite of diverse medical facilities and favourable life expectancy rates, people in the US tend to complain more about their health-related problems, while health does not necessarily constitute a major concern for people in the Indian context in general. Again, studies by Anderson (1976) and Shanas et al. (1968) show that the elderly usually have a propensity to perceive their health as good, even in the presence of clear pathological symptoms, and attribute their discomforts to the normal ageing process. It is therefore evident that there are conceptual differences in the way different groups think about health, given the multiplicity of the sociocultural landscape involved (Bott, 1971; Kelman, 1975; Twaddle, 1969; Zola, 1966).

Because of the wide ethnic and cultural diversity that exists in India, the health practitioners are constantly called on to interpret how the cultural context influences health meanings, how they are constructed and practised (Airhihenbuwa, 1995; Dutta, 2008; Lupton, 1994).

More specifically, slum settlements as unique areas entail 'intimately shared physical and social environments' for their inhabitants (Lilford *et al.*, 2017). Living in slum areas is characterised by insufficient access to water and sanitation facilities, inadequate housing space, job and housing insecurity (UN–Habitat, 2003). In addition to that, slum settlements have a spatial dimension that entails strong neighbourhood effects (Oakes, 2004), where high social and spatial proximity to others affect the residents' health outcomes (Ezeh *et al.*, 2017). For example, overcrowding leads to higher competition for scarce resources and hence to crime, but also epidemics due to collection of garbage and excrements in concentrated areas, or catastrophic effects of extreme weather conditions (Ezeh *et al.*, 2017; Meijer *et al.*, 2012). Post–migration further leads to problems of acculturation, cultural shock and bereavement, the discrepancy between expectation and achievement, loose social support, lack of group solidarity, lack of access to appropriate resources, low perceptions of safety,

#### Chapter 2

financial precariousness and the like. Altogether, it creates significant biological, social and psychological dysfunction and disorganisation among the residents and their immediate environment.

This neighbourhood-built environment coalesces to constitute the central axis to public health risks, shapes health behaviours, beliefs and even disease (Dalgard & Tambs, 1997; Ellaway *et al.*, 2001; Wen *et al.*, 2006; Wight *et al.*, 2013). Because of these peculiar circumstances, slum health needs warrant scholarly attention, as interventions that can improve health conditions in non-slum areas might not be transferable to slum settings (Ezeh *et al.*, 2017).

As a coping mechanism to the new form of social desirability, the slum migrants accept the social structure (rules and resources) encircling them, while constantly modifying some of this urban context with their practices (Giddens, 1984). Hence, the co-existence of traditional collectivism with emerging individualism in the same neighbourhood (Pedersen and Rytter, 2018) with different health effects (Conde *et al*, .2018) can be witnessed. This calls for research aimed to gain a proper understanding of the health perceptions harboured by the slum residents which in turn is heavily dependent upon their new sociocultural backing, demographic and economic changes that form the crux of the self-perceived health (Castaneda et al., 2015; Ghosh and Shah, 2004; Neto *et al.*, 2017).

We respond to the call towards the understudied topic of slum health by introducing a culture-centered approach. This is because, to effectively explore the utilisation gap in the health-care system, unlike the predominant top-down approach; the culturecentered approach treats communication as a gateway to participatory avenues. It emphasises on cultural members' articulation about their shared meaning of health experiences derived from socially constructed identities, relationships and norms (Airhihenbuwa, 1995; Dutta, 2008; Dutta-Bergman, 2005). This approach is constructed upon culture, structure and agency as a means to explain social behaviour. Structure refers to the arrangements of institutional and organisational interactions that affect the availability of resources (Dutta & Basu, 2007). Agency, on the other hand, constitutes the thoughts and actions of the subjects to either reproduce certain culture-derived behaviour or challenge the status quo to address the emerging demand of real-time situations (Emirbayer & Mische, 1998). Culturecentered approach expostulates that both structure and agency are deeply rooted within culture, which itself is a dynamic set of values influencing the attitudes, perception and behaviour of the subjects thus enabling or constraining their social action. While the culture-centered approach places agency at its theoretical core, Dutta and Basu (2007) recognise that culture 'emerges as the strongest determinant of the context of life that shapes knowledge creation, sharing of meanings, and behaviour changes' (p. 561). Situating agency within a cultural context adds personal and social history to the structure–agency framework, where different 'contexts support particular agentic orientations, which in turn constitute different structuring relationships of actors towards their environments' (Emirbayer & Mische, 1998). Agency, then, creates the possibility for actors to transform their relationship to structure and offers the possibility for social change through time.

Subaltern studies theory (Guha' 1988; Spivak, 1988) proposes that the dominant paradigm regarding historical, ideological and economic forces often stifle marginalised communities by imposing a standard set of values that are not tailored to individual needs, thereby excluding endogenous community values. Subaltern subjects are marginalised through different institutional mechanisms that are sometimes invisibly enacted through their diverse cultural ideologies on the healthcare system. This results in the lack of information on the subaltern sectors from the dominant spaces of knowledge. Through verbal communications and dialogues about locally constituted stories, culture-centered interrogations seek to understand how community members at the margins of mainstream healthcare systems negotiate meanings of health and constitute their actions located within dominant structures of meaning. Many studies guided by culture-centric approach have already been applied in various context-specific areas to explore their healthrelated perceptions (Basnyat a& Dutta, 2012; Jamil & Dutta, 2012; Kandula & Baker, 2012; Yehya & Dutta, 2010). In India, however, this approach has been limited to studying the health perceptions of tribal populations (Dutta & Basu, 2007; Dutta-Bergman, 2004). Drawing on the concepts of the culture-centered approach, the present study attempts to get a more nuanced understanding through the narratives of urban slum dwellers the diverse components of knowledge, neighbourhood, material culture and symbolic drivers of a place that interweave in shaping their patterned way of valuing health and managing in practice.

# **METHODS**

## Study setting

This study is part of larger qualitative research investigating the diverse health beliefs and practices of people living in urban slum settings. Motijheel Basti and Sahid–Smriti Colony from Kolkata, and Nakkale–Bande and Ullalu–Upanagar from Bangalore as the research settings were purposively selected, because of their distinct and diversified history of slum emergence, living conditions, cultural landscape and plethora of health services (Das *et al.*, 2018; Dyson & Moore, 1983; Karve, 1965; Miller, 1981; Nagendra *et al.*, 2012; Sopher, 1980). A transcendental phenomenological approach was adopted in this study, in consideration of the fact that generating the essence of the lived experiences and meaning–making on health concept shared by the participants is the core objective of the study. This design

allows researchers to hear and illuminate how the participants apply meaning to the phenomenon without prejudgement (Dowling, 2007).

## **Study participants**

The participants in this study included 67 men and 68 women from Kolkata slums and 62 men and 48 women from Bangalore slums. The respondents were selected with a stratified purposeful sampling technique, to ensure a theoretically representative sample in terms of gender, age, religion, place of origin and linguistic/ cultural variation. In each subgroup, a saturation approach was adopted to ensure appropriate sample size, and respondents were recruited until information redundancy occurred (Angeli et al., 2018). Mostly, after the 8th interview, no new shared themes were generated from the interviews. Therefore, based on the data saturation model (Sandelowski, 2008; Saunders et al., 2017), it was accounted that the data collection had reached a saturation point. Snowball technique was deemed to be appropriate for recruitment because participants found it confounding to openly discuss about their multiple situations (e.g., pertaining to sexual and reproductive health or illnesses that are associated with social stigma) with the first researcher with whom they were not familiar with and perceived a risk associated with selfdisclosure (Sydor, 2013). The first author's 'native' status offered the opportunity to recruit initial informants by using existing networks and contacts. Participants were selected based on two essential eligibility criteria. First, the participants must include a composition of the older migrants (both in terms of age and stay that is <15 years), new migrants (residing in the slum for a minimum of 5 years) and native migrants (born and bred in the slum) and these terminologies will be maintained throughout the paper. Second, the participants must belong to the predominant religious and cultural group of the slums. Regarding the cultural and religious background of the respondents, we noticed that cultural minorities (Buddhist, converted from an originally Hindu caste) were present only in the Bangalore slums. When interviewed, we noticed that other than the rites-de-passage (that is ceremonies related to birth, marriage and death) daily based rituals, in particular, health-related activities, were followed in line with the Hindu customs. Based on these observations we inferred that their cultural practices were not strong enough to induce cultural changes in the neighbourhood or bring new forms of social desirability in residents' perception of health. In fact, the minorities tried to assimilate their rituals with those of the majority culture to avoid cultural isolation and instead secure community trust as a resource for social and material support. At the same time, they kept the very major life events intact to preserve their cultural identity as Buddhist. The demographic characteristics of the participants are presented in Table 1.

	Kolkata				Bangalore			
	Motijheel (n=69)		SahidSmriti (n=66)		NakkaleBande (n=48)		Ullalu- Upanagar (n=62)	
	Men (n=33)	Women (n=36)	Men (n=34)	Women (n=32)	Men (n=29)	Women (n=19)	Men (n=33)	Women (n=29)
Age								
Below Twenties	4	3	3	3	2	3	3	4
Twenties	6	14	6	13	8	6	8	10
Thirties	10	9	12	7	12	5	12	8
Forties	7	6	10	6	4	4	6	4
Fifties	4	3	2	2	2	1	2	1
Sixties	2	1	1	1	1	0	2	2
Religion								
Hindu	12	12	12	12	12	12	12	12
Muslim	12	12	12	12	12	4	12	11
Christian	9	12	10	8	5	3	9	6
Place of Origin								
Rural	1	10	24	27	9	9	9	8
Within the city	15	17	5	2	5	3	4	10
Displaced	6	0	0	0	4	0	16	9
Outside State	8	9	0	0	11	7	4	2
Outside country	3	0	5	3	0	0	0	0
Linguistic/Cultu	ral group	)S						
Hindi (Bihar, and UP)	15	17	4	7	8	10	12	12
Bengali	18	19	30	25	0	0	0	0
Kannada	0	0	0	0	12	3	10	8
Tamil	0	0	0	0	5	3	6	7
Telegu	0	0	0	0	4	3	5	2
Years of Stay								
Older Migrants	8	12	13	18	11	4	6	5
New Migrants	6	9	16	12	9	5	7	3
Native Migrants	19	15	5	2	9	10	20	21

#### Table 1: Demographic characteristics of participants

Source: Based on data collected in the earlier phase of the field study

## **Data collection**

The interviews were primarily conducted by the first author, in colloquial languages of the respective cities, namely Bengali and Hindi in Kolkata and Kannada and Hindi in Bangalore. However, under the supervision of the first author interviews in Kannada were conducted with the help of a Kannada-speaking female translator who was a native, having a linguistic back– ground (M.A in Kannada, PG Diploma in Bhasha Vignana [Linguistics]) and was working in a health and social care organisations. A semi-structured interview guide was used for the face-to-face in-depth interviews that lasted between 45 and 60 minutes, depending on the participants' interest. Interviews were conducted at locations chosen by the interviewees (homes and workplace) and the guiding questions covered participant's knowledge about health, the process of sense-making about health within their sociocultural settings, and method of preserving and managing health and illnesses. Interviews were tape-recorded with the participants' consent.

The authors' host institution has followed the study throughout and guaranteed for the ethical suitability of the adopted methods in the local Indian context. Oral informed consent to participate was obtained from all the participants. The study has thoroughly followed the ethical guidelines for social science research in health framed by National Committee for Ethics in Social Science Research in Health (NCESSRH) (Jesani and Barai, 2000; Shah *et al.*, 2000). Ethical approval for the study was obtained by the Institute of Socio–Economic Change in Bangalore, India.

#### **Data preparation**

All the audio-recorded in-depth interviews were transcribed verbatim in their respective colloquial language. Translation occurred concurrently with data collection, to enable the research findings to be shared with research participants and the local research assistants who could check and confirm the interpretations accurately reflecting their perceptions and experiences. For this cross-cultural study, Brislin's (1970) model of translation was followed where two bilingual persons were assigned to reach concordance of meanings between two different languages. One bilingual person who was proficient with both English and Kannada was assigned for forwards translation of the field transcripts from the source language (non-English) to the target language (English). Another bilingual person, who also acted as a translator in the field, back-translated the documents from the target language to their source language to ensure the accuracy of the translation. The translated versions were compared to achieve equivalence between original and targeted language. Any discrepancies that have occurred during the process were resolved through discussions with the two bilingual translators.

#### **Data analysis**

Transcripts were analysed with an inductive approach or 'bottom-up' way (Frith and Gleeson 2004), preliminary coding and subsequent themes were identified from the data after reading and re-reading and was not informed by pre-existing theory or hypothesis. Interviews' transcripts were coded using the guidelines of Braun and Clarke's (2006) thematic analysis for identifying themes, build patterns and develop complex themes. In particular, Gioia et al., (2013) three-step approach was applied, that involves coding process of open coding and axial coding, in line with described by Strauss and Corbin (1990). In the first step interviewees responses were deconstructed into common codes based on shared ideas. Codes were assigned to words, phrases, sentences, or paragraphs from the transcripts. By this first process of open coding, 455 segments were coded along with 78 first-order codes. The second step followed axial coding that consisted of identifying relationships among the open codes and collate them to develop abstract themes from an empirical to a more theoretical level. This process allowed clustering of 16 general themes into second-order themes. In the last step, the second ordered themes were analysed for emerging common threads, resulting in five abstract aggregate dimensions.

During each iterative cycle, transcripts, codes, aggregate concepts and global themes were compared in all directions; transcripts were re-coded and re-categorised as themes emerged from the data. Consultation with the second author helped refine aggregation of the last themes and overcome biases, as the second author did not participate in data collection and was hence having the role of an independent observer. While the open coding was fully conducted by the first author, the processes of axial coding and generation of abstract constructs followed iterative consultation rounds between the first, second and third author. Because the second and third author was removed from the field and did not participate to data collection, they acted as impartial and independent observers, therefore reducing the potential bias that the first author - being fully knowledgeable and immersed in the field - could have carried through in the analysis of the material. These consultation rounds, leading to a process of collective coding, was also important to reduce the bearing of any of the authors' cultural background and identities on the understanding of the collected evidence. The first author is of Bengali heritage and ethnic group, which could have led to a more in-depth understanding of the Kolkata slum, a setting that is closer to the first author's cultural and linguistic background. However, the second and third author each hold a different cultural and disciplinary make-up, which allowed for a multicultural, interdisciplinary view on the interview material, and on the coding results. Finally, an important aspect of the research design of this study is its comparative approach, which further reduced the potential bias related to the first author's cultural identity. In fact, cultural meanings and theme aggregations have been gauged through the inclusion in the sample of a second site,

Bangalore, where most respondents did not share any linguistic, cultural or ethnic commonalities with the main researcher.

## Measures to ensure the validity and reliability of data analysis and interpretation

To ensure methodical clarity, structured and provable approaches throughout the analysis; various techniques were applied. The validity of our findings was further enhanced by utilising the methodological and investigator triangulation methods. Methodological triangulation allowed comparing and contrasting the data collected during individual interviews while investigator triangulation ensured participation in data analysis by multiple members of the research team both in and outside the field. The former triangulation method included the availability of topic guides as mnemonic devices, digital audio-recording, independent preparation of the verbatim transcripts by the research team, thorough rechecking of the translations against the original audio-file, standardised coding and analysis of the data along with the creation of an analysis audit trail to document analytical decisions. To address deviant cases or possible conflicting interpretations, discussions with the research team were conducted to assess the robustness of our findings and ensure a wide range of participant views. Our analysis was further aided through investigator triangulation by regular discussions about the findings with the multidisciplinary, international researchers and co-authoring team, to mitigate potential biases of the first author that might relate to her disciplinary background and/or her embeddedness into the study context. Data generation continued until the point of saturation, where no new major ideas or perspectives were emerging.

# RESULTS

A dichotomous concept on health meaning emerged from the interviews with the participants where health is internalised either as wellbeing (positive aspect) or illbeing (negative aspect). However, this concept is not confined to the abstract idea but furthermore manifested in their cultural sporadic practices in the form of preventive and curative care as well as in their every- day living arrangements. Such abstract ideas, every day or occasional activities are conditioned by a complex arrangement of physical, psychological, financial, sociocultural and environmental dimensions that primarily shape the self-construction of health. The results are presented in five broad themes further explained in this paper, with their relevant subthemes.

## Wellbeing/Ill-being understood in the realm of physical elements

The majority of the participants considered the physical dimension of health as the initial and core of self-assessed health. The concept of wellbeing for them is embedded in the absence of any symptoms of an abnormality in the body. As a participant expressed,

'My health is excellent. I have not lost weight; my body is toned even at this age and my face is still graceful like those of young girls.'

However, perceived susceptibility differs between older migrants and native or new migrant participants. Older migrants exhibited better self-rated health compared to the latter. For instance, when asked to all the three groups of participants how they contemplate the 'symptoms of abnormality'older migrants referred to a functional definition of health in terms of physical aspects. Reported examples are pain and tiredness, feeling of being overwhelmed by their daily activities or when tasks take longer than usual to complete, they consider it as a symptom or clue from the body that they are not well. In this context, one participant expressed,

'When I experience shortness of breath, I can do a little activity at a time and then had to rest as I don't feel well.'

The severity and importance of health problems were controlled more by the capacity to deal with problems than by the problems themselves. This ability was associated with retaining traditional rural-urban dual social structure such as strong family support, traditional family-based caring, well-built social and kin network ties with the native kins attenuating the perception of difficulty in obtaining care-giving. Such social position, network size and normative practices are outcomes of past life course events. As one older migrant expressed,

'When we came here seventeen years back, there were no worries about eating, no worries about drinking. You see ... there were no worries about money. Even today for us continuing care for the family, eating right and healthy, observing healthy habits, maintaining strong bonds with the roots constitute to fight with depressive symptoms, stress, chronic diseases, and functional limitations ... this generation everyone is running after money. Yet no one is happy. Money cannot secure everything. They (indicating native and new migrants) are lonely; don't eat right and simple food, no space for respect, security and belonging. Inter-generation relations have undergone a drastic change that simultaneously slowed down their chance of well-being.'

At the new and native migrants' level, for an illness that is not serious in its initial manifestation, a common practice is to not consider it as ill-health in its early stages and to hope it disappears in a few days. However, when physical functional ability and stamina severely decline, the participants acknowledge that their bodies are becoming hard to control. As said by a participant,

'I kept on pushing myself in doing work thinking that everything will be fine... because feeling sick is so emotionally demanding. But one day when I suddenly collapsed, I tried to retrospect that my energy was actually getting worn out faster and faster and then suddenly stopped.'

Further inquiry with them revealed that health by habit is not an everyday concern. For new migrants fear of denunciation, lack of knowledge as to how to navigate the health system and access to costly treatment negatively impact their healthpromoting habits and entails negative health consequences. The moment when diseases become unbearable is where they acknowledge their concerns for health and that defines their construction of health. To this, a participant responded,

'I don't know whom to approach here, there are so many doctors, different types like you know different doctors for different diseases, I feel like they are all moneysuckers!!! Just sitting there for you to come and give every penny that you have with you. Back at home, we used to have one doctor, whom we could approach for each and any kind of health issues, yet he is friendly and nice. Here, going for the treatment itself is very confusing and doubtful ... so we try to avoid those places until emergency calls.'

For native participants in spite of having better social integration and local support (due to home communities), stressful economic (difficulty to enter the labour market and securing the position) and social experiences (low self-esteem, acceptance, struggle for quality and sustaining resources) related to living in a slum environment demand everyday solution and health; therefore, does not constitute one of those factors; impeding adequate use of health services. For instance, many participants reported an irregular water supply, forcing them to buy water drum for cooking. To this, a participant said,

'We use pond water for washing and bathing. So, the water is not for drinking and the drum that we buy cost us Rs.500 monthly ... living in a city where everything is so expensive this amount of money also matters and is quite difficult to earn ... but every month you have to earn this money to ensure the provision for drinking water, which is more important than healthcare.'

#### Wellbeing/Ill-being understood in the realm of psychological elements

In this context, health and illness are professed as two different entities and not as contrariety. This means that disease does not inevitably lead to ill-health and that absence of disease is also not an assurance for good health. It is a matter of how one is doing (feeling) in the actual situation. As one participant replied,

'During the day I might be happy but by night I may feel sad from inside and may not feel like eating. This, however, does not mean that I am actually ill but is not healthy either ... maybe for some reason I am too stressed out.'

Therefore, the holistic senses of feeling healthy are subjective; it is about feeling good, being content, even if a person is ill.

While the subjective notion of health for some participants is purely measured by psychological factors, for a few participants the nature of illness controls the mind-body expression of subjective wellbeing. For instance, bodily experiences such as cold, cough and fever are considered a small illness that does not match an individual's emotional response with more serious or chronic illness. The mundane illnesses are so commonplace in their life that they hardly consider it as perceived risk. As a participant said,

<sup>6</sup>Every night I get this headache and pain in my body which disappear during the day. Yet I say I am healthy because I can endure this pain, feel contented and can do my work without feeling unpleasant. Now, I cannot say I will feel the same if I had cancer; I will be more worried and stress.<sup>9</sup>

Chronic illness, on the other hand, once detected leads to emotional dysfunction among participants, like anxieties, uncertainties, fears and losses. As a participant said,

'I am trying to become hopeful...but often I get devastated; I know I cannot afford the money for treatment and I am dying too ... I am lost and don't feel like to live life anymore.'

Coupled with that are strained social relations and isolated life due to the inability to work. Participants said that social relations are of particular help for improved wellbeing, as they provide social support in the form of emotional and practical assistance. A participant recalled her experience,

'I was bedridden for 3 months and felt like totally cut off from the outside world ... I used to miss badly my friends where I work because, other than work, we used to chitchat and give emotional support to one another for dealing with practical problems of life.'

An important toll on the psychological wellbeing of slum dwellers is taken by the financial insecurities related to living in a slum settlement. Participants said that loss of work changes their financial situation, which directly affects their social life and consumption patterns. This results in feelings of isolation, loss of self-esteem and

feelings of hopelessness that affect their mental wellbeing. Feelings of hopelessness and longer duration of unemployment also, in turn, affects their physical wellbeing (*e.g.*, in terms of sleeping problems and triggering damaging health behaviours such as smoking and drinking problems). As a participant said,

'Like this will sound really stupid if someone says that he lost his job and yet he is very happy ... you understand it right!! losing a job means no food, no peace of mind, quarrels at home ... you feel like sinking ... sick from both in and out.'

Some participants mentioned that they have to do various types of work completely unrelated to their former work experiences; often they do not have the appropriate skills, cannot endure the physical demands of the work, or find that the wage is too low to cover ongoing living costs. They face myriad of health-related challenges while getting accustomed to the job. As a participant said,

'To pursue wellbeing is really difficult here ... I, for example, pull a rickshaw, have to work entire day to earn a decent amount and at the end of the day I feel sores all over my body ... no matter how we feel health... in a positive or negative way, we pay no heed till we can endure.'

#### Wellbeing/Ill-being understood in the realm of spiritual elements

Majority of the older migrants and women participants indicated spiritual health purely in terms of restoring and preserving better health and quality of life. Spirituality has been found to be important in making meaning of life, combating physical and mental illness and is a predictor for the use of traditional practices. The participants believe that one who does not tend to shape a relationship with God or spiritual power cannot combat illness. The ascription of misfortunes to an individual pervaded by spirits was observed to be common among the participants. Sicknesses, contagious or chronic diseases and even accidental or painful death were explained in terms of divine punishment by enraged or malevolent spirits. As a participant said,

#### 'Offering namaz (Islam's five daily ritual prayers) is a way of mind-body therapy. Namaz provides not only physical but also spiritual and intellectual growth.'

Many participants believe God to have human personalities; that is, they are benevolent and kind if they are worshipped, while they can get angry or irritable when they are hungry or get jealous if more attention is given to other deities. Spirits and Gods demand tributes in return for protecting physical and emotional health and punish for failure to pay proper homage. Not practicing religious beliefs such as praying, visiting temples, mosque or church or organizing religious ceremony attracts malevolent spirit and a projection of sufferings and death. Spiritual rituals and practices are mean to exorcise spirits for a participant, 'We must show respect to God through proper rituals such as praying, observing the local customs and values, etc., in this way you can ward off the bad spirit and keep your family safe from harm and bad health.'

Sorcery and witchcraft are also considered as a causative agent of ill-being. Participants consider them as a human creature who can metaphorically suck the soul out of another human being until the victim gets very sick and die. It is commonly believed among the participants that witches operate through fowl-wind and fetishism. As a participant said,

'Customarily after marriage for 1 year we don't allow the new bride to cut her hair, wash her bridal sari or pull off a head veil ... witches can easily use them to create a fetish object, cast spell on them resulting into sudden death of the husband or an unhappy marriage.'

Again, the construct of health and spirituality for some older migrants is typically determined by diminishing family support. Religious activities and faith-based organisations, therefore, compose the most objective dimension as social and instrumental assistance that is available from one's social network (e.g., providing transportation, care when sick). Being involved in religious activities as group members' further enable these older participants to experience not only support but help anchor identity by connecting with people from their community and derive inner strength. One participant, for instance, expressed,

'Our children remain preoccupied with work and fulfilling family demands, so they cannot offer much time to providing companionship to their ageing kins. Therefore, to avoid isolation, bad thoughts that make us sad, or to gain inner strength by thinking that we are not alone; we engage ourselves in religious practices and domestic rituals such as prayers, attendance, services or celebrating religious functions with our fellow brothers ... we get the feeling of the homeland.' Social support mediates resources and opportunities for healthcare services such as hospital visits and medical examinations, understanding clinical care and translating its languages, and transportation to see physicians. Therefore, greater social support simultaneously functions in greater healthcare services.' As added by a participant,

'My son does not stay here to take care and she (indicat ing daughter- in- law) is already juggling with the tasks of taking over her husbands' roles and caring for the children. I do not want to overburden her with making care arrangements for me. The Sangha (faith-based organisation) with whom I am attached give adequate care assistance whenever required...they have good connections with big doctors. Therefore, Sangha members can easily and usually organize for our treatments and help us by paying the associated cost...once they even arranged my transportation to the hospital along with the medicines, they also have their own brand of common pain relief medicines which they provide free of cost when asked for. I made my daughter- in- law join the Sangha so that she too can avail the facilities. They helped with some loan in starting up her home-based businesses.'

New and native migrants (primarily male participants) mainly relied largely on their faith to cope with physical hazards, misery and isolation. They put down their destiny in the hands of Supreme because of their inability to control circumstances. Religious support also manifested itself through local agents (religious institutions, faith-based organisations, traditional healers, priests, church members, etc.) trusted as intermediaries between the slum residents and the divinity. These associations also provide much needed assistance with money, basic needs for survival and legal assistance in adapting and securing their place within the slum and, at the same time, keep up their cultural legacy and warrant their ethnic identities. Some participants said that they believe in visiting the church every day as the form of healing retreats and do not prefer any other form. This is because the Church helps them provide conventional health care through community-based interventions such as frequent medical camps, wellness clinics or wellness group sessions. A participant commented about wellness group sessions *as* 

'they give us knowledge on how to engage in healthy behaviours and help us practice them by providing us with food and medicine. They deliver various messages as for how to remain healthy, make godly choices and conduct programs on healthy habits.'

Despite witnessing escalating transcultural habitat because of rapid migration processes, participants' particularly older males and females (both young and old) demonstrates to still heavily draw on their cultural framework to conceptualise health. Participants said that, throughout the year, they perform manifold rites and rituals associated with village folk deities who are the pivot of disease controllers. These activities seem to be quite constant in the study slums of both the cities. Although, religious and communal variations are witnessed in names and forms as well as in obligatory methods; but all of them have the most codified and monitored

set of health practices, have explicit prescriptions and proscriptions about health behaviours, food habits, teach their members to respect and take care of their bodies by showing gratitude towards God through various ritual manifestations (prayers, animal sacrifices, calendrical worships etc.). For instance, in Kolkata slum, *Shosthi* is worshipped in various forms with various significances. She is worshipped in the form of Shosthi pujo (for maternal and infant mortality), jamai shosthi (for the wellbeing of sons-in-law), sheetal shosthi (sexual wellness), neel shosthi (child's safety and prosperity). One participant said,

'she is considered as the guardian angel in every household and these rituals are primarily performed by women only, some by young unmarried girls and some by both.'

Hindu participants of Bangalore slums worship Mariamman who is believed to take care of several diseases like a 'general physician,' and is quite popular among the slum dwellers. As an older male participant said,

'We worship her by offering boiled rice, fruit, flowers, kumkum, burn incense and camphor and she protects us from all demonic attack.'

Muslim participants approach spiritual or folk healers, locally known as fakir or Pirbaba, who observes various healing rituals. They use various kinds of herbal made ointments or give talisman or amulets made of religious scripts or dohas (lucky chants in written form) to ward away any malignant forces. One woman participant said,

'When I was pregnant, I used to get terrible dreams at night and shivering as well. Baba gave me a tabiz (talisman) inscribed with Doha and said this will protect me from an evil spirit who was trying to enter my womb.'

For treating diseases, spiritual healers recite verses from Quran or employ touch, breathe over the forehead, apply coolant herbs or scented massage, or use physical objects such as talisman, amulets and mascots to touch the skin.

#### Wellbeing/ill-being understood in the realm of cultural practices

Post-migration challenges such as loss of social structures, self-identity and cultural values produce and reproduce (mobilising, enacting, validating) cultural capital in a new way and health construction is of no exception. Health conceptualisation in slums is compounded of congruity of the culture of origin and culture of the destination.

The older migrants, who migrated to the city 15–20 years ago, have seen a rapid change throughout the period and gave retrospective accounts of the change in lifestyle that they have witnessed. They made comparisons between native villages or then newly built slums and the current living conditions affecting their wellbeing. Regardless of circumstances, they moved in the past mainly to able to enjoy the quiet and the good weather, going at a slower pace with less bustle and aspirations of a better life, especially for their children. They share health meaning in general as an individualistic search for 'the good life'. As one participant remarked,

'When we arrived here, we came not with the notion of the rat race ... we wanted a decent life, good education, good food, large information-based network, we had an optimistic attitude towards life and future, which is consistent with good health. We could do that because we had more native-based counterparts on whom we could rely unlike this younger generation ... we migrated at a very early age, were, therefore, ahead in time and settings (e.g., work, neighbourhood, recreation centres etc.) to develop and maintain social ties. These days kids miss those opportunities, ... these places nowadays are of no prospects or good life as everyone started to migrate here from every corner ... faces are unfamiliar and hard to trust ... people here often had to even leave the family to get better work, they feel isolated and without friends which is very depressing.'

Many participants mentioned that earlier when they moved in, they use to live in open spaces and relatively bigger houses with good ventilation, but gradually influx of migration and crunching space made them shift in a one-room house, which is congested and over-crowded, making them unable to move around freely. The expectations and practices of the older generation that they acquired over time through historical position are difficult to maintain in the new environment and they do not possess the right capital to claim desirable field positions. As a participant said,

'When we first arrived in Nakkale-bande, the slum was comparatively new, it was not that crowded ... everybody knows each other ... we all came from nearby villages, friendly atmosphere it was and everything was so pure and fresh ... air, water and vegetables ... I felt like I was still in my village ... it never came to our mind we have to stay fit and healthy ... I mean what is health ... I don't remember talking anything related to health or even knowing its existence ... in due course, everything has changed ... the city has become crowded and polluted, more people started to come in to settle, we don't know many of them or what they did in the past ... we now ask people in the form of greetings ... are you in good health ... is everything ok.'

A considerable proportion of widows shared their views about foods that activate sexuality are avoided. These foods comprise of non-vegetarian (meat, fish, eggs,

onions and garlic) and spicy food and certain pulses such as red lentils. They are substituted by cold food such as muri (puffed rice), cheera (beaten rice), green lentils, flatbread or dietary products such as curd, milk or cottage cheese. Also, on the eleventh day of each lunar month (Ekadasi) fast is observed. When asked how fasting is connected to their understanding about health one young widow participant said,

'Fasting is observed not to attain salvation. It is simply to weaken the body from sexual desires.'

Elderly married women as well as male participants also observe the food restrictive code (though not necessary for them to follow if they do not wish to) out of 'habit' or to maintain a celibate status. To this; one woman participant said,

'For me, food avoidance is not associated with sexuality because anyway I am asexual after menopause but I prefer to eat cold food to make mind and body self-contained.'

Another old male participant also similarly remarked that

'We are not imposed with these diet restrictions but still with growing years we get inclined towards cold food as our system itself cannot digest hot food.'

Food taboos for young female participants primarily revolve around the concept of 'hot and cold' foods and divergent opinions were noted on its avoidance or restrictions ... For instance, pregnant and lactating women believe that following food restrictions helps to avoid health risks and mortality of both mother and baby. As a pregnant woman participant said,

'We avoid eating ripe pineapple, papaya or any food that makes your body hot. This directly affects the foetus and leads to abortion.'

Although eating well to remain healthy is a known knowledge yet in many instances adolescents and young participants believe that these food restrictions are not feasible to follow in urban settings where everything is added to the expense. To this, a male participant said,

'These do's and don'ts fit in villages where everything is very cheap or where you grow vegetables in your backyard ... but here you have to get everything with money and therefore it is not wise to become choosy ... you have to eat what gets into your heart ... Someday it may be fish, meat or someday very plain food like salt and rice.'

Almost every Hindu participant abstain themselves from taking beef while some of them never eat or handle meat, fish or eggs. For them consuming vegetables and plants in the form of food is considered less morally wrong than killing animals. For a participant, *food that requires slaughter and sacrifices causes pain, distress, and disease*. Muslim participants abstain themselves from taking pork or dead fish and the reason described by them as,

'Any dead animals and flesh of a pig are not permissible for consumption as they are considered to be unclean and is the root cause of many diseases.'

However, no food taboos are observed by the Christian participants as they believe in consuming any edible that are readily available in the market and are fresh.

Adherence to traditional cultural practices for older males was related to the length of stay in the slum. For instance, older generations participants who are also matured residents do not have to face the stresses of fresh migrants who constantly fight adapting the strange and unpredictable environment of the host culture. Being older residents, they learned social competencies such as (community and leadership skills, cultural capital and coping skills), and established social and organisational ties (social capital, local network closure and extra-community skills). As a cultural majority, being able to share social meaning and cultural values, older residents could maintain their original religious beliefs as a source of comfort to attenuate both ageing-related and new age challenges. In the case of women, it was changing authority within the household, traditional family structure, gender roles and expectations. For instance, in female-dominated households; a household is a symbolically fixed resource that serves as an anchor for the members to preserve their cultural identity. These home-based rituals provide space to worship in familiar method and also create avenues to connect with familiar ethnic ways of life, community information in the migrants' native language, psychological and instrumental support for newcomers who need health care, housing and jobs (able to organise themselves and their communities in a way that reconstitutes their native systems). As one participant remarked,

'This is not just an occasion or a ritual ... we now stay in cities, faces many disputes and hostility, family problems, job insecurity ... these festivals give us strength to survive, get a chance to rejoice amidst sorrow, to connect with people of my community and makes us feel one family in an alien land, feel my culture through language, food or festivals. Even, religious rituals carried out in the home helps to maintain my cultural identity. I feel still connected to my roots otherwise here everyday things changes ... food, dress, lifestyle even your "self".

Economically dependent female participants expressed that their culture undervalues, especially women's freedom and decision-making autonomy. This dependency promotes the stereotype among them that they are the 'keepers' of religious norms and practices. It is their prime duty as a caregiver. Traditional values further impart that woman are responsible for a performative act such as care-giving to preserve the life and happiness of their family even to the extent of sacrificing personal aspirations. As one woman participants said,

'I believe I must protect and promote the wellbeing of our family ... I perform and fulfil my role by following those every ritual taught by my elders that can bring the good prospect to the household including health.'

Women are helped in their caring mission by access to resources or stake-holders that are close at hands such as following traditional customs and rituals or approaching faith healers or traditional medicine men. These arrangements are more often seen as offering complementary rather than adversarial services involving easy access to free or inexpensive health services. As a participant remarked,

'I feel little confidence in my abilities to make health-related decisions, go out and seek a doctor, because I don't have money of my own. Hence kind of care that is traditionally acceptable is following these rituals. I don't know whether these works or not but; at least gives me a sense of safety and helps in meaning-making to my actions as a caregiver.'

#### Wellbeing/III-being understood in the social realm of the slum environment

Many participants mentioned that living in a slum can itself become a reason for unhappiness, as life is harder than before, food more expensive and jobs difficult to fetch or earns them little money. Consequently, crime exists, social cohesion not easily available, familial conflict and stress and lack of support give rise to psychological distress that contributes to the construction ill-being of health among the participants. Many women participants revealed about intimate partner violence, which profoundly affects their overall health. As a participant said to this, 'We understand health as happy from inside but when I see many women here being beaten by their drunk husband, I feel though they show happiness they are very sad from inside ... and when you are distressed from inside you are not healthy.'

Some participants highlighted that unsettling is also caused due to lack of social solidarity, lack of supportive spouses and lack of supportive environment in the slum. According to many women participants, their husbands do not contribute money to meet the household expenses as a result of which they have to go out for domestic work without any formal leave. Most children are left alone at home during those hours with no one to look after even when they are unwell. To this, a participant remarked,

'...there is no way in relieving your stress ... you have to go leaving your small kids back at home with your main door locked and no one to look after ... many women like me goes out so you cannot say anyone to take care. While we are away, we constantly fear about the safety of our child.'

Again, some women participant expressed that, because of some antisocial activities that take place in the public toilets at night, these usually remain closed at that hour and they had to control their nature's call. To this a woman participant said,

'we don't go to any faraway public toilets at night because it is not safe for a woman to go out alone at night and the one which is very close to our slum remains closed during nights ... this is very uncomfortable and we are not happy with such arrangements.'

Almost every participant expressed that they do recognise health to be a vital element of existence and taking care of health is of equal importance for subsistence. However, the everyday problems that they experience like the dirty environment, lacking toilets facilities and insecurities without any viable alternatives do force people to exhibit hopelessness towards maintaining good health and dejection that things would never change. Consequently, they choose to overlook health, regardless of whether they are in good or bad health. As a participant said,

'Often it is also good to try and feel satisfied with what you can afford ... facing problem is nothing abnormal so one should not constantly worry about health ... in the course of life sometimes you will be ill and again you will revive. While another participant said, I can't say I am satisfied but we have to adopt certain survival strategies by overlooking things and accepting the problems of life the way it is.'

## DISCUSSION

The current study addressed the subjective construction concerning health, as well as views about the key drivers shaping the concept of health among the urban slum dwellers of Kolkata and Bangalore city. Understanding the direct perspectives of slum dwellers around the implication for their health of being a member of urban slums has been rarely explored in the Indian slum context. The findings suggest that the study participants associate health with existential meaning (DeMarinis *et al.*, 2011), understood in their cultural setting. Existential sense making in here refers to all sorts of expressions and to how health is interpreted, such as traditional and religious expressions as well as other circumstantial expressions (Lilja *et al.*, 2016). Health is conceptualised as a feeling that can control every mechanism of the human body, including their physical, psychological, social, emotional and spiritual features, and this aligns with the model as defined by the World Health Organization (1946). The holistic understanding of health is consolidated into a binary concept of wellbeing and ill-being and can be summarized in the statements of 'feeling good' and 'feeling bad'.

As an explanation of their health construct, participants affirmed a general acceptance of bio-psychosocial understanding. The idea of health implies healthy body syndrome, which is an accepted concept among the slum participants and is considered as an ideal. This view finds support from the findings of another study that explores the meaning of health and wellbeing (Saltonstall, 1993). Participants recognised that when far-reaching physical endurance gets exhausted without any further resilience, this is when they consider the health implications. The key predictor that emerged for producing health meaning is any abnormal somatic symptoms that disturb the equilibrium of their daily life. Slum participants understand health as being associated with not only physical wellbeing but also liveliness, contentment and serenity of the mind, which indicate that our results are similar to those of other studies (Alfinger and Causey, 1995; Corbin, 2003). From the narratives of the participants, a double hermeneutics emerged while viewing health (even though ill) from psychological constructs: (i) feels good and can do and (ii) feelings of bodily vulnerability. The former phenomenon emanates in the context of 'knowing one's body' (Corbin, 2003). Brief instances have been accounted in this context, where participants remarked that as an individual, they may be ill and yet may feel healthy. From their perspectives, it can be deciphered that participants

trust their mental body's language till they can adapt with physical peculiarities, usually unconsciously, such as knowing in what manner their body reacts to stress, how much they can conform with the routine before becoming fatigued and what is the perceived time to carry out chores till the body cease to function no longer as desired. This is consistent with Lidler's observation (1979) that conceptions about the body are the creation of one's interactions with the society where he lives. However, for the latter phenomenon, when participants experience that there is a change in sensation or a change in appearance that cannot be anchored meaning but requires a clinical interpretation of vital signs, that leads to the suffering that is more emotional than physical. This is because of the self, which is affected by what happens to the body (Ware, 1992; Williams, 1984).

Health as spiritual and cultural knowledge shapes diverse perceived health risks and goals across different genders and age groups, as corroborated by previous studies (Moridi et al., 2016). Specific health behaviours differ among demographic groups due to their distinct health values and goals. This study shows that some demographic groups, for instance, women and older migrants, engage in a healthenhancing behaviour to achieve a health goal that emphasises maintaining a balance of opposing forces to promote health and supplement the clinical care that implies costs. Its preservations and restorations are delineated through various long- established traditional rituals, sociocultural practices, dietary habits and food taboos, including notions of hot and cold foods, versus body habits which still hold meaning and relevance (Nichter1987, Raman et al., 2014). All these personified images of spirituality, as reflected in the participants' narratives, regulate the slumdwellers' poor attitudinal and behavioural outcome, as influenced by the strained slum environment. In support of Troyer's (1988) findings to harness spirituality, participants furnish a set of practices to follow in their everyday life. For instance, diets, prayers and corresponding religious activities helped them transform tragedy and despair into the positive meaning and thereby preserve wellbeing (Walton et al., 2004). The findings build on previous studies, as religiosity and spirituality have been found to help immigrants in making sense of their life and circumstances (Wong & Tsang, 2004); acceptance of illness, and coping and managing it (O'Mahony et al., 2013; Schreiber et al., 1998). Instead, the new and the native migrants re-interpret religious devotion, and connect it with wellbeing not simply through calendrical and customary rituals but by involvement with faith-based organisations. The quotidian practices ushered by religious beliefs, norms and values are rather observed to render instrumental and sociocultural support and to amplify their chances of leading a quality life.

The above described spiritual-cultural norms and practices embracing health indicate that all domestic and traditional behaviours have not completely changed, rather re-positioned with the new cultural settings, depending on the respondents'

experience as migrants. The pathways by which culture and religion shape the health meaning can be traced through cultural capital and gendered ways, by which extant sociocultural practices acquired different meanings and validations. For instance, cultural distances between older migrants were rather small; as enabled due to longer period of stay in the urban slum that helped to retain the cultural identity and life satisfaction. It is further validated by past literature that established homogeneity plays a major role for the cultural clustering of immigrant groups (Gross & Schmitt, 2003), and also a strong predictor of preserving identity in host society due to linguistic and physical proximity created by the closer cultural atmosphere (Bredtmann *et al.*, 2017). Religious services in the intimate atmosphere mediate social support and life satisfaction which is an indicator of positive health outcome (Yoon & Lee, 2007).

The various sociocultural practices illuminate how religion and culture are used as a means of social security. Although new migrants reach the destination in search of livelihood and financial security; in this context, the concept of security can be pushed forward and can be argued that it goes beyond just economic outcome. It is about sociocultural identity. New and native migrants consider their wellbeing and their security not as individuals but also as members within the social and cultural framework of the new society. Therefore, as cultural agents, their decisions get reflected in a larger social structure where they want an opportunity to survive and thrive and to practice their culture in a safe environment.

Living in a slum alone can cause illness due to social divisiveness, like broken and marooned families, weaker social ties, financial hardship, job and housing insecurity and widespread inequity that inhibits managing a healthy lifestyle (Vaughn et al., 2009). Influences of the slum environment on residents' health perception are pervasive and span across the physical domain, where attention to symptoms is reduced because of hardships of daily life; the psychological domain, where job insecurity induces worries and distress that inhibit a sense of wellbeing. This finding aligns with the recent studies published on Lancet (Ezeh et al., 2017; Lilford et al., 2017) that argue that insecurity is one of the foundational and unique characteristics of slum settings. Another feature typical of slum settlements is; the presence of neighbourhood effect, namely the negative influence of close physical and social proximity on health outcomes (Ezeh et al., 2017; Meijer et al., 2012). Interestingly, our findings highlight neighbourhood effects that are mostly related to psychological wellbeing. While the slum-defining 'intimate sharing of physical and social space' has been often associated to increased epidemics and disease exposure (Lilford et al., 2017; Oakes, 2004), the respondents in our study have instead highlighted its mental health repercussions, pointing to lack of solidarity, crime, feeling of unsafe and lack of supportive environment, stress and domestic conflict as psychologically burdensome aspects of slum dwellings. Rather than favouring the development of

strong and stable social bonds, the proximity of people in slum areas leads instead to heightened competition for scarce resources and therefore to an environment more prone to conflict and criminal activity, with related psychological distress. Given the hardship of slum life, and despite the inherently multicultural environment due continuous migration flows to and from slum settings, respondents display strong attachment to their cultural practices, that they have retained mostly unaltered from their previous village life. Observing local rites and customs seems a way to avert the significant role that sociocultural, environmental and behavioural factors play in health in the form of poverty, social support and medical compliance with treatment schedule, flexibility and acculturation. Slum environment remains inescapable and implies casual influences on health and health disparities, adding new meaning to health constructs, and has a profound effect on overall wellbeing. Acceptance within these environments makes it a plausible coping mechanism, giving them a sense of control and enabling them to survive (Lapierre, 1986). Essentially, the structural circumstances of the slum participants we studied are difficult for them to change or alter. What they seem to have become accustomed to is the body that is conditioned by a complex arrangement of physical, psychological, financial, sociocultural and environmental dimensions in a manner that a person has some control over. Dennis-Antwi et al., (2011) have noted that lay perspectives of health and wellbeing are not static, but are unceasingly constructed in the contexts of changes and continuities in the social, cultural, economic and political experiences of individuals.

#### Limitations and strengths of the study

Some methodological strength and shortcomings of the study should be mentioned. The strength of the study lies in its informative knowledge extracted by focusing on the target group's understanding of the concept of health through differential interactions within the local sociocultural context. Such a dialoguebased understanding of health as applied in this study is functional in other similar settings or formulation of health policies (Horsburgh, 2003) aimed at the slum population. The first limitation of the study is that, since the response rate was restricted to religious groups, the possibilities to generalise the results to a diverse ethnic population residing in the slum areas are limited. Although every possible effort was made for inclusive recruitment to the entire slum study criteria, yet many important voices have likely been left out who could have contributed to this study. Second, perceptions in itself are a subjective matter, not are fixed states but can vary from day to day or situation to situation. Therefore, a thorough understanding of the phenomenon of slum life and its interaction with health needs further exploration for a more valid and generalised understanding of the mechanism of health and wellbeing in a marginalised context. Last, since in one of the studies field local interpreters (even after receiving the required training) were engaged for conducting the interviews, the issue of communicative validity remains, as interpreting the nonverbal communication and the fact that different languages have different concepts may have not been possible to translate directly.

## CONCLUSION

In conclusion, our study illustrates that health is constituted and negotiated among slum dwellers within the exemplified multi-factorial set of representations. Structural conditions of the area, adherence to traditional and modern city culture, fatalism, decaying quality of life and so forth contribute to the health construct among slum dwellers. Despite varied problems surrounding health and wellbeing, slum dwellers maintain hope to survive and learnt to live with their physical incapability. As a result, they take the body for granted and this is reflected in their self-concepts and identities of what they can do instead of what they cannot do. It is not to say that participants do not make efforts to enhance their bodies' efficiencies, as it can be witnessed through their preventive and curative methods. The current study adds to the growing evidence that ordinary members of the urban slums can articulate critical linkages between their everyday sociocultural realities and health conditions that can support the design and delivery of interventions to promote wellbeing.

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Understanding self-construction of health among the slum dwellers of India



# **CHAPTER 3**

# Patterns of illness disclosure among Indian slum dwellers: a qualitative study

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# ABSTRACT

## Background

Slum dwellers display specific traits when it comes to disclosing their illnesses to professionals. The resulting actions lead to poor health-seeking behaviour and underutilisation of existing formal health facilities. The ways that slum people use to communicate their feelings about illness, the type of confidantes that they choose, and the supportive and unsupportive social and cultural interactions to which they are exposed have not yet been studied in the Indian context, which constitutes an important knowledge gap for Indian policymakers and practitioners alike. To that end, this study examines the patterns of illness disclosure in Indian slums and the underpinning factors which shape the slum dwellers' disclosing attitude.

## Methods

In-depth, semi-structured interviews were conducted among 105 men and 113 women who experienced illness in the year prior to the study period. Respondents were selected from four urban slums in two Indian cities, Bangalore and Kolkata.

#### Results

Findings indicate that women have more confidantes at different social levels, while men have a limited network of disclosures which is culturally and socially mediated. Gender role limitations, exclusion from peer groups and unsupportive local situations are the major cause of disclosure delay or non-disclosure among men, while the main concerns for women are a lack of proper knowledge about illness, unsupportive responses received from other people on certain occasions, the fear of social stigma, material loss and the burden of the local situation. Prompt sharing of illness among men is linked with prevention intention and coping with biological problems, whereas factors determining disclosure for women relate to ensuring emotional and instrumental safety, preventing collateral damage of illness, and preventing and managing biological complications.

#### Conclusions

The findings reveal that patterns of disclosure are not determined by the acknowledgment of illness but largely depend on the interplay between individual agency, disclosure consequences and the socio-cultural environment. The results of this study can contribute significantly to mitigating the pivotal knowledge gap between health policymakers, practitioners and patients, leading to the formulation of policies that maximise the utilisation of health facilities in slums.

**Keywords:** Delay, Disclosure, Expressing Illness, Gender, Informing Illness, Slum Dwellers

## INTRODUCTION

In India, numerous healthcare policies aimed at improving the health conditions of the slum population have been adopted and implemented over the past decades. Nonetheless, the poor health status of the urban slum population has consistently been reported (Agarwal & Sangar, 2005; Kapur et al., 2002; Gupta & Mondal, 2015). One of the factors that have been highlighted in previous studies on the poor health conditions of the slum population is their limited utilisation of healthcare resources (Manna et al., 2011; Islam & Ullah, 2009; Basu, 1990). Such underutilisation of care facilities often occurs because slum dwellers do not always disclose illnesses to and seek help from professionals (Uzma et al., 1999), which leads to inadequate usage of healthcare.

In many societies, health problems are primarily handled within familial and social dimensions (Kleinman, 1978; Bagley et al., 1995; Osamor & Grady, 2016). For instance, decisions such as when to seek aid and whom to consult take place in the lay arena based on the lay understanding and treating of illnesses (Sánchez, 2007). Decisionmaking, however, not only involves the time of seeking and choosing care. Decisions also pertain to the way that illnesses are disclosed, in terms of which illness is revealed when, how and to whom (Armistead et al., 1999; Gray et al., 2000; Lugton, 1997; Varga et al., 2006; Boehmer & Babayan, 2005). The disclosure of illness is determined to a large extent by the favourable or unfavourable circumstances that exist within a socio-cultural context (Khan et al., 2000; Chung, 2010; Haque et al., 2012). Discussing illness with others is an important phase in health-seeking behaviour, as it is during this stage that a clear plan of action as to what should be done next (whether to keep it to oneself, see a specific doctor, go to a clinic, start self-medicating or wait for further symptoms to develop) is determined. For this reason, exploring how slum dwellers disclose illnesses and translate them into behaviours (deciding either to seek or to avoid help) could help policymakers in designing tailor-made measures to improve slum dwellers' health status. Insight into illness-reporting patterns as well as into the type of confidantes that slum dwellers choose is crucial to raise awareness of the available clinical and alternative healthcare treatments, which often remain underutilised to the detriment of slum dwellers' health and wellbeing.

There is a great deal of literature in the field of chronic and mental illness (Chandra et al., 2003; Adams et al., 1997; Hinshaw & Cicchetti, 2000) as well as sociocultural context (Calin et al., 2007; Yoshioka & Schustack, 2001) on the extent to which people express their illness to others and on the way that society and culture in local settings influence disclosure patterns. However, very few comprehensive studies exist on how people deal with illnesses (Suchman, 1965). To our knowledge, no studies have considered the disclosure pattern of people residing in the slums of India with their unique socio-cultural context (Littman, 1970).

The present study addresses this gap by investigating how slum dwellers in India disclose their illnesses. We particularly focused on the disclosure pattern before slum dwellers actually start their treatment process. 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 this end, this study specifically aims to uncover the many facets of lay decision-making before future action is taken and the reasons underpinning illness-expressing behaviour among Indian urban slum dwellers. The research questions can be formulated as follows:

- To whom and to what extent do slum dwellers decide to disclose their illnesses?
- What are the reasons not to disclose illness?
- What are the reasons underpinning a delay in disclosing illness?
- What are the reasons underpinning prompt disclosure of illness?

# **METHODS**

#### **Study Site**

The present study was conducted in four urban slums of India equally selected from two cities, Kolkata in east India and Bangalore in south India. The slums were purposively selected on the basis of intra and inter-geographical variation, age of the slum, religious plurality, variation in living conditions and the presence of different healthcare systems. The characteristics of the study areas, the Motijheel slum and SahidSmriti Colony of Kolkata as well as the Nakkle-Bande slum and Ullalu Upanagar of Bangalore are given in Table 1.

	Koll	kata	Bangalore			
Name of the slums	Motijheel Slum (Core urban slum)	SahidSmriti Colony (Peri- urban slum)	NakkleBande (Core urban slum)	UllaluUpanagar (Peri-urban slum)		
Number of Households	6000	2570	650	1500		
Location	Highly congested slum	Sprawling slum surrounded by marshy land	Partly congested	Lots of space and barren land		
Age of the slums (in years)	75	25	40	15		
Origin of the population	Sub-urban Kolkata, Bihar, Jharkhand, Uttar Pradesh, Gujarat	Sub-urban Kolkata, Ban- gladesh, urban Kolkata	Sub-urban- Karnataka, Tamil Nadu, AndhraPradesh	Displaced people from Bangalore city, rural Karnataka, Tamil Nadu, Andhra Pradesh		
Social groups	Scheduled caste and General	Scheduled Caste, Sched- ule Tribe and General	Scheduled caste, sched- uled tribe and General	Scheduled Caste and General		
Religion	Hindus (25%), Muslims (70%), Christians (5%)	Hindus (65%), Muslims (25%), Christians (10%)	Hindus (70%), Muslims (20%), Christians (10%)	Hindus (65%), Muslims (25%), Christians (10%)		
Street and roads	Maze like alleys which are paved	Streets are simple, non- web and paved, sub lanes are unpaved.	Zigzag, paved and non-spa- cious streets	Quite spacious; partly unpaved and partly paved.		
Type of Houses	puccaand semi-pucca houses	Kuccha, semi-puccaand pucca houses	Pucca houses with three storeys	Kuccha, semi-pucca and pucca houses		

## Table 1: Characteristics of the Slums under Study

	Kol	kata	Bang	alore
Name of the slums	Motijheel Slum (Core urban slum)	SahidSmriti Colony (Peri-urban slum)	NakkleBande (Core urban slum)	UllaluUpanagar (Peri-urban slum)
Water supply	30 to 40 households uses common piped-water connection supplied by municipality	Hand pumps, ponds, few private tap connection and some public water taps.	Private piped connection and also public water connec- tion per five families in a street	Public water collection taps and few private piped connec- tions, un- planned setups of all the water pipes; mostly located within the drains and sometimes with leakage allow- ing the waste water to enter the pipes.
Drainage	Both open and covered drain- age	Unplanned and unsystematic open drainage within the slum	Underground drainage (in some places not planned and unsystematic).	No proper drainage systems; Waste waters run in both the corners of the street
Toilet facilities	Approx. 40 households use one common toilet	Individual toilets	Individual toilets and two government community pay-and-use toilets	Few individu- al toilets and public toilets run by a private organistaion

# Table 1: Characteristics of the Slums under Study (continued)

	Kol	kata	Bang	alore
Name of the slums	Motijheel Slum (Core urban slum)	SahidSmriti Colony (Peri-urban slum)	NakkleBande (Core urban slum)	UllaluUpanagar (Peri-urban slum)
Health care infrastructure	two public hospitals, three private hospi- tals, two an- ganwadis, four medical clinics, six paramedical clinics, thirteen homeopathy clinics, two ayurveda clinic, one primary health centre, three mid- wives	one public and one private hospital, one anganwadi, two medical clinics, four paramedical clinics, four ayurveda clinics, four ayurveda clinics, four mid-wives, thirteen traditional medicine men	three general hospitals, two anganwadi, four nursing homes, seven mater- nity hospitals, two super-spe- cialty hospitals, one cardiac and one orthopae- dic hospital, 27 private clinics, one traditional medicine men, two ayurveda and four home- opathy clinics	one primary health centre; two angan- wadis, nearest public hospital 15 kilometres away, ten medi- cal clinics, three mid-wives,

Table 1: Characteristics of the Slums under Study (continued)

Source: Field data

#### **Study Participants**

This study is part of a larger qualitative enquiry<sup>1</sup> investigating health beliefs and practices among urban slum dwellers, which included 245 participants equally selected from both slums, of whom 129 are males and 116 are females. The socioeconomic profile of all the participants within the two study areas are shown in Table 2.

<sup>1</sup> The present paper is part of a broader qualitative study that examines health-seeking behaviour in terms of the health beliefs, health practices, reporting behaviour and treatment-seeking behaviour of urban slum dwellers in four different slums; two each selected from two Indian cities.

		Kol	Kolkata			Bangalore	alore	
	Motijh	Motijheel (n=69)	SahidSm	SahidSmriti (n=66)	Nakkle-B	Nakkle-Bande (n=48)	UllaluUpa	UllaluUpanagar (n=62)
	Men (n=33)	Women (n=36)	Men (n=34)	Women (n=32)	Men (n=29)	Women (n=19)	Men (n=33)	Women (n=29)
Age								
Undertwenties	4	£	£	£	2	£	3	4
Twenties	6	14	6	13	8	6	8	10
Thirties	10	6	12	7	12	5	12	∞
Forties	7	6	10	6	4	4	6	4
Fifties	4	ç	2	2	2	<del>, -</del>	2	1
Sixties	2	-		-	-	0	2	2
Place of origin								
Rural	1	10	24	27	6	6	6	8
Within city	15	17	5	2	5	S	4	10
Displaced	6	0	0	0	4	0	16	6
Outside state	8	6	0	0	11	7	4	2
Outside country	3	0	5	3	0	0	0	0
Linguistic groups	s							
Hindi/Urdu	15	17	4	7	∞	10	12	12
Bengali	18	19	30	25	0	0	0	0
Kannada	0	0	0	0	12	3	10	8
Tamil	0	0	0	0	5	3	6	7
Telugu	0	0	0	0	4	m	ſſ	2

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Table 2: Socio-Economic Profile of the Study Participants

		Kol	Kolkata			Bang	Bangalore	
	Motijh	lotijheel (n=69)	SahidSm	SahidSmriti (n=66)	Nakkle-E	Nakkle-Bande (n=48)	UllaluUpa	UllaluUpanagar (n=62)
	Men (n=33)	Women (n=36)	Men (n=34)	Women (n=32)	Men (n=29)	Women (n=32) Men (n=29) Women (n=19)	Men (n=33)	Women (n=29)
Family types								
Nuclear	18	10	6	8	23	17	20	24
Joint	15	26	28	24	6	2	13	5
Occupation								
Fully employed	19	16	16	-	15	7	19	6
Contractual	6	7	11	0	12	6	12	17
Unemployed	5	13	7	31	2	ю	2	6
Monthly income (INR)	INR)							
0-2000	6	4	14	11	0	0	-	0
2001-4000	17	19	12	15	11	8	12	12
4001-6000	7	10	6	5	12	8	13	14
6000 and over	3	3	2	1	6	3	7	3

Table 2: Socio-Economic Profile of the Study Participants (continued)

Source: Author's own calculations

## Patterns of illness disclosure among Indian slum dwellers: a qualitative study

From this sample, 218 participants (105 men and 113 women) reported to the researcher to have experienced illness during the twelve months prior to the interview. Their subsequent responses towards illness gave rise to three different patterns of disclosure, to wit prompt disclosure, delayed disclosure and no disclosure at all.<sup>2</sup> These participants were purposively selected for this study and were subsequently interviewed to investigate their behaviour in relation to illness disclosure. During the pilot study, we realised that a six-month recall period was too limited to collect extensive data on reporting behaviour. We attained data saturation after two to three interviews, since many participants reported not having experiencing any major or minor health incident in the past six months. As a result, a one-year recall period was used for both minor and chronic illnesses. A study by Kjellsson et al. (2014) also indicates that using a recall period of one year is preferable to scaling up a recall period of one, three or six months. According to Sudman et al. (Sudman et al., 1984), respondents are aware of the risks when being questioned on the recent past and prefer to disclose a more distant yet noteworthy event. As such an approach might influence their responses, it has been suggested as a way to reduce reporting errors. For multiple minor illnesses that occurred within a period of one year prior to the interview, the most recent case was considered for the study. The minimum age of the participants eligible for the study was fixed at 16 years, as it is assumed that the onset of puberty establishes self-awareness about one's body and health.

## **Data Collection**

In Kolkata, data on the health-seeking behaviour of slum dwellers were collected during August and October 2012. The main researcher personally conducted the interviews due to her familiarity with the local language (Bengali). All the respondents were told the purpose of the study, their part in the research, and the time and energy that they had to provide, as well as the possibility of pain, discomfort and stress that they might experience during the interview. Participation of the respondents was voluntary. Women were interviewed in their homes, while men were interviewed during their leisure period or sometimes in their workplace near their homes. The researcher audio-recorded the interviews and took notes. Each interview lasted for about 30 to 40 minutes. The Bangalore field study took place from July to December 2011. In-depth interviews were carried out in a conversational style with a semi-structured interview schedule for data collection. A female field investigator collected the field data under the guidance of the main researcher, as the local language (Kannada) was unfamiliar to the latter. Prior to the start of the fieldwork, the investigator received one week of guidance from the researcher to

<sup>2</sup> Individuals in the category of non-disclosure who experienced illness in the one year prior to the study chose not to disclose their illness to anyone at the moment when the problem occurred, but they did report the illness episode to the researcher.

understand the scope and objective of the study, and to conduct mock interviews and pilot interviews. All interviews were either conducted in a separate room at the participants' homes or in a separate spot at their workplace away from other people, in order to safeguard the privacy of the participants.

A semi-structured interview schedule was constructed according to the basic framework of Arthur Kleinman's Explanatory Model of Illness (EMIs) (Kleinman, 1988; Kleinman & Benson, 2006). The questions were of an open-ended nature in keeping with the emic perspective of this study, which aims to gather an in-depth understanding of the sociocultural context, respondents' perceptions and selfconstructed meanings (Garcia, 1992; Godina & McCoy, 2000; Saville-Troike, 1989; Patton et al., 2017). The researcher had already established a rapport with the participants through frequent visits in the field, participation in their day-to-day activities, and the first session of interviews where their perception of health was explored and discussed. To understand the reporting behaviour of the participants, the interview schedule encompassed questions on perceptions of the concept of illness, the threshold for recognising illness, aetiology of illness, types of confidantes and the type or nature of illness (minor, chronic, communicable, reproductive and sexually related ailments). Whether or not this information was shared underpins the causes of disclosure attitudes and the timing of disclosure. Probing questions were used for clarification if more information was needed to explore issues raised by the respondents or to confirm the validity of their answers through cross-checks. Prior to the interview, the researchers decided not to define concepts such as pain, discomfort or inability to perform duties, which are inherently socially constructed. As such, the same condition can trigger different levels of pain and discomfort between individuals or within the same individual at different points in time. One reason behind this choice is that explaining and defining such concepts to the respondents before the study would have failed to create a 'common understanding' of these constructs, because they remain inherently confined to the subjective sphere. Another reason is that such an attempt to quantify how respondents experience these constructs would have felt as an imposition of the researcher's point of view and violated the emic perspective of gathering in-depth, subjective, socially constructed perceptions.

## **Data Analysis**

Recordings and field notes of the in-depth interview series were transcribed verbatim in their original Bengali and Kannada languages. Bengali and Kannada transcripts were then translated into English. One Bengali and one Kannada speaking person were hired for this purpose. The first researcher double-checked all data for unclear passages and potential translation errors. Passages that raised doubts were cross-checked by the first and second author and, if applicable, further discussed with the translator.

Once the body of text deriving from the interviews had been cleaned up and processed, the data were analysed using the 'thematic analysis' method. This manual analysis adhered to the guidelines of Braun & Clarke (2006). Initially, the data were read through several times to ensure a thorough understanding. Patterns within the data were identified manually, coded and subsequently labelled according to their meaning. Codes sharing a common meaning were grouped under non-overlapping themes or categories. These themes were re-examined for further refinement by comparing them with the original statements in the participant's accounts of their experience or perception of illness, their propensity to accept illness and their attitude towards reporting.

# **Ethical Considerations**

In the absence of a formal committee to assess the research on ethical conformity, the study scrupulously followed the guidelines established by the National Committee for Ethics in Social Science Research in Health (NCESSRH)<sup>3,4</sup> in order to conform to minimum ethical standards for doing research in the Indian context (Jesani & Barai, 2000; Shah et al., 2000). Ethical approval for this study was provided by the Institute for Social and Economic Change (ISEC), Bangalore, India. All the respondents were told the purpose of the study, their part in the research, and the time and energy that they had to provide, as well as the possibility of pain, discomfort and stress that they might experience during the interview. Participation was voluntary. Verbal consent to tape-record the interviews was sought after explaining the purpose of the research to the participants and after assuring anonymity and confidentiality. The explanation specifically included the information that comments would not be attributed to a named individual without permission. The interviewers only tape-recorded interviews after receiving and noting down permission from the participants. In order to promote an atmosphere of trust, intimacy and informality, which was believed to create the necessary conditions for the respondents to feel at ease and respond openly and truthfully, written consent was not sought.

# RESULTS

All the selected participants reported that they had suffered from at least one type of illness during the one-year period prior to the study. Overall, respondents showed an instant openness to talk about their illness; they expressed intense emotions or even talked about it for a long time with the researcher. However, they also revealed multiple situations (for example, pertaining to sexual and reproductive health or

<sup>3</sup> See http://www.cehat.org/go/uploads/EthicalGuidelines/ethicalguidelines.pdf.

<sup>4</sup> See http://www.anusandhantrust.org/centres/Ethics\_in\_health\_research\_-\_A\_ social\_science\_perspective.pdf.

illnesses that are associated with social stigma) in which it was difficult for them to disclose their illnesses as openly to family, society and often professionals.

In general, the findings highlight that the decision to disclose illnesses as well as the choice of confidantes is influenced by the complex interplay between gender, the nature of the illness, marital status and socioeconomic conditions. During the coding procedure and the surveying of the results, an attempt has been made to systematise the findings and to disentangle the main themes from the inherently much more complex nexus of causes. For grouping the themes, four main aspects of illness disclosure have been used which mirror the main research questions: 1. Choice of confidantes; 2. Reasons to delay disclosure; 3. Reasons not to delay disclosure; 4. Reasons not to disclose. From these overarching topics, the following twelve themes emerged: healthcare professionals as the final recipients of illness disclosure; social norms and fear of future social sanctions driving the choice of confidantes; bearable physical burden; negative prior experience of illness; coping with livelihood and everyday financial struggle; unbearable discomfort; therapeutic value of disclosure; fear of unfamiliar illnesses; previous negative outcomes of non-reporting or delay; withdrawal as a coping strategy; perceived threat to social image; and deteriorated atmosphere in slum environment. These themes are presented as motivating the choice of confidantes, early illness disclosure, delayed illness disclosure or nondisclosure. However, because the themes per se are not connected to a specific category but are grouped in one category for the sake of systematisation, we number the twelve themes subsequently rather than in connection with any overarching topic. Table 3 summarises these themes, which portray the various reasons behind disclosure patterns among men and women.

<b>Table 3:</b> Overview of Themes and Subthemes behind Different Reasons for Disclosure Patterns
among Men and Women

General category	Themes	Men	Women
		Confidantes: spouse and clinical doctors Reasons: share about chronic illness to ride out intense emotions and to receive treatment	Confidantes: husbands and natal families are initial confidantes for illnesses that lead to stigma, familial defamation and social penalty Reasons: feel that natal family members are more compassionate, attentive and considerate caregivers than in-laws
Choice of	Healthcare professionals as the final		Confidantes: in-laws are involved in more common health problems Reasons: do not require emotional support
confidantes	recipients of illness disclo- sure	Confidantes: occasionally parents, close relatives and sometimes other people Reasons: people who are going through similar phase and can understand the distress	Confidantes: outside the family, informal healers are considered as the initial confidantes Reasons: female-related illnesses and communica- ble diseases that primarily involve physical examina- tion and that are complex to understand in the lay domain Confidantes: clinical doc- tors are sought at the final
			or acute stage Reasons: mainly sought to cure illnesses

General category	Themes	Men	Women
Choice of confidantes	Social norms and fear of future social sanctions driv- ing the choice of confidantes	Expressing illness is related to: time, place and person; illness considered as symbol of agony and dis- tress may spread negative vibes during ceremonies and festivals, and can bring ill fate to the people who participated Social sanctions: social penalty drives them to reveal only to spouses or natal families in order to avoid social exclusion, familial defamation and individual disgrace	Expressing illness is related to: time, place and person; talking about illness can bring ominous effect to the people who are related on auspicious occasions that are held at familial and social levels status, age and gender; prescribed norms drive single and young married couples to talk about common health problems with immedi- ate and extended family. Sexually related illnesses are open for discussion with informal healers (because they treat illness in trying to uphold cultural norms) but not with family members, non-kin and clinical professionals of the opposite sex, who can be deemed to share a liaison relationship
Reasons to delay disclo- sure	Bearable phys- ical burden	Illnesses or pain that can be handled are considered too normal to report	Ignorance about the severity or effect of an illness results in leaving it unnoticed
	Negative prior experiences of illness	Job loss in the past pre- vents reporting the reap- pearance	Exclusion from any socio- cultural participation at familial and community level creates an identity crisis for women
	Coping with livelihood and every- day financial struggle	Income crisis forces men to devote more time to the workplace and downplay the severity of the illness	Financial burden compels women to ignore illness as long as possible

**Table 3:** Overview of Themes and Subthemes behind Different Reasons for Disclosure Patternsamong Men and Women (continued)

**Table 3:** Overview of Themes and Subthemes behind Different Reasons for Disclosure Patternsamong Men and Women (continued)

General category	Themes	Men	Women
Reasons not to delay disclosure	Unbearable discomfort	Unexplainable and un- bearable internal pains are experienced as severe	
	Therapeutic value of disclo- sure		By discussing illness, emo- tional, instrumental and informative support can be attained
Reasons not to delay disclosure	Fear of unfa- miliar illnesses	Physical symptoms that cannot be linked to common health problems are cause for confusion, alarm and reporting	Skilled to remain calm and composed, and socially approved to report any unfamiliar symptoms immediately
	Previous neg- ative outcomes of non-report- ing or delay	Severe impairment to the body because of ignoring illness. As a result, failure to carry out gender role as provider of livelihood	Severe impairment to the body because of ignoring illness. As a result, failure to carry out gender role as caregiver
	Withdrawal as a coping strategy	To retain normal balance of life as long as possible by self-coping with difficult feelings	
Reasons not to disclose	Perceived threat to social image	To secure one's position in the family and society by safeguarding masculine ego	
	Deteriorated atmosphere in slum environ- ment impeding disclosure	Busy coping with adverse physical and mental condi- tions of the slum	Busy coping with adverse physical and mental condi- tions of the slum

Source: Based on in-depth interview data

## **Choice of confidantes**

#### Theme 1 – Healthcare professionals as the final recipients of illness disclosure

The choice of the confidantes to whom illness is firstly disclosed is markedly different between men and women, as well as being dependent on the nature of the illness. Women involve different people to disclose their illness at different levels. For instance, women initially said that they prefer and feel more comfortable to discuss their health problems with family members. By family members, they meant natal relations, particularly mother and sisters. Although in-laws and other affinal kin are occasionally involved, this choice depends on the nature of the illness. Common health problems are generally expressed to in-laws, but illnesses that lead to stigma, familial defamation, or negative and informal social sanctions are usually held back as long as they do not attract the attention of others. After natal kin, husbands are informed of illnesses the most often. Such reporting behaviour may find its roots in how families and society respond to and treat their illnesses. Women feel that natal family members are more compassionate, attentive and considerate than in-laws and their families. In this context, one woman said:

'Since childhood, I have been very weak and I am frequently seized by health problems... My mother is my power; she will always encourage me by making me feel special; whenever I am ill, she will not allow me to work, she will give me hot food, remain awake the whole night to check whether I am okay or not...My mother-in-law will not understand that. Instead, she blames my mother for giving them a physically unfit bride.'

Women in the study expressed that they experience severe anxiety and fear when it comes to female-related illnesses and communicable diseases which involve physical examination. Indian women are conditioned by multiple socially prescribed codes associated with sexuality surrounding marriage. For example, they are requested to maintain physical distance from men other than their husband, not to attract men by flaunting or exposing body parts and to protect their sanctity before marriage. To keep things comfortable, women therefore report their health problems to informal healers, which marks the first step for them to report outside of the family. Informal healers are preferred to professionals, because the former generally reside in the neighbourhood and are well acquainted with all the households in the area, their health habits, practices and behaviours. As a result, respondents feel more at ease openly to discuss health-related problems at length. According to one woman:

'I talk at length [with the informal healer]. I tell him exactly how I feel about my illness; if it sometimes sounds funny, still he listens, comforts, encourages and helps me to come to terms with the trauma.'

Another reason for approaching informal healers in the study is women's perception of such illnesses as complex conditions, which creates the need for them to confide in people who have knowledge about the illness and are better able to understand their mental stress. As one woman said: 'It's okay to talk about your problems with family members, but they cannot always comfort you; there are certain female-related problems which are complex in nature and need to be understood by some knowledgeable person who can understand our emotions thoroughly.'

Reporting to formal healthcare professionals in case of health problems only happens when they become acute or severe. Women in the study expressed that professional do not have the habit of allowing patients to share their views and distress about illnesses, or to give emotional and social support in order to cope with the illness. Rather, they conduct an immediate diagnosis and treatment whenever patients visit them. In this context, one woman recalls her experience:

'I went to him [the doctor], not with the intention to start treatment immediately but first to share my suffering and feel relieved. I expected him to comfort me by saying good and positive things and to give me the mental strength to deal with the illness, but he was focusing more on treatment than on listening to me and my feelings.'

This kind of distance which women perceive in relation to formal healthcare professionals influences their disclosure pattern, prompting disclosure to either family members or informal healers rather than to doctors. By contrast, men prefer not to discuss general health problems with anyone, because they consider these problems to be too normal to discuss. In case of chronic or serious health problems, however, they report to their wives first and to the health professionals next. Parents, close relatives and possibly people who are going through a similar phase are occasionally informed about an illness in order to receive support when men are overwhelmed by negative feelings. Most men report involving their wives mainly to receive emotional support when they are going through a difficult time. Some men said that they disclose illness to their wives because they know that wives would not speak about a *'husband's illness'* to others, as this information will hurt both her and her husband's self-image. As one man said:

# 'She feels that my illness is her illness and so she respects my emotions by not raising the issue with others.'

Outside of the family, men habitually hold back from informing friends, fellow employees and acquaintances. Many men found that when they tried to disclose their illnesses to these persons, their intense emotions were underestimated and their manhood was questioned. Showing emotions and weakness was considered as uncommon for men, with many of them expressing that it is very essential in a group of men to show off one's manhood even when they are experiencing immense internal turmoil. As one man said: 'Whenever all us men folk gather in the evening, we discuss downright everything from poverty, politics and problems in the family to the workplace; however, everyone is conscious not to discuss one's health problem. No one reveals health problems, as this is the only place where men can show off their manhood and vigour.'

Unlike women, men find formal healthcare professionals to be quite efficient in providing comfort during stress. Many men in the study related that they can express their most intense emotions when they talk to doctors. This experience is linked to the way that they deal with formal healthcare professionals. Most of the men said that professionals react normally when men pour out their emotional turmoil related to illness. Some men also expressed the sensation during their communications with professionals that doctors find it quite natural and obvious that patients talk about their problems, irrespective of gender. In addition, formal healthcare professionals find the perception of manhood as related to health quite funny and irrational. As one man said:

'He [the doctor] started laughing and though it was a joke when I told him that I cannot express my feelings to friends in the same way as I did with him, because I will be labelled as a woman.'

# Theme 2 –Social norms and fear of future social sanctions driving the choice of confidantes

The choice of confidantes highlights a complex interplay of gender, status and the nature of the illness. For instance, many men and women who were interviewed expressed that; young men and women, both married and unmarried, according to prescribed norms are allowed to talk about common health problems with immediate family (spouse, parents, children, uncles, grandparents, nephews, and so on), extended family (great-grandparents and other common ancestors) and family-in-law (parents-in-law and siblings-in-law) irrespective of age and gender. However, for specific illnesses such as female-related illnesses, sexually related illnesses and sexually transmitted diseases, discussion is not allowed between young and old or between genders when they share a liaison relationship<sup>5</sup> such as brother and sister, father and daughter or father-in-law and daughter-in-law. As one woman said:

'It is very embarrassing and equally unmannered if you talk about female problems even when your father-in-law is in the other room.'

For other communicable or for chronic diseases, it is observed that no rules are prescribed. However, as these illnesses create penalties such as social exclusion,

<sup>5</sup> Considered as a secretive or adulterous sexual relationship.

familial defamation and individual disgrace, participants said that it is they who create informal rules; for example, revealing it only to spouses or natal families in order to protect their honour. One man commented:

'Society has not told us to suppress serious health problems, but we sometimes have to do so in order to secure our and our families' position in society.'

No rules have been prescribed for men in informing non-kin and professionals. However, as women's relationships with professionals and non-kin (other than healers) of the opposite sex are considered to belong to liaison relationships, they are not allowed to talk freely about sexually oriented illnesses. As one woman said:

'People will look at you unfavourably if you frequently talk about sexual problems, even with doctors and other males.'

It is observed that women's marital status and the nature of their illness also influence the way that illness is disclosed to the families. For instance, many unmarried women with abnormalities related to reproduction or imperfections of the body prefer an early disclosure of the illness. They consider marriage as essential to obtain both personal and financial protection. As it is their belief that society views them as vehicles to produce progeny, the chances of getting married are largely determined by how physically fit they are. Consequently, women and their family tend to ensure that any problem related to health is sorted first before it creates any obstacle to their marriage process. One woman talked about severe consequences which her sister had to face because of an initial failure to disclose her illness: 'She had been suffering from abnormal vaginal discharges since two years and had not informed anyone in the family, not even my mother. When my mother was finally told, she was shocked not so much by hearing about the illness but sensing that it may cause problems in her marriage...at that time, we were planning to get her married. My mother consulted a doctor who detected damage in her 'baby pipe' [fallopian tube]. The doctor said that unless it is operated on, she cannot conceive. There was nothing we could do; the surgery would bring a huge expense that we cannot afford; everything was out of control. She remained unmarried, as we could not get her through [marriage] without telling the truth. Every alliance turned her down when they came to know the truth. There was no end to our problems. As time passed, we started to face new problems. As she is beautiful, she was naturally harassed often by some men from other localities. We even came to hear that there were men waiting for any opportunity to make a sexual move. It was becoming difficult for my parents to keep an eye on her every time and everywhere. As my sister started to feel unprotected, my father sent her to our village.'

In the case of married women, a few said that they sometimes reveal their problem to the family in-laws immediately as well, with the intention to gain their support and confidence. By talking to their mothers-in-law, women aim to show them that they are equally concerned about producing progeny. Indirectly, they also manage to secure their own marriage and financial security. One woman explained how this action worked positively for her:

'I took my mother-in-law into confidence by talking to her. I expressed my struggle with intense emotions and how I coped with them in battling the guilt of not being able to give them a grandchild. I also told her that I will do whatever is required to conceive and that's a promise. By listening to my sorrows and pledge, her heart melted and she started to sympathise. She told my husband that I have no wrong intentions; in fact, I am trying hard to give him a child. She also told him to take good care of me in every aspect and to be by my side during this turmoil. Now, as my husband can't disobey his mother, he is doing what he has been told. I am getting attention both mentally and financially. Of course, I am trying hard to sort the problem and give him a baby, but at least I can do so without the constant worry of being thrown out of the house and out of my husband's life.'

It is equally essential for both men and women to take care of the way in which they relate their illness. Many participants expressed that time, place and person are crucial when it comes to sharing illness-related emotions. A woman said that they are not supposed to talk about illnesses on any auspicious occasions such as initiations, marriages, baby shower parties and religious ceremonies held at familial and social levels. As illness is considered a negative element, people believe that talking about

it on joyous occasions and festivals will create an ominous effect. Another man expressed his belief as follows:

'Occasions and festivals are pious and holy moments where everybody is intent and bent on blessings, goodwill and affluence in life. As illness symbolises agony and sadness, talking about it on such occasions will damage the atmosphere and spread negative feelings which nobody wants.'

#### Reasons to delay disclosure

Slum dwellers reportedly delay the disclosure of illness to family members, kin, nonkin and professionals because of various reasons. The main categories of reasons are bearable physical burden, negative prior experiences of illness and coping with the insecurity of the slum.

#### Theme 3- Bearable physical burden

Most men in the study looked primarily at biological aspects as determinants for reporting, such as the level of physical pain and their capacity to bear it. Physical pains that are minor and that can be handled are considered by men as belonging to general health problems and are therefore delayed in reporting. They psychologically made themselves resistant to general illnesses and consider these to be very normal in everyday life, as is reflected in one respondent's attitude:

'Minor pains can be handled... they are not that serious; cold and fever are like frequent guests... they come and go; for these, I do not need to tell everyone immediately.'

As women in this case are far more sensitive, they are not seen to delay reporting. Although women do not intentionally delay reporting illness, however, a few of them said that they sometimes do so when they lack proper knowledge or information about the severity level or the effects of an illness. As one woman commented:

'I was not having my period for several months and I was ignoring it [considering it to be a normal phenomenon]. My mother told me that it was not normal, as it can create a problem while conceiving, and disclosed it to our guruji.' [informal healer]

#### Theme 4- Negative prior experiences of illness

For both men and women, expressing or reporting illness is related to their past experiences with the responses that they received from others. Illnesses related to unpleasant memories discourage slum dwellers from reporting when the same symptoms reappear. Men and women shared their experiences with unpleasant memories differently. Many men in the study stated that disclosing illness negatively affected their livelihood in the past. This situation meant that the frequent discussion of illness and the expression of feelings in the workplace signalled to others and to the authorities either the person's lack of interest in his job and his desire to leave on the pretext of illness, or an attempt to raise his pay by triggering others' sympathy in the name of illness. As a result, they had often been fired for displaying illnessrelated emotions and had had to bear a sudden financial crisis. One man described the difficulties that he faced when expressing illness in the workplace:

'It's just that I was talking about my illness to one of my colleagues for two consecutive days. My boss noted this fact and misunderstood it as if I was doing so intentionally for him to hear. The third day, he dismissed me from the job, saying that he can understand my feelings of not being satisfied with the job and therefore inventing the excuse of illness.'

For women, unpleasant past experiences associated with reporting illness are more closely related to sociocultural context. Many women in the study found that too many negative discussions about their own illness with kin and non-kin result in exclusion from familial and social ceremonies. As one woman said:

'I used to tell all the negative things that I felt about my illness to my sister-in-law. Some months later, I discovered that she had not invited me to her baby shower ceremony. I was hurt. Later, I came to know from one of my distant relatives that she had been saddened and that she feared a bad omen. Therefore, she did not want me to be there during that auspicious ceremony. I know all that happened because of my talking too much about bad things.'

## Theme 5- Coping with livelihood and everyday financial struggle

Both men and women commonly acknowledged that their livelihood and the everyday financial struggle which they face prevent them from promptly disclosing their illness to anyone. Instead of focusing on health and illness, the slum dwellers feel compelled to concentrate on securing the basic necessities of life. For instance, the struggle to retain their job plays a crucial part. Most slum dwellers work in the informal sector under the constant threat of losing their jobs. It is important for them to secure their job by making an extra effort and showing their commitment to the job, by meeting the daily or weekly targets and by remaining present onsite for long hours. Many men who were interviewed expressed that they do not consider illness important enough to be shared and discussed, as it will bring no immediate harm to their livelihood. Rather, it is their bread and butter which are primarily affected if they do not talk with others about the job market situation or think about better chances in employment. One man said:

'My health will not take away my bread and butter if I do not think or talk about it for five days. But if I do not show my commitment to work and do not take it seriously for even one day, I have to think for the other five days what my family will eat.'

Consequently, some men mentioned their attempts to divert their mind from thinking about illness or burdening it too much in order to secure their wages. As one man said:

'If you talk about illness, this means you are thinking about it constantly, and thinking about it means you are actually not well. The next day, you take a leave from your work feeling very sick; and your one-day wage is gone. The moment you stop talking about it, you will find life is normal...it's all about your mind.'

Closely related to this topic are financial struggles, which involve a lack of or a meagre family income, depletion or lack of savings, unemployment or underemployment, excessive debt and uncertainty about the future flow of income. All of these factors force slum dwellers to consider health as a secondary aspect. Some women said that they delay the disclosure of health problems to professionals because they find that the professionals are expensive. They fear that going to professionals early on will bring crises after treatment, such as selling or mortgaging property because of debt. On this topic, one woman commented:

'Forget about sharing things with him [the doctor]. Once you go there, he will immediately start his expensive treatment and you have to start selling everything for the treatment. The later you go, the better. At least then, the impact of the crisis will be less.'

## Reasons not to delay disclosure

This theme illustrates the reasons that prompt the participants of the study to express or report illness. In many cases, the intention behind informing others about illnesses in time is related to finding solutions, coping with the distress or preventing potential collateral damage. The themes that emerge are unbearable discomfort, therapeutic value of disclosure, fear of unfamiliar illnesses and previous negative outcomes of non-reporting or delay.

#### Theme 6- Unbearable discomfort

Men report disclosure when the pain becomes unbearable or unusual, as reflected in one man's comment:

'I have had enough of this leg pain and cannot bear it anymore. I reported it to a doctor immediately.'

Some men noted that it is difficult for them to assess the intensity of illnesses which occur internally, due to a lack of knowledge related to human anatomy or body functioning. Any strange internal pain or discomfort that happens, even for the first time, is therefore experienced and labelled by them as severe and reported without delay. As one man said:

'One day, I vomited three to four times. It happened to me for the first time. I felt something very wrong was going on inside. I got so scared that I immediately talked about it to one of the local doctors.'

#### Theme 7- Therapeutic value of disclosure

Women are found to be very sensitive to illness or bodily discomforts and show more willingness to express symptoms of distress to others for psychological relief as compared to men. Sometimes, expressing distress rather had to do with the complexity of the female reproductive system and represented a coping mechanism and a deliberate act of self-encouragement. Most women consider female-related health problems as unavoidable because of the complexity of the reproductive system. Such belief has emerged from their socialisation process, as they have been told and made to believe since childhood that their biological composition is responsible for their morbidity and even puts them at risk of death. As a result, women developed the coping strategy of reassuring themselves by continuously expressing their distress to others. As one woman said, reporting to others actually helps women to comfort themselves that everything will be alright and that reproduction-related morbidity will not necessarily lead to death. The same woman mentioned the following:

'We tell our distress only to hear from others about women whom they know, who led a healthy life and died due to old age. By listening to all these accounts, we actually try to create hope in ourselves that we can also live in the same way and die due to old age rather than from female-related problems.'

Moreover, they share their health problems with each other to find out various possible solutions to similar experiences that they have had in relation to illness. Such sharing of experiences raises increased interest among the women who face challenges. One woman described how she benefits from the illness-related talks with her friends:

'Every evening, we sit and chat about our daily life experiences; talking about health is one of our favourite topics. We have come to know many unknown things from each other, and we share various techniques and methods to protect and prevent illnesses from occurring. This information seriously helps...at least, I am confident that I can come up with whatever is needed to protect me and my family.'

Many women find that a failure to express or disclose one's illness even for a single day means allowing the illness to breed inside the body. They further feel that this approach will yield nothing positive but will instead bring unhappiness in life, as well as weakening one's immune system and strength to survive. As explained by one woman:

'The sooner you pay attention to health problems, the better you feel. These things are not meant to be hidden; at least, they should be shared with family and friends the day you sense them. Otherwise, the distress will eat you up slowly, making you more miserable and lifeless.'

#### Theme 8- Fear of unfamiliar illnesses

One of the major concerns raised by men and women in the study relates to their unfamiliarity with symptoms or their lack of knowledge with which to assess the severity of the illness. Symptoms that do not show similarities with common health problems such as heart conditions, lung problems or abdominal pains are difficult to interpret and therefore cause preoccupation. Such symptoms include the presence of any kind of blot or patch without pain, any unusual disfigurement or any prolonged unexplained illness. Many men realise that they very easily get anxious about such unknown symptoms and start creating a commotion within the family. As one man said:

'I got very scared... the whole area around my genital parts was full of several abscesses...I only sensed that something terrible had happened to me and immediately informed my wife.'

Some men said that they get puzzled and therefore feel the strong sense to report it to the professionals. One man who was suffering from cyanosis recalled his first reaction:

'I was too confused to even think about it, I have never seen or heard such strange things happening to others. It was awful to see the colour of your skin changing. Without wasting any more time, I immediately asked a doctor for help.'

Such non-delay in reporting is due to a lack of knowledge about the nature and severity of these unfamiliar symptoms whose effect cannot be predicted.

A number of women in this study also experienced unfamiliar symptoms. They immediately disclosed them to the family but remained composed while dealing with the situation, as they are mentally prepared to accept and adjust to any kind of illness. As one woman said:

'These things [unknown illnesses] are very dangerous; you never know how it's going to spill over. In this situation, you need to be very cool and calm in order to act wisely. Throwing tantrums over it will only make it worse.'

#### Theme 9-Previous negative outcomes of non-reporting or delay

As already discussed in an earlier section, the previous experiences of the participants relating to the expression of illness can become a major cause of their delayed reporting. However, this factor is an equally important reason for the timely reporting of illnesses. Such reporting patterns vary with the situation, though. In this context, for instance, the immediate reporting of illness is linked with unpleasant memories of the past where ignoring illness had made the participants face intolerable pain or serious damage to the body. Many men and women in the study related the unforeseen consequences that they had to face because of delaying disclosure or not reporting illness. One man commented:

'Once, I fell off a truck. I did not find it that important to discuss with everyone. Within a month, I realised that I could not sit or stand straight. After consulting with the doctor, we discovered an injury in the spinal cord that had actually occurred during the accident. I was out of work for almost seven months and there was no earning in my house.'

One woman said:

'My right hand became paralysed and remained invalid for several years because of disregard. I felt that I was becoming a burden to the family-in-law, as I was of no help [in doing household chores]. They were angry that I had not at least informed them about my illness. They blamed me solely for my situation.'

As a result, the participants are scared to take a second risk when they experience similar symptoms relating to the mishap and therefore report the problem immediately to the family or the professionals.

## **Reasons not to disclose**

It seems that men and women in the study sometimes deliberately withdraw themselves both emotionally and verbally from family and others. In this section, we are concerned rather with the explicit notion of avoiding to express feelings in relation to illness.

## Theme 10-Withdrawal as a coping strategy

Most men noted that they try to avoid highlighting problems by deliberately downplaying their impact or severity. The function of this behaviour could be interpreted as the avoidance of difficult feelings by self-coping with illness and looking for a way towards a normal life. One man described his strategy as finding ways in daily life to prevent illness from entering the mind:

'I do not let any illness hover in my mind...I talk to others about the usual things rather than about illness, I play with children, do light work at home, play cards with friends in the evening and go to the local temple. These things help me to distract myself rather than getting preoccupied with illness.'

Some men feel that telling others is equivalent to allowing emotions to grow, which further deteriorates their mental state. In this quest of finding a normal equilibrium in daily life as soon as possible, they therefore refrain from reporting illnesses to others. As one man said:

'People will not let you forget your illness if you share it with them. They will constantly make you feel ill by asking every time you see them how you are feeling and what steps you have taken to deal with it. It's a struggle with yourself and your will, so I find that it's easier to make yourself feel normal by not letting others know about your illnesses.'

## Theme 11-Perceived threat to social image

Although men do not have to bear social consequences to the same extent as women, they nevertheless remain under the pressure of gender-related societal perceptions where they are expected to be strong, tough and resistant to illness. As a result, men expressed that they find illness to reduce their status in the male hierarchy. For a man, displaying toughness represents a badge that they always have to wear, lest they lose their value and identity as a man in society. The more they bear pain and suffering, the more their degree of manliness increases. Many men consider masculinity as a symbol of strength, while talking about illness is seen as a 'feminine' thing. One man said:

'We cannot show our health problems, you know...it's a female thing to show weakness... we will become the laughing stock of our friends.'

Another reason why men do not reveal their health problems in the family is linked with a shift in positions of power with women. As one man said:

'I was bedridden for months and Razala [his wife] started taking me for granted in every aspect...I felt powerless. It's really very difficult to accept that suffering from some health problem makes you invalid; your family, who once used to respect and listen to you, starts taking you for granted. I don't want this to happen again, so it is better to keep the illness within myself.'

One man described the erectile dysfunction that he developed for some months as a consequence of ignoring his diabetes symptoms:

'My doctor told me that it happened because of not checking my diabetes. Actually, I did not find it [the diabetes] that important to talk about...It was a blow to my manhood. I felt like committing suicide.'

#### Theme 12-Deteriorated atmosphere in slum environment

The slum dwellers occupy marginal positions in the sociocultural system of the community, inhabiting an unfit environment. In this respect, some male and female participants expressed that they struggled to cope with many slum-related practical issues such as environmental decay, poor infrastructural facilities, displacement, poverty and crime. All of these aspects severely undermined their sense of safety and security. Many of them described their daily struggle in relation to some of these issues. Prior to focusing on any health-related activities such as identifying, disclosing and treating illnesses, they believe that faulty basic infrastructure should be addressed such as improper toilet facilities, improper shelter, open drains or sewages and that basic needs should be satisfied including proper sleep, clothes and food. The feeling of insecurity when these basic needs are not met can overpower their attitude towards sharing illness. As one woman said:

'If there are no proper water and toilet facilities, it is obvious that we will get ill... so there is no question of talking about illness and wasting time until and unless these problems get sorted.'

Slum dwellers deal with life-threatening situation and sexual violence. As they have had to face the challenge of frequent displacement, they often become victim of theft, murder, molestation and rape. For women, securing protection during displacement and finding their way among various uncertainties hardly provide any room for illness. One man talked about his struggles during displacement and his constant fear, which do not leave any space to talk about illness:

'When we all were thrown out from our previous location... we all came to a land that was already littered with waste and that was filthy. I somehow made a small, fragile tent to ensure my family's security; I had two adult daughters during that time and was worried about their protection. I used to spend sleepless nights keeping a watch on my daughters' safety. My son used to study in a nearby school free of cost, but he had to stop that too because of the distance. Even now, we live every moment in constant fear of being thrown out from this land as well. Now I am old and cannot struggle as before. After listening to all these things, do you think that we have the mental condition to sit and talk about illness? Whenever I suffer from any illness, I find a way out for myself. I do not have the habit of discussing it. Everyone here is busy fixing their own problems. So it's as though I neither have the patience to discuss illness, nor do people here have the patience to listen'.

# DISCUSSION

In light of the emic perspective used in this study, the novelty of its work resides in unravelling the patterns of illness disclosure within the specific setting under examination, to wit Indian urban slums. Low-income, resource-constrained settings are characterised by a high level of idiosyncrasy and specificity, which impedes any generalisation of findings to other contexts or a transfer of evidence collected in other contexts to the one under investigation. As a consequence, findings and patterns found in other settings – even in the Indian context – cannot be used as a vantage point to understand illness disclosure behaviour in Indian urban slums.

Our findings painted an expansive portrait of the patterns of illness disclosure. Although the factors for men and women are similar in the studied slums, men and women often related different reasons underpinning their disclosure pattern. Our findings also indicate that the choice of illness disclosure is basically a coping mechanism adopted by participants to deal with any adverse situations linked with illness, which is related to whether they suspect the illness to constitute danger both for themselves and for the community. The decision to delay, not to delay or to avoid illness disclosure is not determined solely by the recognition of illness, but largely depends on the interplay between their agency, the consequences of disclosure and the sociocultural environment (Azia et al., 2016).

The present study indicates that women are more active than men in expressing their illness to others. Although they involve several people as confidantes, they have reservations in particular about the way that they disclose illnesses. This finding is consistent with existing literature which has shown that women are more frequent disclosers than men (Hood & Back, 1971; Cozby, 1973; Mathew et al., 2012). It is observed that natal families and husbands are the major resources of moral and social support as compared to other kin and non-kin. The literature identifies family

as the initial and most important source of support for patients, since the highest level of social support is received from the family (Aghajanloo & Ghafouri, 2011; Letchmi, 2011; Al Nazly et al., 2013; Hjelm & Mufunda, 2010). However, the quality of social support is equally important to women. For this reason, they mobilise the support system of informal healers for both social and informational support in complex problems of reproductive health. The choice to mobilise professional support is related to women's need for specific medical interactions and actions rather than just lay discussants.

Most of the time, men avoid expressing their emotions regarding illness to others, except in the case of fatal illness. They have a very limited network of support and mostly rely on their partners and on professionals. When men experience any vulnerable situation with illness, in order to receive special attention, they sometimes open up to relatives and friends who also went through similar situations. Partners are approached to receive emotional support and to keep illness secretive, while professionals are sought mainly to gain pre-emptive sympathy without harming the dominant status of their hegemonic masculinity. Earlier studies have also reported that men and women differ in their sources of support (Antonucci, 1994; Belle, 1989). Men basically rely on their partners as primary sources of support, whereas women draw support from a broader social support network (Revenson et al., 2005).

It is important to see that the participants' cautious disclosure of illness is also articulated within the culturally prescribed norms. These norms are similarly reported in other studies, revealing that the decision to disclose is influenced by cultural orientation (Mason et al., 1995; Kleinman & Kleinman, 1991). The desire to share illness is controlled by the state of affairs, status, age, gender and the type of illness. Stigma and social exclusion specifically attached to some illnesses, such as those related to sexual and reproductive health, appear to influence disclosure behaviour heavily in terms of disclosure delay and choice of confidantes. As a consequence, illness disclosure behaviour - particularly that of female participants - cannot be viewed in isolation and should be understood within a complex nexus of determinants related to gender, type of illness, type of confidantes, and socioeconomic and sociocultural conditions. Though men are more socially and psychologically adaptive in remaining secretive about illness, women cannot always express illness either and sometimes have to hold their feelings at bay in order to minimise the impact of unsupportive social interactions. Negative reactions that result in adverse social support are in fact a strong predictor of non-disclosure, as seen in the findings of another study (Figueiredo et al., 2004). Culturally prescribed norms have also created the preconditions for selective confidantes of selective illnesses in both men and women. This finding confirms previous studies which have shown that family cultural norms govern the rules regarding appropriate expressions or acceptance of illness (Kleinman & Kleinman, 1991; Kalichman, 2003). As women

utilise more support during crises, common culture accordingly promoted women's habit to involve more confidantes overall. In turn, the impact of culture among men is undermined as they are psychologically bound to talk less about illness (Verdonk et al., 2010). However, in the case of fatal illnesses, the cultural constraints that discourage participants from full disclosure so as to avoid the burden of isolation, social sanction, and the rejection of both oneself and one's family grow weaker and at times overlap with the social norms.

In our findings, we observed that the choice of disclosure is a complex decision based on the potential risks and benefits of disclosing, which are in turn multifaceted and which rely on factors such as gender, type of illness, marital status, timing, confidantes, and so on. In the literature, difficulty in choosing confidantes to disclose has been documented (Alonzo & Reynolds, 1995; Lee, 2005; Wirtz et al., 2014). Men's approach to delaying or avoiding the disclosure of illness may be generated by self-perceived images of masculine health-related beliefs and practices, as well as by the fear of not being able to meet the gender role expectations both in the family and at workplace, framed as a self-focused coping strategy for battling with the insecurity of being a slum resident. By contrast, women's delay in disclosing illness is linked to the biological, social and psychological challenges unique to their disadvantaged social position. Again, while men share their illness to others without delay mainly to prevent or cope with biological problems, women promptly report illness for security or emotional and instrumental support when they face severe and unknown biological challenges, unforeseen crises and a loss of security similar to what they have previously experienced. Regardless, the slum environment plays a pivotal role in shaping the attitude of the slum dwellers towards disclosing illness. Structural phenomena unique to the slum community (disintegrated life, poverty, inequality, crime, fragile physical infrastructure) have an overpowering effect on their health-seeking attitude. As their struggle of being in a slum community leaves no space for health concerns, the need to report illness is hardly recognised. This construction, evoking a complex nexus of needs, desires and powers behind healthseeking behaviour, conforms very well to Maslow's theory of motivation based on the 'hierarchy of needs' (Maslow, 1943). This theory explains that higher-level needs such as health, family, relationships, security of environment and employment are dependent on the fulfilment of lower-level innate or basic needs such as food, shelter and sleep. The slum dwellers in this study confirm that health is perceived as a higher-order need, which can be addressed only once the more basic needs have been met.

The strength of the study lies in its large number of respondents and its multidimensional approach, in which the perspectives of both male and female respondents as well as the context of disclosure are taken into account. Its results have implications for the nature of disclosure among slum dwellers. These insights can inform future interventions, in which the supply of health resources can be shaped so as to meet slum dwellers' needs. The study also suffers from a number of limitations. First, both men and women were interviewed by the main researcher, a woman. While this fact favoured the openness of female respondents, who are traditionally more reserved, it could have introduced a bias in gathering male perspectives. Second, the perspectives of partners, kin and non-kin linked to the individual participants were excluded. Although we found the family to be a source of disclosure and support, we did not examine their subjective views about the participant's disclosing behaviour. Third, the incorporation of the individual's perception of illnesses as suffered more than one year before the study period could have revealed more patterns of disclosure which were not reported by participants reviewed here. However, it might also have introduced a significant bias in recalling experiences that are further removed in time. Fourth and finally, because the participants were left free to interpret or use self-constructed concepts and meanings of illness, pain, discomfort, inability to perform duties and any other illness-related aspects, such notions are likely to differ in future and across people. In line with a social-constructivist emic perspective, these findings cannot be generalised to other social groups or to the same social group over time.

# CONCLUSION

The findings of this study demonstrate that the relationship between the act of disclosing and the characteristics of illnesses is dependent on the typical sociocultural settings where the behaviour occurs. Men tend to delay disclosure or to prefer non-disclosure and have a very limited number of confidantes. The disclosure of illnesses is delayed or avoided because physical pain in some occasions can be kept under control, to protect one's job and income, to retain a normal life as long as possible by undervaluing illness and to secure one's position in the family or society by safeguarding masculine ego. Prompt reporting is mainly associated with prevention and coping with biological challenges that people experienced before. Women involve several confidantes at various stages of illness, which attitude can be linked with culturally mediated support systems. Reasons for delay or non-disclosure are a lack of information about the nature of the illness, avoiding stigmatisation or emotional loss because of social exclusion and identity crises, financial crises pertaining to healthcare expenses and struggling with the adverse situation of the slum. Prompt disclosure of illnesses is related to receiving therapeutic experiences in sharing illnesses, gaining confidence to fight unknown physical complications, preventing the recurrence of negative consequences due to delay or nonreporting, and avoiding future social sanctions. The study may indicate a pathway to policymakers and proves that disclosure comprises an important component of health-seeking behaviour prior to seeking treatment. For a successful use of healthcare resources and the improvement of healthcare utilisation by slum dwellers,

disclosure patterns therefore need to be addressed within the local sociocultural context where slum dwellers reside. This approach can be realised by encouraging the slum dwellers to share their feelings about illness more openly through decreasing their sense of marginalisation, removing the inhibition to disclose to certain people and increasing professionals' awareness of unsupportive social interactions.

#### List of abbreviations

EMs	Explanatory Model of illness
NCESSRH	National Committee for Ethics in Social Science Research in
	HealthISEC Institute for Social and Economic Change

# DECLARATION

#### Ethics approval and consent to participate

This study was approved by the Ethical Review Board of The Institute for Social and Economic Change (ISEC), Bangalore, India. Oral consent to participate was obtained from all participants.

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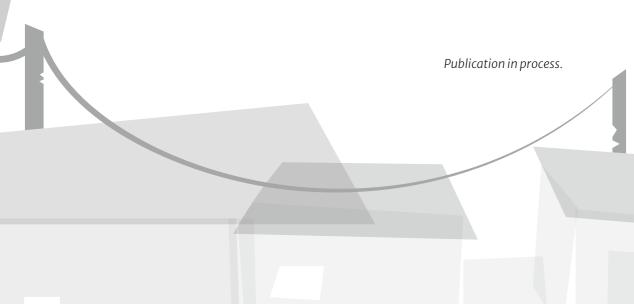
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# **CHAPTER 4**

Habitus and capital determining perceived healthcare needs and use in India's urban slums: A Bourdieusian study



# ABSTRACT

Bourdieus' choice of the necessity guides this study's focus on how two key concepts - habitus or neighbourhood and capital- impact urban slum inhabitants' healthcare demands, as well as how they actually access, seek, and get care. The contrasting socio-cultural characteristics of two urban slums in Kolkata and Bangalore were chosen to demonstrate the multitude of distinct neighbourhood (habitus) and capitals at work. A total of 245 individuals of the study slums were interviewed face-to-face. The findings imply that neighbourhood's amount and type of capital effects respondent's perceptions of when to seek curative and preventative primary care, as well as their embodied actions when seeking treatment. It reflects cultural attitudes and tastes for social necessity. It also reflects conflicts and investments in health and well-being. Economic capital plays a role in postponing therapy or even addressing their health issues. Forced choice leads to adaptation to and acceptance of life's essential conditions. As a result, the need to invest in an imagined state of good health may appear inapplicable and even ludicrous. Social capital enabled or inhibited the utilisation of health care services in the study, depending on the networks' attitudes about the perceived need for healthcare. In the Bangalore slum neighbourhood, diversified social networks allow the spread of information more broadly, but in the Kolkata slum neighbourhood, restricted intra-group norms or knowledge of health care options were barriers to access. Cultural capital is instilled more through the practise of a variety of coping strategies with healthcare exclusion (avoidance, low self-esteem, and resignation) and negotiating care in alternative healthcare spaces such as traditional and spiritual healing, community clinics, and self-medication at home. This study can assist academics and policymakers in increasing the effectiveness of community health promotion programmes by identifying various neighbourhood features that contribute significantly to the overall makeup of a neighbourhood and its impact on general health.

**Keywords:** Cultural capital, habitus, healthcare utilization, perceived need, neighbourhood, slum dwellers, social capital

# INTRODUCTION

Existing literature have suggested that health-care utilization is determined by only the perceived need for care (Goodwin and Andersen, 2002; Parslow et al., 2004) such as by whether people know that they need care, by whether they want to obtain care, and by whether care can be accessed. Residents of slums are generally aware of their own health care needs and make use of the wide range of healthcare options available (George. et al., 2019). They prioritise and seek out specific healthcare treatments in accordance with their socioeconomic situation, provider knowledge, and the cultural expectations in their treatment plans. Prior studies showed that Indian slum dwellers received a mix of private and government assistance (Islam et al., 2006; Banerjee et al., 2012; Gupta & Guin, 2015; Essendi et al., 2011). Certain individuals appear to be attempting to avoid the healthcare system by purchasing medicines directly from pharmacies, consulting unlicensed medical practitioners, or engaging traditional healers who offer a variety of medical services (Paterson & Britten, 1999; Suarez & Reese, 2000). As a result of indifferent or overly expensive care, patients and their families turn to tailored treatment when they lose faith in clinical care, or when they no longer receive assistance with their recovery (Sutherland & Verhoef, 1994).

This is not to argue, however, that users of alternative health care are necessarily sceptical of medical care or dissatisfied with it (Henderson & Donatelle, 2004). Numerous studies have also shown that people may be attracted to alternative treatments because they are in line with their personal and religious values, as well as their ideas about health and healing practises (Charlton, 1993; Astin, 1998; Vincent & Furnham, 1996). In contrast, studies have also shown that these cultural and religious practises prevent people from getting formal medical care (Rashid et al. 2001; Begum, 2012; Casterline et al., 2001). Prior studies also suggests that clinical care is the preference for many people, which may be related to several factors such as existence of an ageing population and a caregiver shortage (Stabile et al., 2006; Viitanen, 2007; Yang et al., 2012), the length of the illness (Bonsang, 2009), the nature of the illness (Joshi et al. 2003), or preventive care (Bolin et al., 2008). This consumer-driven preference and priority pattern varies by context, resulting in geographic differences in the consumption of both formal and non-traditional health resources (Halwindi et al., 2013).

In explaining the link between the perceived need for healthcare and its use, neighbourhood factors play a critical role (Law et al., 2005). Place affects people's health in ways that go beyond the composition of the people who live in a given neighbourhood. In addition to living in a low-income area, urban slum dwellers face a number of other challenges that contribute to their poor health, such as limited access to healthy food (Donkin et al., 1999; Stafford et al., 2007), crime and lack of safety that restrict their mobility (Burgoyne et al., 2008), a difficult time finding work

because of the negative connotations associated with their community's reputation (Lobo & Das, 2001), poor services and infrastructure (Cummins et al., 2007). Research in India on the relationship between neighbourhood and health care use in urban slums populated by refugees and migrants is very lacking at this time. Slums are defined by a combination of factors, including the availability of basic infrastructure (such as piped water, toilets, and sewage) and the quality of the materials used in the construction of the homes (Lilford et al., 2019). The Indian Census, the Indian Ministry of Statistics, and the United Nations all hold that understanding of slums. Excluding a range of neighbourhood characteristics that characterise the complexity of community environments makes it impossible to identify pathways for, or measure the relative importance of, neighbourhood-level factors in determining health outcomes. This problem is exacerbated by an over-reliance on census-based measurements as the primary or exclusive source of neighbourhood characteristics. There are numerous reasons to conclude that inadequate infrastructure and physical characteristics alone do not differentiate slums from other urban areas. Slums are much more than just locations with low infrastructure (Mahabir et al., 2016). To begin, residents of urban slums are subjected to a variety of environmental stresses, including inadequate sanitation, overcrowding, and a scarcity of open space (Mair et al., 2010). Second, residents in deprived communities are more likely to face criminal and antisocial behaviour, resulting in increased worry and anxiety (Sclar & Northridge 2003; Ludwig et al., 2012). Thirdly, conflict arises as a result of competition for scarce resources in low-income neighbourhoods. Fourth, the desire to use healthcare services is impeded by the need for basic utilities (Kerner et.al 1993). Fifth, those with inadequate economic and social means may have a harder time soliciting aid from their neighbours. Finally, impoverished places have a despairing culture, which saps residents' motivation to better their standard of living and social success (Sampson et al., 2002). These studies in Ahmedabad (Barua & Singh, 2003), Delhi (Das & Hammer, 2007), and Mumbai (Yesudian, 1999) revealed socio-cultural and cognitive barriers, such as low levels of health literacy and unfamiliarity with sophisticated health facilities, which negatively influence people's attitudes about the quality of care and treatment. Additionally, these studies found that an informational challenge exists in knowing where to go for quality treatment. Further, these studies found that the information regarding the required treatment, as well as information about where to seek care, is incomplete. Low levels of social support also result in fewer people obtaining needed care. There is also a presence of bribery and abuse, and people lack trust in health providers.

What appears to be lacking in public health and health promotion research in India's urban slums is a more complete theoretical framework that enables to comprehend the interaction of various types of capital and their function in the creation of population health. This is critical because a sociological understanding of neighbourhood effect (measured in terms of the volume of each capital and the shape of each capital's habitat/field) in the context of Indian urban slums has been largely ignored in health research (Patra & Ghosh, 2020). We suggest that Bourdieu's concepts of habitus and capital can help make sense of the diverse ways in which slum dwellers respond to distinct neighbourhood characteristics and consequently perceive and act on their health requirements and healthcare use across contexts. What makes Bourdieu's theory of capitals interesting is that it is sufficiently broad to encompass not only economic capital but also other forms of capital (social and cultural), as manifested by lifestyle indicators, educational prestige, and the symbolic dimensions of class relations, such as social relationships. This approach enables specific forecasts to be made based on the possession of various types of capital. With an emphasis on the fact that the components of a person's capital structure, such as economic, cultural, and social capital can all have complex effects on health behaviours at the same time, Bourdieu's theoretical orientation generally situates health behaviours in the family and social environment. An emphasis is placed on Bourdieu's habitus and capital in the analysis offered here, in an effort to better understand how slum residents engage with diverse social sectors, accumulating and deploying capital, unconsciously and sometimes consciously, according to their habitus. Using Bourdieu's concept of need, we can infer that individual living in urban slums with smaller capital stocks will only use healthcare services when they are sick, whereas those with higher capital stocks will use them strategically to prevent illness. A more thorough overview of Bourdieusian approaches to capital and choice of necessity is provided first.

### The Constructs of Bourdieu's Habitus, Choice of Necessity and Capital:

A person's amount of capital and the proportions of the various forms of capital they hold – their capital structure – determine where they are located in social space according to Bourdieu's theory. They all share a similar social position within the social space because their capital volumes and capital structures are similar: "all agents are located within this space in such a way that their spatial proximity to one another in those two dimensions increases their sharing," while "their spatial separation decreases their sharing" (Bourdieu 1998). In Bourdieu's analytical framework, each of these social contexts is assigned a "habitus." Habitus is the manifestation of social and material influences that determine people's interests, preferences, and lifestyles.

The term "habitus" is then used to refer to an individual's "day-to-day decision of need" (Bourdieu 1998). His central point is that individuals of the lower classes are incapable of successfully converting economic capital into cultural or social capital, or vice versa. Due to their inferior economic status and lack of knowledge, individuals of the lower classes are forced to attend to the basic essentials, which results in adaptation and acceptance of this minimal essential (Bourdieu 1984). As a result of this logic, it has been argued that "capitals are resources for strategic acts aimed at positioning their holders favourably relative to other social system members" (Veenstra and Abel 2019: 1). For instance, persons with a high level of all capitals have the freedom to choose, which enables them to make more informed, long-term, and strategic health decisions, and therefore to create distinctive habits that can result in a health advantage. This argument is further emphasised in a study by Smith and Dumas (2019), which reveals how Bourdieu's idea of "practical sense" enables us to understand how individuals internalise priorities at the expense of others. Additionally, Dumas et al. (2014) discovered that, despite respondents' understanding of health and weight, their behaviour was influenced by current demands and responsibilities.

Bourdieu also uses the term capital to refer to the kind of resources that actors bring to social interaction or to the outputs of such interactions. These resources may be used intentionally or inadvertently and may take economic, cultural, or social forms. The various forms of capital reveal Bourdieu's borrowings from Weber, who theorised the importance of considering the deployment of resources that are not explicitly economic, such as social reputation and standing. For Bourdieu, economic capital is the foundation for all other forms of capital because it is based on material resources like income or property (Bourdieu, 1986). By contrast, social capital refers to the resources associated with the 'ownership of a robust network of mutual acquaintance and recognition' (Bourdieu, 1986). The concept of cultural capital refers to the cultural abilities that people acquire over time as a result of socialisation and education. Cultural capital can take the form of skills and information that are institutionalised as degrees or certificates, or it might be objectivised in books or tools (Abel and Frohlich, 2012). A critical distinction between Bourdieu's definition of capital and the similarly well-known James Coleman's is that the former clearly rejects the latter's central premise that 'agents' activities can be analysed and comprehended in terms of utility maximisation (Adkins, 2008). Indeed, Bourdieu aimed to give an alternative to Coleman's rational choice sociology by arguing that capital is a class reality, not an individual trait, and that 'choice' is thus socially, not individually, created.

# **RESEARCH QUESTIONS:**

Using Bourdieu's approach to capital, we will study the following:

- 1. The extent to which the volume and types of capital (social, economic, and cultural) in urban slums vary between contexts and demonstrate their effect on shaping perceived healthcare requirements and the kind of care sought.
- 2. How material and symbolic constraints, different perceptions and values, and group differences influence the choice of necessity when it comes to comprehending and practising healthcare needs in an urban slum neighbourhood.

# **METHODOLOGY:**

# **Study Design**

This study is a synthesis of the PhD dissertation of the principal author that explored how residents of urban slum neighbourhood construct health meaning as a sociocultural reproduction and how residents understand and practise health-care needs while keeping in mind interactions between social, cultural, and economic capital of a neighbourhood produced by the conditions of existence. The current study seeks to understand how unconsciously in terms of healthcare urban slum dwellers act and think in their daily lives according to the habitus/neighbourhood, and how they develop strategies for healthcare needs and seeking care from a variety of healthcare services as they engage in various social fields, gathering and deploying capital. Based on a qualitative design, a phenomenological viewpoint was employed to study and describe the subjective experiences of slum dwellers (Malterud, 2001).

# **Study Settings**

Purposive maximum variation sampling (Martnez-Salgado, 2012) was used to choose study regions with large geographic dispersion and diverse built environments (see Table 1). This study was conducted in two cities in India: Kolkata in West Bengal, and Bangalore in Karnataka. Again, a blend of core and periphery slums from each city was chosen to highlight the dynamics and local variation of the core-periphery neighbourhood (Klimczuk and Klimczuk-Kochaska, 2019). Motijheel Basti (central) and SahidSmriti Colony (periphery) are located in Kolkata, respectively, while NakkaleBande Slum (central) and UllaluUpanagar Slum (periphery) are located in Bangalore. Throughout the paper, they will be referred as Kolkata Slums and Bangalore Slums, respectively. The cities of Kolkata and Bangalore were chosen due to large discrepancies in living conditions and quality of life as measured by the components of the UN Habitat Prosperity Index (Belliapa, 2011; Sivaramakrishnan et al., 2020). Alternatively, they are emblematic of India's northern and southern regions, which have been considered as culturally unique by many observers in India (Karve, 1965; Sopher, 1980a; Miller, 1981; Dyson and Moore, 1983). Despite Kolkata being one of the oldest urban centres in the country and having an extensive history of slum construction dating back to before India's independence, Bangalore has seen significant growth in recent years, since it is the second fastest growing major metropolis in India (Nagendra et al., 2012). Although Kolkata was among the more industrialized states of the country at independence, in course of time due to several factors manufacturing industry got stagnated especially compared to other regions (Chandrasekhar and Ghosh, 2008). Bangalore has developed into a prominent focal point for a number of sectors that rely heavily on the public sector, positioning it as a major economic hub, medical hub, and a booming information technology centre. As a result, Bangalore's population is growing. In 2011, Bangalore had a total population of 9.62 million, with 4.43 million people being classified as migrants. By comparison,

in Kolkata, only 0.83 million people are migrants, which represents around 20% of the city's population. The growth rate of the Kolkata urban agglomeration falls every ten years. Over half of intermediate and small towns had negative or extremely slow growth (Yadav and Bhagat, 2015). On the other hand, Bangalore has developed into a rapidly rising metropolis in southern India, ranking as the sixth largest metropolitan agglomeration in the country (Census, 2011; Verma et al., 2017). As a result, the two cities have markedly different ages, geographies, and growth trajectories.

# Respondents

Table 1 details the purposeful sampling procedure used to generate a diverse sample of respondents. The first author relied on personal networks and referrals (such as family and friends) to identify study respondents willing to participate in interviews and discuss their health–seeking behaviour. Health staff from a local clinic and the ward municipal health office first approached respondents in the Kolkata Slums. Respondents in the slums of Bangalore were approached by representatives of a local non–governmental organisation (NGO) that is active in the slums. The study used theoretical sampling (Bertaux, 1981) which emphasised the critical role of a sufficient sample size in producing conceptual depth and richness. In accordance with the underlying assumption of 'data saturation', respondents from the core of the Kolkata slums and 66 respondents from the outskirts were chosen because no more information could be obtained. Similarly, in Bangalore Slums, 48 respondents from the centre and 62 respondents from the periphery were interviewed.

# **Data collection Procedure**

Data collection began in July 2011 and ended in early September 2012. Due to the first author's low familiarity with the interview language, data collection was undertaken in the Bangalore slums by a multilingual interviewer. To ensure that the interviewer felt comfortable discussing highly sensitive and stigmatised themes for certain ethnic groups, the interviewer was chosen based on their training in healthcare or social science. This, paired with their training, reduced the likelihood of interviewers skipping or avoiding sensitive issues. The first author also tried to make sure that the interviewer had a similar cultural and language background to the interviewees' It is well established that individuals with comparable backgrounds are more able to converse and speak candidly during an interview (Randal, 1989; Prior, 2018). Additionally, the researchers used the technique of reflection. The concept of reflection is based on Rogerian ideas, which involve treating the interviewee with kindness and giving him or her unconditional positive regard (Kensit, 2000). The fieldworker summarised and transmitted the information to the respondent in this instance. Probes were employed to elucidate ambiguous information. To assist researchers in comprehending ambiguous problems, individuals were asked to elaborate. This methodology was chosen to emphasise the critical nature of avoiding biases and misunderstandings during the interviewing and data collection phases. The first author and interviewer met regularly prior to and during the interview phase to discuss the research process and progress. This allowed for the early identification of any additional training requirements or potential problems.

A complete semi-structured interview guide was developed around a series of root questions that covered topics ranging from views of experiences and factors that influence healthcare utilisation to information about the slum communities' condition. The interview guide was written with flexibility in mind, allowing for the flow of random questions while also allowing for the exploration of significant but unexpected themes. More precisely, a well-structured questionnaire was developed and distributed to all respondents in order to elicit specified socio-demographic data and responses (such as visiting a hospital or clinic when ill). Apart from her job as the lead investigator, the first author took on the role of respondent observer, observing and participating in daily and care exchanges.

A pilot interview with one respondent who met the inclusion criteria was done. There were no difficulties revealed during the pilot interviews and it assisted the researcher in determining the duration of each interview. The questions were straightforward, which the respondent was aware of. To maintain the instrument's dependability, the questions and interview processes were continuously assessed to ensure that they elicited the appropriate responses to the appropriate questions. The researchers were able to recast questions, simplify them, and employ simpler concepts as the investigation continued. The primary interviews typically lasted between 30 and 45 minutes and were conducted in a comfortable (and pleasant) manner. Each interview was taped and handwritten notes were taken.

		Kol	Kolkata			Bangalore	alore	
	Motijh	Motijheel(n=69)	Sahid Sr	Sahid Smriti(n=66)	NakkaleE	NakkaleBande (n=48)	UllaluUpa	UllaluUpanagar (n=62)
	Men (n=33)	n=33) Women (n=36)	Men (n=34)	Women (n=32)	Men (n=29)	Women (n=19)	Men (n=33)	Women (n=29)
Age								
<b>Below Twenties</b>	4	З	3	3	2	3	3	4
Twenties	6	14	6	13	8	6	8	10
Thirties	10	6	12	7	12	5	12	8
Forties	7	6	10	6	4	4	6	4
Fifties	4	c	2	2	2	-	2	1
Sixties	2	-		-		0	2	2
Religion								
Hindu	12	12	12	12	12	12	12	12
Muslim	12	12	12	12	12	4	12	11
Christian	6	12	10	8	Ŀ	9	6	6
Place of Origin								
Rural	1	10	24	27	9	6	6	8
Within the city	15	17	5	2	5	3	4	10
Displaced	9	0	0	0	4	0	16	6
Outside State	8	6	0	0	11	7	4	2
Outside country	3	0	5	3	0	0	0	0

# Chapter 4

Table 1: Demographic characteristics of respondents

		Kol	Kolkata			Bang	Bangalore	
	Motijh	lotijheel(n=69)	Sahid Sn	Sahid Smriti(n=66)	NakkaleB	NakkaleBande (n=48)	UllaluUpa	UllaluUpanagar (n=62)
	Men (n=33)	Men (n=33) Women (n=36)	Men (n=34)	Women (n=32)	Men (n=29)	Women (n=19)	Men (n=33)	Women (n=29)
Linguistic/Cultural groups	roups							
Hindi (Bihar, and UP)	15	17	4	7	8	10	12	12
Bengali	18	19	30	25	0	0	0	0
Kannada	0	0	0	0	12	m	10	8
Tamil	0	0	0	0	5	£	9	7
Telegu	0	0	0	0	4	m	5	2
Years of Stay								
Older Migrants	8	12	13	18	11	4	6	5
New Migrants	6	6	16	12	6	5	7	3
Native Migrants	19	15	5	2	6	10	20	21
<b>Occupational Status</b>								
Full employed	19	16	16	-	15	7	19	6
Contractual	6	7	11	0	11	6	10	17
Unemploved	ъ	13	7	31	m	ſ	4	9

Table 1: Demographic characteristics of respondents (continued)

		Kol	Kolkata			Bangalore	alore	
	Motijheel(n=69)	il(n=69)	Sahid Sn	Sahid Smriti(n=66)	NakkaleB	NakkaleBande (n=48)	UllaluUpa	UllaluUpanagar (n=62)
	Men (n=33)   N	/omen (n=36)	Men (n=34)	(n=33) Women (n=36) Men (n=34) Women (n=32) Men (n=29) Women (n=19) Men (n=33) Women (n=29)	Men (n=29)	Women (n=19)	Men (n=33)	Women (n=29)
Various Sources of Health Services Utilized	alth Services L	Jtilized						
Self-medication <sup>11</sup>	18	4	6	5	14	2	10	7
Formal <sup>12</sup>	3	6	6	5	5	3	8	11
Informal <sup>13</sup>	5	12	8	6	4	6	7	6
Homeopathy <sup>14</sup>	4	10	5	6	0	2	0	
Partial Institutions <sup>15</sup>	m	4	6	7	6	m	Ø	4

Source: Field Data

11 Referring to over the counter drugs, traditional method of preventive measures with herbal remedies

12 Both government and private funded registered clinical practitioners

13 Faith healers, quacks, traditional medicine men, folk healers, witchcrafts, sorcery

14 Complementary and alternative medicine to clinical care

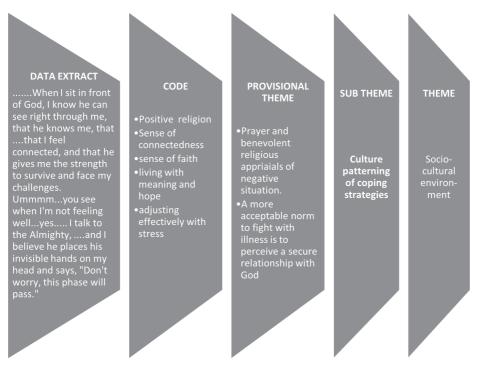
15 Seek both formal and informal care simultaneously

Table 1: Demographic characteristics of respondents (continued)

#### **Data analysis**

The transcripts of the interviews were taken verbatim. It's important to note that this research employs an abductive approach, which means it doesn't rely solely on past assumptions or empirical findings to guide its conclusions. The analysis stage depicted in Figure 1 includes coding, a provisional theme, a sub-theme, and a theme. The first author started by transcribing, reading, and re-reading the data (familiarization with the data). The first author (who was familiar with the cultural backgrounds) also went through each transcript individually to identify patterns and correlations and to mark sections that contained information relevant to each specific point that was being made. The codes in this work were refined through other scholarly means (Thorne et al., 2004; Green et al., 2007). A more informed position was assumed and began to move away from the empirical level toward the theoretical level by finding parallels between first-order codes. Thus, a preliminary analytic structure was built from the provisional themes on the basis of which respondents' experiences could be grouped and differentiated (Hunt, 2009). Credibility was boosted through preliminary findings being noted in observation notes. The analysis was further characterised by an iterative process of comparing and re-combining provisional themes at various stages to form the sub-themes. Comparisons with constructs gleaned from existing literature helped to identify where the study's findings differed and where they were similar to previous work, which were maintained at arm's length to maintain the "semi-ignorance." Each author reviewed similar themes, and where disagreements arose, the transcripts were discussed until concordance was achieved. The evaluated sub-themes were guided by Bourdieu's concept of habitus and capital (Bourdieu, 1986), with the goal of elucidating mechanisms at various levels through which neighbourhood factors influence perceived healthcare need and determine the timeline and motivation to seek care. Finally, three interconnected themes with explanatory sub-themes throughout this process were developed, which were later defined as: a) Impact of built environment b) The socioeconomic environment, and c) The socio-cultural environment.

# Figure 1: Stages of Analysis



# **Data Triangulation**

Lincoln and Guba (1986) proposed a criterion for 'trustworthiness' that was used to maximise trustworthiness and minimise validity threats (Forero et al., 2018). The requirement for credibility was met through open-ended inquiry, extensive interaction with the data, and an exhaustive discussion of the techniques. The requirement for transferability was met by providing detailed and in-depth descriptive data, as well as by quoting respondents. The dependability criteria were satisfied by the use of data triangulation and researcher triangulation. The observation materials are reflective memoranda from the first author's professional experience as an academic researcher with a master's degree in sociocultural anthropology. She shared a common cultural heritage with the respondents. Clearly, she undertook this study as an academic researcher, a cultural mediator, and an anthropologist. All of these roles may have an effect on and influence her behaviour, particularly in light of the preconceptions and biases she brought to the study. Nonetheless, her perspective is shaped by her position as a researcher, which includes reading the literature and attending academic conferences on the research topic, as well as reflexivity, which enables researchers to reflect on and critically analyse their assumptions, as well as deal with prejudices (Mantzoukas 2005). Additionally,

the study incorporated a diverse group of people and locations to ensure that data was cross-checked across informants.

All the data was gathered by the first author, who has prior experience working and conducting research in social care settings but is not a clinician. To ensure reflexivity, the first author kept a reflective diary with field notes to document her possible biases and role in shaping interactions. Integrating data collection and analysis with emerging ideas has led to a more refined and trusted understanding of identity (Lincoln & Guba 1986; Shenton 2004; Srivastava & Hopwood 2009). She frequently worked with the other two authors and monitored the results of the analysis. All three authors (who are well-versed in the fields of inclusive healthcare, healthcare organisations, structure, and management, and public health and preventive medicine) read the interviews, were involved in the analysis, and served as references for issues within the Indian health care system. All of these triangulated, reduced investigator bias, and helped the integrity of findings (Patton 1999).

# **Ethical Consideration**

The ethics committee of the Institute for Social and Economic Change (ISEC) approved the research project, and the study was conducted in accordance with the Helsinki National Committee for Ethics in Social Science Research in Health (NCESSRH) guidelines (Jesani & Barai 2000). Due to their social vulnerability, each respondent gave oral consent (Manti & Licari 2018) to participate voluntarily in the research project, with the right to withdraw at any time, and permission to audio-record the interviews throughout this consultation. The data was presented anonymously, with only the research team having access to it.

# RESULTS

The key themes that emerged from the interviews indicate that geographical variations in health have arisen around neighbourhoods and manifest as compositional, contextual, and communal (MacIntyre et al., 2002). The research revealed three major overarching themes on perceived health needs and healthcare use: 1) Impact of built environment 2) The socioeconomic environment, and 3) The sociocultural environment, including explanatory subthemes.

# Impact of built environment

We first used a mapping technique to locate the essential facilities available in the study locations and then assessed how they influence healthcare consumption. Following that, respondents were asked to rank utility service facilities according to their demands. This aided in determining the relative importance of health care demand and need on their priority list (see table 2).

Table 2. Listing and	Ranking of Preferences
----------------------	------------------------

Kol	kata Slums	Ban	galore Slums
1.	Housing	1.	Solid Waste Management
2.	Sanitation and water Provision	2.	Sanitation and water Provision
3.	Solid Waste Management	3.	Sewage and Drainage System
4.	Sewage and Drainage System	4.	Housing
5.	Need for Healthcare services <sup>16</sup> and its usage	5.	Need for Healthcare services and its usage

Source: Based on Field Data Analysis

## Housing

The majority of Kolkata and Bangalore Slums respondents mentioned the impact basic needs have on their overall health and wellness. In case of housing, for example, many respondents of the Bangalore Slums reported cost of renting housing, poor housing condition or overcrowding was a prominent problem as seen in the following quotes.

'This truly bothers me. In order to feel safe in it, everyone needs to be accommodated. Peace of mind is possible if you have a place to go'. [Bangalore Slum respondent]

'It's damp in the house. Yes, because of the moisture, we frequently have persistent discomfort, such as lower back pain on the foot'. [Bangalore Slum respondent]

Whereas concerns in social aspects of housing, such as safety, have caused obstacles for Kolkata Slum respondents.

'To me, the most critical thing is security and well-being. Excellent neighbours supply security, safety, and calm. No, I don't like the old unit, and you're not safe because they've stolen your bikes twice'. [Kolkata Slum respondent]

# Water supply and Sanitation facilities

The respondents of both Kolkata and Bangalore slums spoke about inadequate access to clean water and sanitation services. While contaminated water is a significant issue specific to peripheral Kolkata Slums, sporadic services impose unique constraints

<sup>16</sup> Healthcare services refer to the health clinics and hospitals available around and within the slum areas

on core Kolkata Slums and for Bangalore Slums; both core and periphery. Kolkata Slum's ponds and small tube wells were mostly used for bathing, washing dishes, and clothes. A person who dislikes drinking water stated as follows,

'Most pond water is used for bathing and cleaning kitchenware. Buffalo visits often contaminate the water. We also avoid hand pumps due to the saline content of the water'.

# [Kolkata Slum respondent]

There are no public water facilities in the peripheral Kolkata Slum. Thus, respondents disclosed that they purchase a 30ltr water gallon for INR 30 or USD 0.50 for drinking and cooking every 15 days or as needed (additional household members result in increased water consumption), which they consider exorbitant.

'There are eight people in the house, and we need 9 to 10 litres of water each day for drinking and cooking." That necessitates buying water every fourth or fifth day. It becomes nearly impossible to pay for this water gallon on a regular basis.' **[Kolkata Slum respondent]** 

Another respondent described his water phobia as follows:

'I get very frightened and irritated whenever my wife asks for a refill. I strongly advise her not to waste the water, and I explain how she should be using it so that it lasts at least 30 days. Even though I do not do the typical household chores, I know nothing about how the water is used, and I sound stupid to her, she says. I am powerless to convince her that paying for water is an unnecessary expense that I am unable to afford'.

### [Kolkata Slum respondent]

Vended water is expensive, which reduces water use in the area. It is common for houses to resort to hand pumps for water after it has been treated, as a last resort. Residents of the neighbourhood experience frequent kidney stones, urinary tract infections, diarrhoea, and abdominal pain because of the contaminated water.

Piped water delivery is the primary source of water for core Kolkata Slum and Bangalore Slum, with an unpredictable start and end time. Respondents complained about having a set schedule for when the tap water was available for use. Due to the time constraint, a large number of people congregate around the tap at the same time, resulting in lengthy lineups and potential confrontations. Chapter 4

'...there was a huge brawl in the street and people started beating each other'. [Kolkata Slum respondent]

'Water wars almost always occur when women try to cut ahead of the line. Complaints are filed with the police'. [Bangalore Slum respondent]

Most respondents consider water under low pressure and meeting twice a week to be time-consuming (especially during working hours). As a result, many houses are using hazardous water that is collected from near sewage and trash dumps, which is often visibly contaminated by holes. Numerous residents of both study slums also reported that they pay exorbitant charges to illegal water cartels. The respondents discussed their water-related stressors regardless of their water supply. For example, large drums left at the edge of narrow lane entrances are typically rolled inside, or water is delivered to the home in multiple visits using smaller containers. As one woman respondent put it,

'when men are at work, the physical strain and difficulty of navigating rolling drums loaded with water down small slum streets falls disproportionately on women and children.'

[Kolkata Slum respondent]

A respondent criticised the water quality, saying,

'It bothers me because there are several times when I want water to drink, I have to drink it with the dirt or wait for it to settle. Eventually, you'll see rust at the bottom of the container. Clearly, the water is contaminated, and I'm continuously concerned.' [Bangalore Slum respondent]

The core-periphery study slums treated and stored water in different ways. Periphery slums in both cities highlighted a prevailing awareness of the need for preventive measures. In general, those interviewed reported that moving gallon of water in metal pots or dirt pitchers for storage is the most prevalent mode of transport. Respondents discussed their motivations for participating in such activities, which included concerns about recontamination during transportation and the reuse of containers for gathering and collecting water from a water source. Additionally, they believed it was a beneficial practise because metallic pots or earthen pitchers frequently have a narrower neck and aperture, minimising the possibility of contamination. For the periphery region, treatment options included boiling water, alum, chlorine or carbonated water to improve water quality, whether for use in cooking or drinking.

Habitus and capital determining perceived healthcare needs and use in India's urban slums

'I do not like to cook with unfiltered water, cooked rice looks white because after boiling the water is cleaner'. [Kolkata Slum respondent]

'Sambar (lentil soup) tastes significantly better when made with filtered water'. [Bangalore Slum respondent]

Only a few people reported drinking raw water, as it was assumed that the source water had already been treated and that further treatment was unnecessary. Both cities are battling for basic survival (money and a way of life), leaving little time for effective water treatment. Due to the high cost of cooking fuel, the majority of respondents viewed boiling water for drinking as a luxury. They store drinking water in larger pans in their homes due to their inability to afford other purification devices. Except for drinking water storage vessels, it was frequently observed that they were left exposed. Additionally, these locations have been discovered to employ inefficient storage and use techniques. As a result, stored water is more likely to harbour bugs. Women conserve and reuse water in numerous ways; for example, bath water is reused to clean the interior of the house. As a result, the most frequently reported health problems in the neighbourhood are skin infections, diarrhoea, and other stomach-related disorders.

Respondents of both Kolkata and Bangalore slums emphasised the importance of more latrines.

'What we lack are latrines; the few that we do have are inadequate.' [Kolkata Slum respondent]

Certain core Kolkata slum families lacked access to lavatories and therefore resorted to open defecation in the adjacent bush.

'There are fewer toilets than there are users; for example, a single toilet may be shared by at least twenty people'. [Kolkata Slum respondent]

During one of the interviews, a resident of Bangalore slum described the extent of the overcrowding as follows: '*in our area, ten households share one latrine; these latrines fill up after about a month.*' Her portrayal was not unique; it echoed sentiments expressed by Bangalore slum respondents in several in-depth interviews. Furthermore, numerous female respondents described numerous instances of how substandard bathrooms impede sexual assaults, contributing to gendered psychosocial stress.

'Males lurk and watch us defecate and then make fun of it in public. This frequently caused embarrassment for my husband and even squabbles (between us)'. [Bangalore Slum respondent]

'They might have caught a glimpse of my nakedness, I believe. I'm ashamed. I return home, pause for a few moments, and then depart once more. I occasionally have an urgent need to travel somewhere, but I am forced to make do; I have no choice'. [Bangalore Slum respondent]

The respondent brought up latrines that were smelly and full of insects, specifically cockroaches. The respondent added,

'There's also the stench from the latrine, and cockroaches from the latrine invade our houses in great numbers.' [Bangalore Slum respondent]

Men and women in the slums were dissatisfied with practises that contributed to persistently dirty latrines, such as the lack of drop-hole covers and the use of community-owned latrines rather than family-owned latrines, which made assigning responsibility for cleaning more difficult. In addition, the study found that women in both cities reported parasitic infections and frequent diarrheal episodes as the most prevalent health concerns in the study slums. In addition, the majority of communal toilet facilities in peripheral Slum A lacked water faucets and other hygienic amenities such as hand-washing receptacles, disinfectants, and anal cleaning products. Core Kolkata slum is as bad off as underserved Bangalore slum in that the frequency and unpredictability of water supply outages puts critical personal hygiene habits to the test.

### Solid Waste Management

For the vast majority of study respondents, households are not dedicated to using clean practises to protect or improve environmental health conditions in their homes and surroundings. Respondents experienced solid waste disposal problems because dust bins were rare and garbage collection trucks were infrequent. Worry about garbage disposal is prevalent in both core and periphery areas, due to social disorder and incivility. Excessive littering often results in arguments and neighbourhood disputes. Residents repeatedly complain about the persistently unpleasant surroundings.

'Caretaking this atmosphere generates uneasiness, impatience, bad temper, mental unrest, behavioural and personality problem, and mental breakdown.' [Bangalore Slum respondent]

Interviews with periphery slum residents demonstrated a correlation between a municipality's regulatory shortcomings and improper solid waste disposal techniques. According to a nearby slum resident,

# 'No vehicles service trash collection if no access road exists. It's very sad.' [Kolkata Slum respondent]

These services are only available to families who reside near a major thoroughfare. We must tolerate adversity in any way we can. The absence of residential garbage cans furthers the practise of locals dumping various solid waste products into nearby waterways and open sewers. Yet more respondents claimed that the municipality's inadequate solid waste management has led to garbage build-up in open areas, the open drainage system, and nearby residences, resulting in nuisance and foulsmelling pools. Garbage dumps left untouched may lead to water backups and increased fly populations.

The core slums don't have suitable land for trash disposal. A majority of the respondents in Core Bangalore slum felt that trash should be disposed of using city vehicles. On inquiry, waste collection and disposal infractions were discovered. Bangalore slum residents leave their garbage bins uncovered, and thus they have a lot of trash. Trash is also dumped in drain and ditch. When waste containers are covered in mud, garbage is discarded around the containers. Trash dumping caused flooding. Residents of core Kolkata Slum reported that trash collectors and waste pickers often work with the unemployed to avoid collecting garbage from lane-based residences. People commonly form informal waste collection firms and dispose of waste by utilising their social networks. Many families make no impact and become non-observable. This gave rise to alternative dumping practise that led to communal brawl. As one Hindu respondent said,

'They used to dump garbage in their backyards near our colony (referring to the Muslim neighbourhood). Scavenging dogs and cats break down plastic bags, emitting stinky fluids and endangering nearby residents (referring to beef skin and bones, which are considered taboo foods). Traffic often immobilised people by impeding routes. They remained silent when we complained. Our brother was injured due to the sum effect, and we called the police. Everything was in disarray. Officers were mediators and go-betweens on our behalf.'

[Kolkata Slum respondent]

According to a Muslim respondent,

'we suffered because of this incident. Garbage cans are scarce and inconvenient, as we do not have a designated dumping zone, and people are arguing over where they should dispose of their waste. Nobody is here to hear our wails. This forces us to walk far distances to dispose of the garbage.'

[Kolkata Slum respondent]

#### Sewage Facilities

Slum dwellers noted the critical need for well-maintained, sustainable sewage systems that assist in regulating surface water runoff. Because of a lack of a drainage system, rainwater gets into natural drains in the peripheral study slums. Due to the nearby drain network, unsanitary conditions arise. Discharging trash into gutters blocks water flow, causing overflows. This overflow occasionally enters residential complexes, resulting in stagnancy and exposing residents to insect-borne illnesses.

Both core slums have pucca open and closed drains. Over the other hand, encroachments on open drains are a major source of concern for core Kolkata slum. Numerous respondents alluded to the neighbourhoods that are growing up without enough planning. According to one core Kolkata slum resident,

'This reflects the people's character or the way they use the drainage system. You will learn that some people intentionally clogged the drainage system with sand only to allow vehicles to enter their premises or because they are building a house and need to make room for the vehicles that are coming in. This is intolerable'. **[Kolkata Slum respondent]** 

Yet another core Kolkata respondent expressed,

Habitus and capital determining perceived healthcare needs and use in India's urban slums

'due to a shortage of space, several neighbours have converted sewers and culverts into waste dumps.'

## [Kolkata Slum respondent]

A primary problem for core Bangalore slum respondents is storm water drainage. Eroding slopes and frequent flooding are particular problems when building homes on uneven terrain like unstable hillsides and swampland. Torrents of water form in minutes, inflicting water damage that is permanent. When it rains, flooding in core slums is considerable. But poor drainage has other consequences. Many people were concerned about gastro-intestinal issues, to name a few. Mostly due to runoff contaminated with untreated sewage mixing with low-pressure water supply, poisoning drinking water. In general, the majority of respondents in both cities' study slums agreed that poor drainage and decaying built environments are significant factors to the causes of both mental and physical sickness. Respondents identified the following related risk:

<sup>(</sup>Flushing waste water from kitchens and bathrooms with rain water is an incredibly common practise. Diseases such as dengue, malaria, and typhoid grow the problem.' **[Kolkata Slum respondent]** 

'Inadequate gutters lead to insect infestation, mould, mites, and allergies. It is dark, wet, and stinks. This causes anxiety and delirium.' [Bangalore Slum respondent]

### Socio-economic environment

Slums have been shown to have an effect on a person's demand for health care because of their difficult socioeconomic situation. Respondents discovered three key health-related problems: financial hardship, environmental stress, and poor healthcare worker performance. In each of these investigations, numerous respondents claimed that, despite their understanding of a proper diet, they could not afford it. They claim that lower wages lead to housing insecurity, inadequate nutrition, and other problems, all of which increase the risk of disease.

'The main problem is poverty, since poor living conditions are the source of many illnesses. We look casual, but we can only eat three meals a day. This is the reason we're sick. After that, it starts to affect our mental health.' [Kolkata Slum respondent]

'Good health is more easily attained through affluence. If you're depressed and have the means, you could, for example, take a vacation near the sea (referring to the beach). If you live in poverty, you'll eventually be in a dump; it's not the same.' [Bangalore Slum respondent]

Having a job does not necessarily end poverty for low-wage workers. Poverty, according to respondents, makes it difficult to maintain one's health. They are always on the lookout for methods to survive, closely monitoring their income, and attempting to meet their fundamental needs (e.g. food, commodities, clothing, transportation, etc.).

'A lack of money shortens your lifespan, since you cannot afford even the simplest essentials. Whether you have the money to buy the required supplies or not, the doctor still offers his/her advice.'

### [Kolkata Slum respondent]

For the respondents, frequent visits to the doctor were challenging due to financial constraints, the need to rely on others, and a busy job schedule. Instead, people choose to self-medicate.

'My earnings do not cover my basic needs, which include health care, and hospital costs are equally exorbitant. In this country, if you are sick, you usually begin with pharmacies; if the case becomes serious, you go to the hospital.' [Kolkata Slum respondent]

Being involved in stressful life events, such as job loss, family and personal disputes, or moving into a new residence, can alter an individual's appraisal of their health, their perceived need for healthcare, and their use of healthcare. Many slum respondents of both the cities, for example, thought that social incivilities such as crowding, feeling uncomfortable, noise, dirt, and violence led people to feel lousy in general, leading to a higher chance of sickness regardless of their actual physical health. Lack of basic knowledge about lifestyles and health, ignorance of longer-term implications, lack of value for or recognition of health concerns and a loss of the capacity to distinguish between the causes of health problems were widely reflected as a joint set of neighbourhood poverty-induced processes in both areas of study. Most respondents believe that to live a better life, they must spend more time "*making money*", which drives them to sleep less, eat less, and take less time for themselves. Less well-off

individuals cannot "*buy*" a healthier lifestyle or swap money for time and health. In other words, economic and societal restraints limit their lifestyles to the utmost extent possible. As a result, their psychological health has deteriorated considerably, as evidenced by the interviews. The respondents felt that the impoverished are more stress-prone and this has an impact on other members of the household,

'When your family cannot afford to support you, your wife will show concern, followed by the rest of your family members. Financial trouble is everything. I believe there are multiple pressures. It is like a pressure cooker. Isn't it only a matter of time before we can't take it anymore?' [Kolkata Slum respondent]

'Yes! Quarrels... financial hardship... these make us unhealthy.' [Bangalore Slum respondent]

'Yes, just like my husband initiating quarrels and domestic violence. These are unhealthy indeed.'

[Kolkata Slum respondent]

The second inquiry focused on ways to overcome health issues and mental distress. When the needy are in danger, the healthcare system frequently provides a "*compassionate*" support system. However, respondents' experiences in the study slums revealed that having little resources to purchase preventative treatment and prompt access to medical services may contribute to the vicious loop between poverty and poor health. For example, numerous respondents with chronically ill patients at home agreed that the poor have fewer options for routine body checkups and preventive medical care due to budgetary constraints (in the private sector).

'We desire a body check but will abstain from action because a basic body check will cost us approximately a thousand rupees (in the private sector). And if we visit government hospitals (public sector), we will not be able to obtain equivalent body checks unless you bribe. As a result, disease prevention becomes increasingly challenging for us'.

[Bangalore Slum respondent]

The interview revealed that, as a result of a passive primary care system, the poor have fewer options, higher costs, transport expenses and longer wait times for outpatient care for non-acute or non-critical conditions.

Chapter 4

'If I don't have enough money, can I still receive medical treatment? It's a big question mark'.

# [Kolkata Slum respondent]

'Private hospitals are typically faster to operate, whereas government hospitals are slower. Due to the commercial motivation, a health-care system run by a commercial firm must operate at a significantly faster pace. Public healthcare is inefficient and time-consuming. Just so long as you don't die.' [Bangalore Slum respondent]

Nonetheless, respondents agreed that, if they are elderly or severely poor, they will obtain outpatient medical treatment in the public sector at a low cost that is fully subsidised by the government.

'Yes, we do receive a cash buffer." Being destitute doesn't mean you have to forego medical care'.

[Bangalore Slum respondent]

Even if a person qualifies for government-subsidized healthcare, this does not guarantee timely access to their medicines. Despite the government's support for a wide variety of drugs and therapies, several respondents reported difficulty obtaining more effective but more expensive prescriptions. As said by a respondent,

'Drugs provided by the government are almost certainly the least expensive to purchase. However, if I want to utilise a specific medication, I will have to purchase it myself because the government's prescription list does not include it.' [Bangalore Slum respondent]

# Socio-cultural environment

The findings, as indicated by the data analysis, show how culture influences the evaluation of disease and governs what people perceive as a need for aid, as well as what care options are preferred. According to the interviews and sub-themes, unequal distribution of social resources has an effect on or generates cultural institutions that define healthcare demands.

# Socio-spatial isolation and networks

In both study slums, social networks are influential in determining whether health care services are available in the neighbourhood. Kolkata slum's networks are resource-poor, consisting mostly on personal (village) networks which retain relationships with family members in the local region. Individuals lack access to healthcare resources due to their social network, which is small. Further, indigenous links provides a means to sustaining the traditional culture. As a result, many avoid

accessing modern health care facilities where they relocate. It has contributed to increased use of traditional health care and the search for low-effectiveness therapies. According to numerous interviews,

'For three generations, we have sought our kabiraaj moshai (traditional healer), and we have no desire to seek it elsewhere.' [Kolkata Slum respondent]

'We would prefer immediate access to baba (quack physicians and ancestral traditional healers) via many referrals available in the neighbourhood over doctors who require lengthy waits.'

[Kolkata Slum respondent]

'If I visit an allopathic doctor for every disease, my mother-in-law will consider it an affront to our traditional practises, so we prefer to visit community-based kabiraaj.' [Kolkata Slum respondent]

Additionally, because the social network is influenced by people in poverty, it perpetuates norms and behaviours that reduce the likelihood of escaping poverty, and thus the use of informal care, which is significantly less expensive, is a result of their limited options due to low income or instrumental support. As one respondent expressed it,

'I utilise allopathy only when my disease becomes worse; otherwise, I prefer homoeopathy, which is equally affordable and effective.' [Kolkata Slum respondent]

Another respondent stated,

'We received a great deal of indigenous knowledge from our forefathers about healing using indigenous and readily available techniques around the home, and we also learned not to visit doctors for minor ailments; rather, we should prevent disease through physical activity.' [Kolkata Slum respondent]

Respondents in Bangalore slum, on the other hand, extend their social connections through a resource-rich network that includes social ties outside the locality and across social strata, implying not only access to a broader range of resources, such as information about health care providers or health knowledge, but also practical assistance, such as financial aid for shopping, household maintenance, or resources required for caring of the children. According to one female respondent,

### Chapter 4

'the place where I work as a full-time housemaid covers my medical expenses on a general basis or frequently provides funds to purchase medications for my family's typical illnesses. They routinely pay for my daughter's school tuition and birthday clothes.'

## [Bangalore Slum respondent]

'My employer's husband is a doctor, so we go to him whenever anyone in our family is sick, and we don't have to pay anything.'

## [Bangalore Slum respondent]

'My sir assisted me in obtaining medical support through a certain medical programme, I was unaware of the programme, and even if I had known about it, I would not have taken advantage of it due to the often complex and frightening paperwork'.

## [Bangalore Slum respondent]

While another respondent, who works as a security guard for a private company, claimed,

'My colleague's brother, who works at a charity hospital, informed me that I could send my father there for a heart surgery for Rs.30,000, which would have cost me more than Rs.1 lac in any other hospital.'

### [Bangalore Slum respondent]

Resource-rich networks embed people with access to resources they don't have on their own, such as western medical facilities, giving them new opportunities to improve their socioeconomic standing.

'Having more social ties also raises the likelihood of having at least one tie that is available for support at a specific moment.' [Bangalore Slum respondent]

Bangalore slum's integrated social groups led to cultural heterogeneity, which resulted in a weakening of traditional norms and beliefs, and ultimately a greater utilisation and acceptance of western allopathic medical care. The majority of interviews concluded that:

'We adopt western medicine because it is easy to acquire from our friends, colleagues, or masters.' Whatever medical assistance we receive from various known sources, we primarily use them to facilitate access to western medicine. For example, we obtain medication from health care workers for treatments, we receive referrals for reduced-fee and effective treatment, and we frequently receive money or left-over medications for general ailments from our known ties'. [Bangalore Slum respondent]

# Culture patterning of coping strategies

According to the findings of spatial mismatch, the perceived need for healthcare originates from culture's importance in supporting varied coping mechanisms. In general, society accepts illness or avoids uncomfortable thoughts, feeling that reticence or avoidance is preferable rather than outward emotion.

'I am suffering from cancer', one respondent explained, 'and I feel I did something incredibly awful in my past lifetime, which is why God punished me.' [Kolkata Slum respondent]

'There is no point in nagging about minor problems like fever or stomach distress, or even major problems like leprosy, tuberculosis, or jaundice... These things will happen and they will happen frequently; regardless of how many times we can attend, it is best to leave this in God's hand.'

[Kolkata Slum respondent]

Religious and cultural influences were highlighted in Kolkata Slum, and members indicated in multiple interviews that they relied more on religious prayers for emotional and spiritual healing, particularly during illness.

'The Hindu faith and culture instil in their follower's self-control, emotional restraint, and social limitations.' [Kolkata Slum respondent]

Low-wage jobs or limited professional possibilities intensified religion's prominence as a necessary and effective coping technique in many respondents' lives.

'Religion, on the whole, provides us with a sense of self-satisfaction, contentment, and self-esteem, especially when no other kinds of fulfilment are available on a limited salary.'

[Kolkata Slum respondent]

Certain respondents believe that their suffering, sacrifice, and good deeds in this life will be rewarded more abundantly in the afterlife, and they typically adhere to their

religious beliefs in order to get the power and strength necessary to handle their illness (Gordon et al., 2002).

This demonstrates that a person's cultural background had a significant influence on how he or she perceived illness and chose coping techniques. Consistent with the preceding results, we discovered that women had unique experiences with illnesses and, as a result, developed coping mechanisms that were distinct from those of men. Women, for example, will often avoid telling family members about their health problems in order to avoid worrying them. As a result, they choose to ignore the issue and put off receiving treatment. One cultural aspect of gender is "*being a strong lady*", which entails a woman taking care of others and avoiding unpleasant circumstances with her family (avoiding letting others know about illness or other problems). Women recognised that this mode of coping was a source of stress that had a detrimental effect on their health.

When it comes to making sense of their subjective experience of disease, Bangalore Slum respondents rate confrontation as a more effective coping strategy. In terms of perceived clinical care needs, respondents place a greater emphasis on post-onset sickness experiences. On the other hand, for pre-onset sickness experiences, they place a greater emphasis on therapies that are passive in nature, such as informal healing, spiritual activities, self-care, and so on.

'I go to the clinic when I feel the disease is interfering with my daily income; I go to get treated promptly because I don't want to lose my job; surviving in a city without a job is difficult.'

# [Bangalore Slum respondent]

'I try to stay healthy by praying or taking herbal medications that protect me from mundane illness, but if any illness worsens and I feel it is interfering with my daily work, I seek doctors to get treated quickly, because I cannot stay away from work for an extended period of time or I will face financial hardship.' [Bangalore Slum respondent]

Access to a larger social network has been utilised as another positive reappraisal in order to generate new meanings for the illnesses and to face them with a positive attitude.

'we are not only convinced, but we have also experienced what Rajani akka (health worker) told us... by hiding or suppressing our illness, we are actually making the situation worse and ourselves vulnerable, rather sharing can help in solving problem...um...may not be by the immediate person, but he or she can tell ways how to deal with the situation'.

## [Bangalore Slum respondent]

According to the interviews, the active participation of other stakeholders such as health workers, social workers, and NGO members, particularly those who are being trained in the medical field, served as a bridge for establishing better communication between doctors and patients and for sensitising about various medical assistance and benefits provided by the government. These have had a favourable impact on the perceived need for health care.

'for simple health problems, we get free drugs, and for significant health problems (chronic sickness), we get advice or support from the centre (pointing to an NGO office) on how to receive medical support.'

[Bangalore Slum respondent]

Some respondents, on the other hand, have informed of infrequent resignations, with reasons given as failure to continue formal care owing to financial load, lack of effective results from formal care, stigma associated with formal care, lack of obvious progress from informal care, and so on. As a result, respondents may wind up attempting a number of techniques until they find one that "*works*" — that is, one that achieves the desired aim. Individuals coping with situational pressures have an impact on culture, offering a means of coping for those facing similar issues.

# Culture of low self-esteem

In both Kolkata and Bangalore Slum, perceived marginalisation resulted in stigma and low self-esteem, manifesting as fear of being inferior, concern, self-doubt, and mistrust. These features are viewed as a cultural reaction to their geographic and social marginalisation, which is perpetuated through social contagion, and are viewed as another trigger factor in defining the type of treatment they require. Doctors, for example, were portrayed as ignoring patients, shouting at them, and speaking derogatorily about them (giving a sense of inferiority and anxiety).

'I visited the hospital numerous times, and there were moments when I felt enraged and simply left the place since no one paid attention to me.' [Kolkata Slum respondent]

Numerous respondents believe that physicians assume their superiority and do not treat patients with compassion. Additionally, they indicated that staffs especially do

not treat them with respect, which is a source of contention for them. These attitudes were proven to influence people's decision to seek or not seek therapy depending on the circumstances. For example, quite a lot of respondents reported that if the problem were not so severe (as determined at the familial level), prior negative experiences would result in avoidance of clinical care or premature abandonment of therapy without obtaining necessary assistance. Whereas when respondents believe they have a significant health problem, they choose self-care or informal treatment above going to a doctor due to concerns about bad clinical professional attitudes and mentality. According to several respondents, their family members are fearful or cautious about seeking a diagnosis because they worry, they will be unable to obtain a doctor or essential therapy. Fear of being diagnosed with a life-altering illness also adds to a patient's unwillingness to seek treatment, as they believe that what occurs after the diagnosis is out of their control.

As a result, the attitude and judgement of healthcare professionals reflects a low sense of self-worth, encouraging people to believe in their vulnerable state of poverty, illiteracy, or impoverishment, and therefore in their worthlessness (self-doubt).

'There are also challenges where doctors perceive or regard us differently as a result of our poverty, our lack of education, or our lack of money, and this has an effect on things.'

[Bangalore Slum respondent]

'There's no escaping the fact that we are poor, we are not well-educated, and we're not as brilliant as the wealthy, so we will be ignored and unnoticed by everyone.' [Kolkata Slum respondent]

'Doctors only treat the wealthy because they have a connection, whether through rank, education, or money, and we have a connection with healers who understand us and our circumstances.'

# [Kolkata Slum respondent]

Kolkata slum respondents prefer informal and traditional healers because traditional healers, as family physicians, are better equipped to mitigate the effects of poverty on health by understanding each patient's unique challenges and coping mechanisms and by being aware of available community resources.

Additionally, hopelessness in receiving aid and a low perceived need for clinical care were observed. Family members are aware that they require assistance but lack the means to receive it, such as if they are uninsured. This despair pervades the

healthcare system, with many desiring improvements but remaining pessimistic about any reforms.

'Yes, I would like to, but I don't have a chance. I'm not feeling well. I'm not feeling OK. I'm not sure I have a chance.' [Kolkata Slum respondent]

The interviews found that the respondents lacked health literacy, as seen by their misunderstanding of their entitlements or rights as citizens, as well as their lack of understanding of how the health system worked and how to access it. General illiteracy is defined as the inability to read health information brochures, posters, or other similar objects frequently exhibited in healthcare settings, as well as prescription instructions. However, many respondents in Bangalore Slum claimed that they were aware of their entitlements and how the health system functioned as a result of word-of-mouth promotion by local NGO employees. Others were unaware of their rights due to a lack of interest in learning, not a lack of information.

'I'm not sure, one person stated. I didn't inquire because I wasn't interested.' [Bangalore Slum respondent]

# DISCUSSION

Drawing on Bourdieu's concepts of habitus and capital, the primary objective of this study was to analyse the relative importance of habitus as well as economic, cultural and social capital in terms of shaping the choice of necessity in healthcare needs and its utilization in the urban slums of India. The results suggest that all three forms of capital could help to predict health behaviours in the urban slum contexts; meanwhile, their effect sizes and directions seemed to be distinct, and some significant place-based disparities were also identified. These findings not only establish a direct link between contextual capital structure and health behaviours, but also provide new evidence to explain the issue of health inequalities through a Bourdieusian capital-based approach. Studies in the past emphasised the importance of place-based research that focuses on neighbourhood features, as well as the function of neighbourhood social and built environment elements in establishing the context in which health is determined (Yen et al., 2009).

The study found that the choice of necessity that stems from the habitus or the built environment was one of the most influential determinants of health behaviour. Our findings indicate that the urgency of needs and the visibility of the outcomes related to fixing the problems associated with the inadequate physical environment influenced the respondents' perceptions of priority setting in both study slums. Because of the inevitable and perpetual struggling with infrastructure majority

of respondents chose to discuss the daily issues they experience as their priority and plays a pivotal role in delaying seeking treatment for their health problems or even acknowledging them. The forced choice creates a form of adaptation to, and consequently acceptance of, the necessary produced by the conditions of existence. As a result, a need to invest in an imagined health may feel inapplicable and even absurd which therefore has become the general understanding in terms of their health behaviours. Between Kolkata Slums and Bangalore Slums, more granular differences in experiencing the built environment's quality, such as housing, hygiene and sanitation, water quality and accessibility, solid waste management, and its exposure to health-damaging mechanisms, were depicted, which influenced their health-related behaviours. When it came to discussing how the physical environment affected slum dwellers' perceived need for or consumption of health care, none of them addressed the subject explicitly. Rather than that, they concentrated on the impact of the deteriorating environment on their overall health. Surprisingly, despite the fact that their environment is degrading and negatively affecting their health, they do not view preventative healthcare actions as vital. Rather than that, they emphasise the burdensome influence that their local surroundings have on their health on a daily basis. It is also a problem that there is a significant shortage of affordable housing in slums. It limits housing options for families and people, frequently relegating lower-income families to substandard housing in hazardous, overcrowded neighbourhoods with higher rates of poverty and fewer health-promotion amenities. The lack of affordable housing, as demonstrated in the Bangalore Slums, impairs families' ability to meet other vital expenses, putting many individuals in financial trouble. According to a study by Cunningham et.al (2008), low-income individuals who struggle to pay their rent, mortgages, or utility bills are less likely to have access to routine medical care and are more likely to delay treatment until an emergency occurs. It has been demonstrated that they are aware of how their inferior surroundings affect their physiological and cognitive well-being. Although they did not mention how their local environment influences their healthcare utilisation choices, it is obvious from the interviews that they are aware of and preserve good health in the face of unfavourable conditions that are not conducive to health promotion or maintenance. And this is evidenced by their preventative water treatment and storage practices. Despite their efforts, the environmental impact is so severe that factors such as a lack of adequate hygiene, sanitation, and solid waste management expose them to a variety of dangerous diseases and social ills, such as parasitic infections, stomach ailments, urine infections, skin allergies, and uncontrollable sexual violence. It is a never-ending war, not only with the environment, but also with one's own well-being. Additionally, the foul scent emanating from dumping grounds and sewage polluting the air creates a hazardous environment that is unsafe to breathe, making it impossible to live a healthy life. Thus, from their view, these are the most pressing needs that require urgent attention, and coping with them on a daily basis precludes them from thinking independently about healthcare. As a result, healthcare is ranked as the least important perceived necessity. According to the interviews, slum dwellers do not see diseases in isolation from environmental problems. As a result, it is not considered prudent to seek clinical therapy for every condition. This was reinforced when respondents were asked why health care utilisation was regarded as the least perceived, to which they gave no concrete or definitive answers, instead expressing fear, anxiety if some hidden illness is discovered or until their body is functional, ill treatment from doctors, disbelief in doctor's prescription, and so on. It has been discovered that they avoid seeking clinical care until their threshold of endurance or resilience, because dealing with these everyday physical problems is so taxing that going to a clinic is considered an extravagance. This has been demonstrated in studies where respondents indicate that seeing doctors is a waste of money and results in undesirable behaviour (Taber & Persoskie, 2015).

Besides, three forms of capital had different patterns of influence on perceived healthcare need and their notion of choice in seeing care. More precisely, economic capital increased the odds of seeking care, social capital partially did the opposite while cultural capital draws on social ideas, religious beliefs, situated experiences and specific world views which are utilized in the daily life as coping strategies to health practices. The findings indicate that respondents understand why they are ill or poor and frequently have suggestions on how to improve their situation. They express their appreciation for excellent health. As previously stated, a low degree of economic capital constrains the resources available for risk avoidance and healthy behaviour. According to respondents, poverty affects health by limiting access to proper nutrition and healthful foods; shelter; safe communities in which to learn, live, and work; clean air and water; and utilities. The exorbitant cost of health care is frequently discussed. According to respondents, these costs can be catastrophic when paired with income loss during illness. Additionally, respondents emphasise the critical nature of health care services to their existence and livelihood. However, the importance that the poor place on health services is masked by widespread disappointment - and in some cases outrage - about service quality and access to care. These issues include the direct expense of physicians' fees, medications, and bribes, as well as the indirect cost of transportation to health care facilities and time spent waiting for treatment. Abusive treatment by staff serves as an additional deterrent to obtaining assistance.

Both study slums use social networks to determine perceived healthcare needs and to endorse which type of therapy to seek. According to a previous study, treating a sick individual is an act connected to the jointly produced and maintained systems of life. After identifying the causes of illness and assessing the consequences, the entire family or community is involved in the financial decisions that result

in therapy (Clayman et al., 2017). The primary difference is that Kolkata Slums are served by a resource-scarce network, whereas Bangalore Slums are served by a resource-dense network. In low-income communities, social determinants of health such as social support, social networks, and social capital may either enhance or exacerbate health outcomes (Matthews & Besemer, 2015). In particular positive effect of neighbourhood social capital is exhibited in Bangalore slums with neighbourhood cohesion, heterogeneous and resource rich social networks. Hence, they were more likely to be active in seeking healthcare. The possible explanation is that heterogeneous social networks facilitate dissemination of information more broadly to produce the knowledge needed, not just about health conditions and diseases, but about the healthcare system itself. In accordance with the findings of the study, Bangalore slums had more bridging social capital than closed networks, which allowed them to have access to a broader range of support and resources for seeking medical attention. Bangalore Slums depends on social network members for a variety of health-related information, ranging from hospital/healthcare provider recommendations and reviews to specific medical difficulties. Previous research has discovered that individuals who have significant access to social support via social networks tend to have a greater ability to obtain innovative and relevant health information and to support healthy behavioural standards than individuals who do not have such access (Uchino, 2006). On the other hand, the findings also exhibited that Kolkata slums neighbourhood with resource poor social capital are like an acquaintance society where the slum residents tend to own more bonding social capital and be more familiar with people living in the same village. The social fabric of the Kolkata Slums is mostly composed of family members, neighbours, and ties who promote and connect residents with traditional healers. According to earlier studies, using personal social networks to solicit replies or connect with a socially mediated healthcare practitioner can be a rapid and painless process (Kim & Kreps, 2014; Cohen 2004). Thus, behavioural norms aligning to conventional village norms are more easily identified within the informal social networks which further influenced residents' behavioural decisions. Consequently, restricted intragroup norms or knowledge of health care resources were observed not conducive to access in this study as opposed to findings from other studies (Lin, 2019). For Kolkata slums, poverty imposes not only material costs, but also deep social costs. Despite their efforts to optimise their resources, the data indicates that they are experiencing a gradual contraction in their social and economic horizons. As a result, as previously demonstrated in other studies (Das et al., 2020), Kolkata Slums respondents commonly consult traditional healers who are connected with their traditional culture and meet their culturally mediated emotional expectations. Additionally, as found in earlier studies, remaining loyal to traditional healthcare is connected to more structural and normative limitations than other social bonds, resulting in patients becoming less malleable and changeable (Blieszner, 2014). As a result, individuals may be unaware of the proper methods for accessing and

utilising accessible materials. These findings corroborate those of previous research undertaken in developed (Williams et al., 2011) and underdeveloped countries (McLaughlin et al., 2012).

Cultural capital is instilled more in terms of practising a range of coping strategies to manage healthcare exclusion (attitude of avoidance, low self-esteem and feeling of resignation) and negotiate care in alternative healthcare spaces like traditional and spiritual healing, community clinics and home-based self-medication. As demonstrated, respondents in both slums resisted sickness and healthcare use through the application of culturally mediated coping strategies. The slum is a religious and supernatural mechanism, entwined with the perception of a need for healthcare. Certain chronic and common illnesses are viewed as normal occurrences in the Kolkata Slums and are commonly associated with religion as a means of escaping, denying, or avoiding their predicament. According to a previous study, the 'moral underpinning of society' is the widely accepted value system, which is still shaped by religion in the majority of emerging countries (Wilber & Jameson 1980). This had a detrimental effect on their perceived need for healthcare. A previous study indicated that for minority groups, the poor, and the uneducated, religion functions as a substitute for resources such as money and healthcare. Additionally, the study discovered that normative expectations as main caregivers are culturally mediated and that people resort to religion to avoid primary and secondary care due to poverty, which hinders individuals from obtaining health care for themselves. As seen in the Bangalore Slums, the stronger one's sense of severity and related causes, the more likely one is to receive official health treatment. As stated earlier, if a disease immediately impacts the quality of their daily life, they choose treatments that are quick solutions, which may otherwise lead to the fear of losing a job due to long-term absences (due to sickness lingering with passive therapy). Also, because of its inability to cover illness-related costs on its own, the Bangalore Slums were compelled to resort to alternate techniques to acquire access to current medical care. These solutions are founded on networks of mutual support and solidarity. Solidarity networks and mutual assistance develop as a result of social capital, which occurs at the micro-social level between individuals, groups of individuals, and communities, rather than at the macro-social level between the state and the citizens (Collier & Gunning 1999). Only Bangalore Slums' social capital had a significant effect on the ability to benefit from much-needed health treatments (Peters et al., 2008). Another goal of the welfare state envisaged for Bangalore Slums was to encourage community accountability systems, which led to more appropriate use of facility-based healthcare services, especially for the poor and most vulnerable. This suggests that the very poor have more relevant networks that can be leveraged to overcome barriers to healthcare utilisation, demonstrating the context-specific nature of social capital.

Finally, the study identified through interviews with a large number of Kolkata Slums and Bangalore Slums respondents that they had a predetermined negative attitude (mistrust) toward clinical healthcare services and staff, which discourages family members from seeking formal care because they believe only substandard care is available. The increased use of complementary and alternative health care is associated with an increase in prejudice perception. Furthermore, as previously stated, cognitive and psychological barriers have a significant impact on whether individuals seek treatment, where they seek treatment (clinical or informal care), and the pathways they take to acquire treatment. As a result, considering the connotation of three capitals, the current study argue that healthcare needs and its uses is not only a personal choice, but an outcome of the socialization process by which durable behavioural norms are gradually embodied in the habitus of agents (Doblyte, 2019).

This study has a number of limitations that should be mentioned. Because the two cities were purposely chosen for the study based on their distinct characteristics, it is possible that some phenomena unique to other parts of India were overlooked, and hence the findings cannot be considered exhaustive. A key study bias is a lack of information about the viewpoints of healthcare professionals, which makes it difficult to quantify the relative impact of various barriers to providing care to slum residents. Due to the respondents being drawn from a single core-periphery site, slum dwellers from other core-periphery sites within the same studied city may not encounter the same set of neighbourhood characteristics and influences that may affect their health care utilisation demand and pattern. Finally, a gender perspective on barriers and enablers may reveal a plethora of data, and it is likely that women's perspectives were not thoroughly explored. We did, however, ask questions about men's and women's perceptions of gender differences in use. This has proven to be highly beneficial in our findings, as healthcare consumption at the family and community levels affects both men and women.

# CONCLUSION

For many years, research on the determinants of health habits focused on microlevel variables. Recently, public health experts have placed a greater emphasis on the larger sociocultural context in which health behaviours occur (Mohnen et al., 2012; Katikireddi 2013). The current study reaffirms the necessity of using Bourdieu's capital-based method to explain health behaviour discrepancies. The findings imply that ownership of economic, cultural, and social capital in a specific habitus might have an effect on individuals' health behaviours, which is interpreted as the choice of necessity. The habitus or built environment's choice of necessity was one of the most powerful drivers of perceived need and subsequent health behaviour. Following that, social capital was another significant predictor that significantly aided or inhibited the use of health care providers, depending on the attitudes of the networks that constructed the perceived need for healthcare. Slum neighbourhoods with diverse or resource-rich social networks enhance the diffusion of information more broadly, but resource-poor neighbourhoods with restricted intra-group norms or knowledge of health care services were not conducive to access. Economic capital is also a significant predictor of healthcare utilisation and need, as well as its avoidance. Even when respondents were aware of their illnesses and poverty and often had solutions in mind, they were limited in their ability to use resources to reduce risk and create healthy behaviours because of their lack of economic capital. Cultural capital is strongly connected with adaptive methods to deal with healthcare exclusion (avoidance, low self-esteem, and resignation) and negotiating care in alternative healthcare settings such as traditional and spiritual healing, community clinics, and self-medication at home. The above findings would help researchers and policymakers improve the effectiveness of community health promotion programmes by better interpreting a range of neighbourhood characteristics that characterise the complexity of community environments. The inability to find pathways for, or evaluate the relative relevance of, neighbourhoodlevel determinants of health outcomes is hampered by the lack to integrate neighbourhood characteristics.

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Habitus and capital determining perceived healthcare needs and use in India's urban slums



# **CHAPTER 5**

The Gendered Experience with Respect to Health-seeking Behaviour in an Urban Slum of Kolkata, India

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# ABSTRACT

#### Background

Empirical evidence shows that the relationship between health-seeking behaviour and diverse gender elements, such as gendered social status, social control, ideology, gender process, marital status and procreative status, changes across settings. Given the high relevance of social settings, this paper intends to explore how gender elements interact with health-seeking practices among men and women residing in an Indian urban slum, in consideration of the unique socio-cultural context that characterises India's slums.

#### Methods

The study was conducted in Sahid Smriti Colony, a peri-urban slum of Kolkata, India. The referral technique was used for selecting participants, as people in the study area were not very comfortable in discussing their health issues and health-seeking behaviours. The final sample included 66 participants, 34 men and 32 women. Data was collected through individual face-to-face in-depth interviews with a semistructured questionnaire.

#### Results

The data analysis shows six categories of reasons underlying women's preferences for informal healers, which are presented in the form of the following themes: cultural competency of care, easy communication, gender-induced affordability, avoidance of social stigma and labelling, living with the burden of cultural expectations and geographical and cognitive distance of formal health care.

#### Conclusion

Our results suggest that both men and women utilise formal and informal care, but with different motives and expectations, leading to contrasting health-seeking outcomes. These gender-induced contrasts relate to a preference for socio-cultural (women) versus technological (men) therapies and long (women) versus fast (men) treatment, and are linked to their different societal and familial roles. The role of women in following and maintaining socio-cultural norms leads them to focus on care that involves long discussions mixed with socio-cultural traits that help avoid economic and social sanctions, while the role of men as bread earners requires them to look for care that ensures a fast and complete recovery so as to avoid financial pressures.

**Keywords:** formal care; gender; health care; informal care; health-seeking behaviour; urban slums

### INTRODUCTION

Past studies have shown that gender and health are related in many different ways (Verbrugge, 1985; Baum & Grunberg, 1991; Culbertson, 1997). This is also the case when comparing the health-seeking inclination of men and women. In fact, gender relations, gendered notions in terms of health, cultural notions regarding how male bodies function differently than female bodies and gendered differences in access to health care have all been shown to shape differences in the health-seeking behaviour of men and women in many complex ways (Courtenay, 2000). Moreover, studies from across the globe show that gender differences with regard to health-seeking behaviour are not only influenced by factors such as power relations (Hindin, 2000), structural positions and age hierarchies (Doan & Bisharat, 1990), culturally-prescribed gender roles (Borooah, 2004) or economic factors apart from cultural context (Sen & Sengupta, 1983), but also illustrate that the way in which gender and health-seeking are inter-linked is unique for each setting (Whitzman, 2006), including slum areas (Shaikh & Hatcher, 2005).

Despite the presence of abundant studies on gender differences in health-seeking behaviour, it would be appropriate to explore these relationships in the context of different cultural settings, given the significant relevance of the socio-cultural context underlying varying health-seeking behaviours. By consequence, the present study investigates how health-seeking behaviour is influenced by gender interactions in slum areas. Urban slums in India differ from other communities because of their complex socio-cultural structure, due to cultural heterogeneity and acculturation (Martinez & Lee, 2000). Being migrants, the lifestyle of the people itself changes a lot once they step into the slums, requiring them to make adjustments at every stage and compromise with every situation, resulting into the emergence of an acculturation in perception, attitude and psychological behaviour different from their native place. The impact of religious and cultural plurality compels the people to improvise their values, morals and attitudes. They adopt an attitude that is a mixture of both modernity and traditionalism (Mechanic, 1973). Many of the folk practices characteristic of urban slums is functional in coping with the disoriented and disorganised social conditions of industrialisation and urbanisation. Previous studies have shown that the health of slum populations is much worse than in other urban areas (Mberu et al., 2016). Also, the public health impacts of health problems in slum areas are immense. As health and illness are identified, defined and categorised by culture based on people's socio-cultural contexts and prior experiences, therefore, in order to discern the true nature of health and illness of the slum dwellers there is a need to understand from their perspective the mechanisms through which culture govern the decisions about recognising and evaluations of treatment. The contextual nature of gendered health-seeking practices like approaching other healthcare resources available in a given area also stems out simultaneously (Yesudian, 1999).

Understanding gender differences in respect of therapeutic choices in the slum context is crucial to developing appropriate policies to promote and provide suitable treatment sources for women's and men's requirements and thereby ensure a better utilisation of health care facilities.

### LITERATURE REVIEW

Several publications in the area of gender and health have established that gender differences exist with respect to decision-making regarding the appropriate type of treatment. Some studies have found, for example, that women in developing countries utilise formal health care to a lesser extent than men (Al-Krenawi & Graham, 1999) and instead are more inclined towards traditional healing options (Vlassoff, 2007). According to Harrison and colleague (Harrison et al., 1992), the gender socialisation process, which is in itself shaped by the socio-cultural ethos, also tends to impact health-related notions and habits, including decisions regarding when and where to seek help.

Gender also leads to differences when it comes to symptoms of illness expressed, social support mobilised thereafter and the socio-cultural ethos that tends to impact access to appropriate treatment and care. Studies examining gender differences in the experience and expression of symptoms propose that women not only ask for increased social support compared to men, but also report significantly higher rates of distress (Kawachi & Berkman, 2001; Tenenbaum et al., 2017). This may be partly explained by the fact that in certain societies social interactions and the exhibition of communal behaviour are considered as part of the feminine role, while the masculine role involves independency and giving prime focus towards familial responsibilities rather than looking into community needs (Carli, 2001). In contrast, Macintyre et al. (1993) consider that men are more willing to report and seek help for common cold complaints than women. They claim that such health-seeking behaviour emerges because illness among men is not easily acknowledged by professionals and that a clinical score based on a highly objective set of criteria, like quantity of nasal secretion, nature of swollen glands and so forth, is required to make their illness eligible for treatment.

Gender relations not only influence decisions regarding the expression of symptoms or distress and treatment, but also tend to create other societal obstacles in accessing health care for women. Vlassof (1994) shows, for instance, that women's inferior status in family and society restricts their access to health care, decision-making, education and economic resources. As a result, women remain uninformed about health issues, fail to acknowledge illness or depend on older family members or men for receiving health care. This is more visible in countries where such structural constraints do not permit women to pay attention to or to seek health care services for their illnesses (Malhotra et al., 1995).

Finally, gender differences may influence actual access to health care, including treatment. Although accepting sickness and getting treatment are more socially acceptable among women, they cannot easily avail themselves of treatment for an illness that is equated with social consequences. A study (Beckman & Amaro, 1986) involving Caucasian men and women shows that women seeking treatment for alcohol addiction face greater social resistance than men. Besides, they are more likely to meet with opposition and a social penalty from family and friends for seeking general health care compared to men, who rarely face such opposition.

The above literature review suggests that gender and health-seeking behaviour can be linked in both direct and indirect ways. The way in which gender shapes health-seeking and access to health can, depending on the social and cultural context, work out positively as well as negatively for either gender. Studies on gender differences in health-seeking suggest that the situation in India is no different. In the Indian context, gender interactions and their inter-linkages affecting therapeutic behaviours in different rural settings have been explored intensively. For instance, studies examining health-seeking patterns across gender in the rural Indian states of Uttar Pradesh, Pune and West Bengal find that due to traditional gender preferences, cheaper public care providers are sought by households for girls, while for boys private qualified providers are consulted, more money is spent and greater distances are travelled, if necessary (Ganatra & Hirve, 1994; Willis et al., 2009; Pandey et al., 2002).

A few quantitative studies report gender differences in health-seeking behaviour in Indian urban slums (Willis et al., 2009; Sundar & Sharma, 2002). However, qualitative accounts of the complex gender relations affecting therapeutic choices behaviour are still missing. An in-depth understanding of the reasons underpinning gender differences is required, considering the different ways in which gender and healthseeking have been shown to be directly and indirectly related, and considering the contextual and cultural nature of these relationships. This qualitative study in line with emic perspective will enable to understand in-depth the combined influence of socio-cultural context, respondents' perceptions and self-constructed meanings (Garcia, 1992; Godina & McCoy, 2002; Saville-Troikr, 1989; Patton et al., 2017) behind their behavioural patterns in healthcare utilization. Moreover, the unique sociocultural context of India's slums characterised by heterogeneous and dynamic populations (Gupta & Mitra, 2002), can be expected to considerably differ from other (Indian) settings. While placing the social context at the forefront of the gender and health-care agenda, this study aims to provide fresh insights into gender differences

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in health-seeking behaviour in the Sahid Smriti Colony, an urban slum in Kolkata, India. The key questions addressed in this study are:

- 1. Do gender preferences exist in making choices among the different available therapies in India's urban slum settings?
- 2. If yes, what kinds of therapies are used by men and women in slum areas?
- 3. How do complex gender interactions function in slum settings and influence the therapeutic behaviour of men and women?

### METHODS

#### **Study Site**

An exploratory study was conducted on slum dwellers in Kolkata during August -September 2012. According to the Kolkata Municipal Corporation (KMC), out of a total of 141 municipal wards, slums are spread in 138 wards. Out of these slums, Sahid Smriti Colony, situated at Baghajatin, under Kolkata Municipal Corporation (KMC) jurisdiction was selected. There were two reasons for selecting the Sahid Smriti Colony slum. Firstly, it is a peri-urban slum located on the south-eastern outskirts of the city. Being in a process of acculturation, a glimpse of both traditional and modern ways of life can be witnessed in a peri-urban slum (Banerjee et al., 2009). Secondly, such a transition is also witnessed in health practices. In Sahid Smriti slum, both folk and alternative healing practices exist and are utilised alongside formal health care. This slum was selected to see how complex gender interactions function within this setting in establishing preferences among these two domains of therapy.

#### **Participant Recruitment**

The participants consisted of 34 men and 32 women living in the study slum. The characteristics of the 66 study participants are shown in table 1. Given the linguistic, religious and cultural heterogeneity, an extensive sample was selected based on the following criteria: (1) belong to any of the three major religious groups predominant in the study slum, namely Hindu, Muslim and Christian; (2) over 16 years of age and limited to adults; (3) are native speakers of the Bengali language; (4) can clearly recall their experiences with regard to the causes, nature of treatment and provider sought; (5) consent to re- interviews, if and when necessary, during the study period; and (6) have been resident within the study slum for at least five years (people residing less than five years were mostly refugees). The sample size was decided following Daniel Bertaux's (Bertaux, 1981) concept of 'theoretical saturation', which states that data saturation in a qualitative study typically occurs by the time 12 interviews have been analysed. Additional new patterns emerge rarely after that, as 12 individual interviews are enough to include 88-92% of information (Guest et al., 2006). Based on this recommendation in relation to the saturation threshold, the present study was based on an initial selection of 12 men and 12 women each from three religious groups in the study area, with a total of 72 participants. However, men and women could not be selected on an equal basis because of absenteeism or unwillingness to participate or refer to anyone. A total of 66 participants, i.e. 34 men and 32 women, agreed to participate. Mostly, after the eighth interview (of each man and each woman in the three religious' groups) no new shared themes were generated from the interviews. Therefore, it was deemed that the data collection had reached a saturation point based on the data saturation model (Sandelowski, 2008; Saunders et al., 2018). Four more interviews for data collection with Hindu and Muslim religious groups and two more interviews with Christian male participants<sup>17</sup> were carried out to ensure and confirm that no new themes emerged, but only instances of the same themes (Francis et al., 2010; Legard et al., 2003; Jassim & Whitford, 2014). The snowballing technique was used to select participants, as everyone in the study area was not comfortable in discussing health-seeking behaviour freely (Biernacki & Waldorf, 1981). Initially, an ex-municipal medical officer (personally known to the first author) was approached because of his good contacts with some health workers residing in the study slum. Sampling was therefore facilitated through one of these female health workers, using her knowledge about the slum dwellers. She introduced the first researcher to two women and three men. These initial five participants were asked to recruit participants of their own gender who not only met the inclusion criteria, but also were willing to discuss freely issues associated with treatment choices.

<sup>17</sup> Only 24 households in the study area belong to the Christian religious group, out of which 18 households including men and women could be interviewed. Of the remaining six households, four were not ready for the interview and two were found closed during the study period. As a result, follow-up interviews with Christian female participants could not be carried out due to the scarcity of participants.

#### **Table 1:** Socio-demographic profile of participants in the study slum

Particulars	Sahid Smriti Colony slum (n=66)		
	Male (n=34)	Female (n=32)	
Age groups			
16-30	10	17	
31-45	19	11	
46 and above	5	4	
Marital status			
Married	25	26	
Unmarried	8	3	
Widow	0	2	
Widower	1	0	
Separated	0	1	
Educational status			
Illiterate	9	12	
Literate	25	20	
Origin of the population			
Rural Kolkata	24	27	
Within Kolkata	5	2	
Bangladesh	5	3	
Social groups			
General	10	7	
Scheduled Castes (SCs)	21	19	
Scheduled Tribes (STs)	3	6	
Religion			
Hindu	12	12	
Muslim	12	12	
Christian	10	8	
Employment status			
Fullemployed	16	1	
Contractual	11	0	
Unemployed	7	31	

Source: Based on data collected in the earlier phase of the field study

#### **Data Collection**

In-depth face-to-face interviews were conducted with the participants by using a semi-structured interview guide with probing questions to keep the participants on track and also allow them to structure the interview by themselves, so as to bring forth the issues that were important to them. The questions were open-ended, so that the interviewer could probe more on particular concepts of interest to the study. The interviews focused on exploring different health choices influenced by gender in terms of the range of therapies utilised, factors influencing health-seeking decisions and the process of evaluating the efficacy of treatment from a gender viewpoint. Each face-to-face interview was conducted in a private room either in the participant's house or in the workplace. At the moment of data saturation (that is, when no new data emerged and the existing literature did not add any new information), the data collection was ended. Interviews were later transcribed and translated into English. The interview guide was first created and piloted in English. After revisions and further piloting, the research team then translated the interview into Bengali. The translation was contextual rather than literal, meaning that questions were translated to relay the best meaning in colloquial spoken Bengali. Following a round of piloting with the Bengali interview guide, the questions were then back-translated into English to maintain consistency of meaning between the two versions. After conducting five pilot interviews in Bengali, the questions were further refined and finalised to best convey the essence of the questions. Each interview lasted around 45 to 60 minutes. All interviews were audio recorded, transcribed and translated into English. Since the field data was collected by the main researcher, a woman, this favoured openness of female respondents, who are traditionally more reserved. However, it may have introduced a bias in gathering the male perspectives and therefore adds a limitation to the study.

#### **Data Analysis**

The in-depth interviews that were first audiotaped were later on written down word for word. Prior to that, the recordings were listened to several times to ensure the accuracy of the transcription. The transcribed data was then read and re-read several times. The transcripts were translated from Bengali into English. Professional help was sought out to examine the translations of the original text. Some corrections were made and inconsistency was avoided. Our analysis used descriptive codes to generate thematic concepts (Braun & Clarke, 2006). The interviews with female participants were coded separately from the interviews with male participants. This approach was chosen to inductively grasp the difference between male and female experiences, in line with the aim of the study to investigate the 'gendered experience' of health-seeking behaviour.

The first author conducted the initial thematic analysis under the supervision of a sociologist (local facilitator) with extensive qualitative methods expertise. Briefly,

the thematic analysis includes several phases: familiarise yourself with your data (team), generate initial codes (first author), search for themes (team), review themes (team), define and name themes (first and second author) and produce the report (team). The initial codes were framed by constantly moving back and forward between the entire dataset. These codes identified features of the data that the first author considered pertinent to the research question. After identifying a list of codes, these were sorted into potential sub-themes by combining different codes. Sub-themes were constantly compared and refined further, bearing in mind the aim of the study. The final themes were defined by focusing the analysis on a broader level and refined again. The real meaning of what each theme dealt with was captured and a satisfactory final thematic chart was developed by making clear and identifiable distinctions between the themes. The final phase consisted of developing a set of fully worked-out themes and writing the report. The reliability of the final themes was confirmed by choosing examples from the transcript to verify whether they illustrated elements of the themes. Issues within the themes could be clearly identified when compared with these extracts and thereby presented a coherent account of the point being made.

#### **Ethical Considerations**

Because of the non-clinical and non-invasive nature of the study, this research has thoroughly followed the ethical guidelines framed by the National Committee for Ethics in Social Science Research in Health (NCESSRH)<sup>18,19</sup> (Shah et al., 2000; Risenga et al., 2013; Jesani & Barai, 2000). In line with these guidelines, oral consent to participate was obtained from all the participants, after the purpose of the study had been explained, and anonymity and confidentiality were assured. It was specifically explained that comments would not be attributed to a named individual without permission. Written consent was not sought in order to favour an atmosphere of trust, intimacy, and informality, which was believed to create the necessary conditions for the respondents to feel at ease and respond openly and truthfully. The Institute for Social and Economic Change (ISEC) in Bangalore, India, endorsed the project and functioned as a partner institution on site. The ISEC's Ethics Committee formally examined the study protocol and provided ethical approval.

### RESULTS

We categorised health care facilities into two broad groups: informal and formal care. The former refers to medically unlicensed practitioners (Rahman, 2007) and the latter to medically registered (Kleinman, 1980) and government-licensed alternative

<sup>18</sup> http://www.cehat.org/go/uploads/EthicalGuidelines/ethicalguidelines.pdf

<sup>19</sup> http://www.anusandhantrust.org/centres/Ethics\_in\_health\_research\_-\_A\_social\_ science\_perspective.pdf

medicine practitioners. Table 2 presents a summary of the different types of health care practitioners under informal and formal care. Table 3 shows the pattern of informal and formal health care usage by male and female participants.

Informal care	Description	Formal care	Description
Herbalists	Unlicensed traditional medicine men skilled in dispensing herbal medicines	Medical doctors	Qualified allopath with a medical license
Fortune tellers	Illegal practitioners involved in the practice of predicting and giving spiritual explanations about a person's life	Para- professionals	Medical assistants with a three-year medical training
Shamans	Illegal practitioners involved in healing through magico- religious means	Homoeo- paths	Recognised as one of its national systems of medicine by the Indian government
Ritual experts	Priests of the local temple who perform chanting for the well-being of individuals and are not legitimised in the health care system		
Unlicensed drug dealers & drug stores	Drug sellers who do not hold the registration certificate of a pharmacist (d.pharm) and usually dispense medicines without a doctor's prescription		

**Table 2:** Types of health care practitioners in Sahid Smriti Colony

Source: Based on data collected in the earlier phase of the field study

Therapies	Men N=34 (%)	Women N=32 (%)
Formal	12 (35)	0
Informal	7 (21)	15 (47)
Partial use of institutions (formal + infor- mal)	0	10 (31)
Have not used	15 (44)	7 (22)

Source: Author's calculation based on data collected in the earlier phase of the field study

#### Women's Perceptions Regarding Informal and Formal Health Services

#### Cultural Competency of Care

The way in which different health care practitioners offer their services determines women's health-seeking behaviour. Formal practitioners focus only on treating the biological symptoms of illnesses without considering the associated socio-cultural issues. Most of the female participants refer to marital insecurity, financial hardship and exclusion from social festivals, family and the community as (potential) consequences of seeking professional health care without any justifiable causes. Scared as they are of social sanctions, women initially seek informal types of care that are more socio-culturally acceptable in case of any illness. Informal healers are generally competent in dealing with the financial and socio-cultural hassles (besides illnesses) that women experience when they seek treatment, thus securing their position both in the family and society. As a female participant said:

'No matter what happens [illness], I consult him first. When I do this, two things happen: firstly, I receive treatment, and secondly and most importantly, I can avoid various obstructions [socio-cultural] that we women generally face.' [user of herbalist, ritual experts and shamans]

Female participants report that only if care in the informal domain fails to show any positive results and creates a life-threatening situation (which is considered a substantive cause) are they allowed to seek formal care, irrespective of its cultural insensitivity. As a woman said:

'Western medicines act well upon us even when the illness is in its last stage.' [user of para-professionals, homoeopathy and herbalist]

Lastly, it is observed that social-cultural norms also have a strong impact on women in terms of influencing their health beliefs and habits. This is quite evident in that women do not entirely stop consulting informal healers, even while they seek formal health care. As a woman stated:

'I will not leave them (informal healers) even when I am using Western medicine. My mother taught me to always respect them.' [user of herbalist, fortune tellers, ritual experts, homoeopathy]

#### Easy Communication

Female participants always tend to look for a treatment that makes them feel comfortable and satisfied during therapeutic interactions. Informal healers sometimes happen to be distant kin of female participants and their families with the same socio-economic status, so they are closely associated. A woman said:

'They belong to ekisampradaya [same class and caste]... we can readily relate to them.'

#### [user of herbalist, ritual experts and shamans]

As a result, women find communication a mutually comfortable process, in which they feel at ease while sharing their health-related experiences. As a woman said:

'They take long hours to discuss in detail and clear our doubts about the cause and nature of the illness.'

#### [user of herbalist, ritual experts, fortune teller and shamans]

Besides healers, informal practitioners are generally good counsellors. Being usually old and wise, they help women escape pressures caused by family or marital disputes. According to a woman:

'Whenever problems arise in my family, I first think of him for getting consoled. I know he is there to resolve the tension.' [user of ritual experts and shamans]

By contrast, women usually avoid approaching formal practitioners because of the absence of smooth and clear interactions caused by the professional and unfriendly behaviour of doctors. As one woman said:

'Their facial expressions are so cold and confusing; we wonder whether they have really understood our problems.'

[strong believer and user of herbalist, ritual experts, shamans and occasional visitor of medical doctors]

Several women feel unhappy when the nature of their illness is not explained to them in a simple way. Doctors instead use medical terms to explain things, which makes it quite difficult for them to understand. One woman commented:

'I feel very annoyed because although he [doctor] can easily and in a simple way explain things in our language, he unnecessarily uses all those English words and deliberately confuses us to see the fun.'

[user of herbalist and ritual experts and visitor of para-professional for illnesses that fail to get cured by informal healing]

Naturally, women feel discouraged to seek medical help from formal practitioners, considering it as an unfamiliar therapy. Some women have a strong feeling that doctors express 'disgust' when the patients' family speaks for her. One woman

describes how the clinical doctors react when her husband speaks on her behalf during interactions:

'They will give an annoying look if my husband wants to explain things as if it is not his business to interfere.'

[user of herbalist, ritual experts and fortune tellers, usually avoids medical doctors unless illness becomes extremely serious]

Moreover, women generally feel that during the patient-doctor interactions family members are more proficient in speaking on their behalf. This is because they think their preconceived notion about clinical care as strange therapy prevents them from discussing health problems freely.

#### Gender-Induced Affordability

The lack of independent financial means often indicates the starting point for women when considering what type of treatment to seek. Most of our female participants did not earn their own incomes and as such, lacked the financial autonomy and decision-making power when it comes to seeking formal care. Men are the main providers of money for women and, therefore, make all the health care-related decisions for them. However, it is to be noted that men's decisions are often not in line with women's preferences. Women discussed several difficulties they faced with men because of dependence on them while trying to seek formal health care. An important obstacle they mentioned is that husbands often suspect that they (women) fake illness. Furthermore, many women remarked that men often do not consider women's health problems as serious. As a woman stated:

'He said this is very normal and I am overstressing. Believe me, it was hurting for more than a month, but he was not ready to understand.' [user of herbalist, ritual experts and homoeopathy]

To avoid such hassles, women find it easier to access informal practitioners as alternatives who generally do not demand money for their services and are willing to accept payment in kind. As observed by a woman:

'I had no money to pay for the treatment during that time. I was left with some rice and gave it to him. He accepted it gladly.' [user of herbalist and shamans]

Most of the women expressed that they do not make use of concessions regarding health expenses due to lack of knowledge and information about accredited health care benefits. As a result, they end up spending huge amounts of money for tertiary care. As they pay out of pocket, they face a terrible financial crisis which they are then

unable to recover from for several years. Such non-utilisation of health services, despite their accessibility, happens because of information asymmetry. As one woman expressed:

'It will be really helpful if they come in person to every door and explain... instead of passing information to only a few in a community meeting.' [user of herbalist, ritual experts and homoeopathy]

Some women expressed that if each of them had been fully informed of health beneficiaries, they could have avoided financial problems. This, in turn, would have encouraged everyone to use formal health care extensively. By contrast, women said that they had enough information about various informal healers, their kind of treatment charges and concessions. This is due to a wide networking system that informal healers have both at the individual and social levels, which clinical providers lack.

When informal care treatment fails, some women feel the urgency to approach formal care providers. However, they still look for options within the formal care domain that limit monetary loss. As a result, women are seen using homoeopathic care rather than allopathic medicine as an initial choice (even though it is not always effective), primarily because of cheap consultation fees and medical expenses.

#### Avoidance of Social Stigma and Labelling

The fear of being labelled seems to play a major role in determining the choice of therapies, even if it means compromising on the quality of care. As one woman stated, there are some specific illnesses such as contagious skin disease, barrenness and female sexually-related problems that create social stigma apart from severe physical, social and emotional problems for both the patient and the family. It is, therefore, important for every women respondent to see that their illness does not bring any disgrace either to them or to their families. Although women do not deny their illnesses and look for treatment, they do seek therapies that are generally of inferior quality (less effective and slow or with a slight improvement) but that primarily help them escape social stigma and illness-related consequences. In this context, women find informal healers more responsive to their health needs than formal care providers, as some of them assert:

'It's far better to seek some other options for care within the community, even if it does not work, then listening to this nonsense and bearing it every time we step out of a clinic.'

[strong admirer and user of herbalist, ritual experts and fortune tellers]

Familiar with this kind of social stigma, informal healers prefer to see only one client at a time. Different timings are allotted to each of the patients in order to protect their identity, thus helping the care seekers avoid becoming the victims of harassment within their community. One woman shared her experience about the abortion of a defective foetus identified after scanning:

'He [husband] asked me to contact any folk healer from my native place, as he does not want anyone here to know about the problem.'

[preference given to herbalist, ritual experts and shamans, often uses homoeopathy]

By contrast, many women respondents complained that doctors do not care to value the feelings of the patient and family, that there is no privacy during consultations and that doctors see too many patients at a time, thus increasing their chances of meeting a known face and the subsequent risk of secrets getting revealed. A female participant gave an instance of a physician breaching privacy by talking openly in front of others about her illness:

'I felt so embarrassed that during that moment I thought of running away from the place... He started asking loud enough for others to hear: "Are you taking your leprosy medicine regularly... Are you keeping the infected area clean...".' [strong admirer and user of herbalist, ritual experts and fortune tellers, denounces and avoids medical doctors and para-professionals]

#### Living With the Burden of Cultural Expectations

Women expressed that they can easily accept any care, provided it does not breach the cultural norms prescribed for women and disturb their normal activities in life. Cultural norms greatly influence women's choice of therapies. Women are taught from early on in life to avoid bodily contact with unfamiliar men or known men outside relations, men with whom they share incest and affiliate relations<sup>20</sup>. Direct physical contacts with these men are culturally proclaimed as a sexual association

<sup>20</sup> Incest refers to having sexual relations with a close relative in the family, such as a brother, sister, uncle, aunt etc., whereas affiliate refers to the relationship formed by the treaty of marriage, such as a brother-in-law, sister-in-law, mother-in-law, father-in-law etc. Establishing sexual relationships with any of these members other than the spouse is considered adulterous.

and women's position in society is marked as impure and unholy. In order to protect their own pride and good name in the society, therefore, many women deliberately downplay the importance of formal heath care, saying that its professionals violate honour codes relating to sanctity. They comment on the uncaring diagnosis process of the formal care system, that informal healers are much more sensitive while diagnosing the nature of the illness, thus handling women clients with care. As evidenced by a woman's version:

'I consulted a doctor (for sexual related problems)... He wanted to examine my private parts. I know they are right and do an accurate analysis. But that was very embarrassing... It was my first and last visit. Baba just touched my wrist, that's all and explained everything right, from the cause to the required treatment. At the end of the meeting with Baba, I felt clean and that really meant a lot to me.' [prefers and seeks care of herbalist and ritual experts]

#### Geographical and Cognitive Distance of Formal Health Care

For women, apart from financial and socio-cultural factors, seeking treatment is also determined by suitable access to care. Women pointed to geographic inaccessibility as one of the factors giving rise to problems such as time constraints, increased travel costs and failure to attend follow-ups. Women often find it difficult to adjust their household activities schedule to accommodate inconvenient appointments (mainly during the daytime) at hospitals and private clinics. As a consequence, they are forced to skip medical check-ups. Furthermore, travel costs discourage women from seeking formal treatment. As remarked by a participant:

'Within the city, it takes hours to travel from one place to another and simultaneously you have to bear travel costs. It's like wasting the whole day and money.' [preference is given to herbalist, ritual experts and shamans, often uses homoeopathy, but avoids clinical care that usually incurs travel and consumes time]

Restricted mobility is not only related to financial issues, but also linked with cultural dimensions that limit access to formal treatment. Hospitals in the study area are situated at a fair distance and women are not allowed to frequently commute alone without company. Family members are not always available to accompany them to hospitals, so they find it difficult to continue their treatment. As a woman said:

'My sister-in-law and I used to accompany each other [in visiting clinics] before her marriage. But now I often skip my follow-up treatments... My husband has no time to accompany me to the hospital.'

[preference given to herbalist and shamans, is discouraged to use clinical care that usually incurs travel and consumes time]

Thus, in spite of being aware of the fact that formal care is effective, they undermine its value, thinking that at some point in time they will have to face mobility restrictions, resulting into abandoning the treatment before its conclusion. As expressed by a woman:

'Though Western medicines are good, it is useless if the treatment is withheld from time to time while you are not totally cured.'

[user of herbalist and shamans, is discouraged to use clinical care that usually incurs travel and consumes time]

The non-availability of proper health care infrastructures also reduces women's interest in formal treatment. Patients are often referred to faraway hospitals due to a lack of sufficient staff, medicines, beds and medical equipment. One woman expressed her inconvenience because of such referrals:

'We have already spent lots of money during the treatment... Suddenly they said they didn't have a particular machine and referred me to a different hospital. Again it started afresh; wasting more money and time which we really can't afford.' [preference given to herbalist, ritual experts and shamans, is discouraged to use clinical care that usually incurs financial constraints and consumes time]

Because of all these problems which women face while seeking formal care, they tend to look for informal care. This has several advantages: healers are found within reach; no travel costs need to be borne; and healers can be accessed any time when convenient, which, in turn, minimises the chances of discontinuing the treatment.

#### Men's Perceptions Regarding Informal and Formal Health Services

Men believe that they differ from women both in terms of biological and environmental features, so for themselves, they find formal care more suitable than informal health care. The majority of them used the term 'hard diseases' to characterise their illness. By this, they mean chronic and communicable diseases. According to men, women nag too much about illnesses, so they are given all sorts of light diseases (i.e. mundane and infectious ailments) as hard diseases cannot be handled by them. For instance, one man commented: 'Since we are strong, we are given the hard ones to fight with.' [display masculine hegemony]

#### Another man remarked:

'These women generally have the illness that comes and goes and therefore they are not that dangerous. Quite justified! They nag too much and they get these easygoing ailments which can be easily tackled. And they come to those healers who can easily impress these women by their magic. These illnesses are nothing but those which actually don't require any medicine. Ours is the real and hard one, these are not that easy to locate and therefore these healers fail to fool us. We require real treatment.'

#### [strong believer and user of formal health care]

Almost every male respondent normally tended to underuse health care services or believed in delayed help-seeking. This is because they believe they can handle 'light diseases' or general health problems. The majority of them responded that they do not seek help for general health problems, however; they look for help for specific and longstanding illnesses. Some of the comments put forward in this background as stated by the men: 'treatment was not necessary' since 'minor illnesses can be fought off,' general illness is not illness, they come and go'. The views of men have been put forward as themes presented below.

#### Ease of Access

Most of the men prefer purchasing drugs from drug stores for general ailments, since drug stores are easily accessible within their neighbourhood. This avoids the need for travel, which they usually consider a waste of both time and money. One man, for instance, commented:

'I usually allot Rs.200 for my medical expenses. If I have to travel to hospitals located far away to meet good doctors, then, out of the allotted money, I have to spend a minimum of Rs.70 on travelling alone. The money left is not enough to get good treatment.'

[self-medication by using medicines from drug stores]

Besides travel costs, the availability of services at any time of the day also influences men's preference towards unlicensed drug dealers. Drug dealers usually reside within the community, close their shops late at night and can be approached at any time. One man commented:

'One day my son was suffering from fever in the middle of the night... When we realised that his temperature got very high, immediately I went to Jayanta's [drug dealer's] house and got medicine for my son.'

[user of medicines from unlicensed drug dealers and drug stores because of accessibility]

Most of the men do not reconsider their inclination towards drug dealers when it comes to comparing their quality of treatment with that of health professionals. Some men consider the medical knowledge of pharmacists as equivalent to that of clinical professionals. Hence, men feel convinced that they can access quality care from drug dealers as an alternative option. According to a man:

'I just have to tell them [drug dealers] my problems and that's all. They give all the directions like a doctor as for how and when to use [medicines]. It gives a feeling of being treated by medical doctors.'

[strongly believes in the efficiency of drug dealers and takes their medicines]

Many others approach drug stores for common illnesses, as no consultation fees are required due to the informal nature of their service. A few others expressed that pharmacists help them save money on medicines by suggesting cheaper medicines (with similar effects) instead of buying expensive ones prescribed by doctors. Even if they do buy more expensive medicines, they apply a degree of flexibility. According to a man:

<sup>6</sup>Often I don't use the whole strip as I recover back before completing the course... Here [local drug store] I can buy medicines according to my requirement... This helps me avoid unnecessary wastage of money and medicines.' [user of drug stores because they are considered as economical]

#### **Quality of Treatment**

The majority of the male respondents also judge the value of care based on the activities constituting treatment. It is observed that the real worth is evaluated only in the case of chronic illnesses (and not for common health problems). This stage involves the employment of different equipment and strategies for diagnosis and treatment, which men use as a parameter for determining the excellence of care. Many men perceive illness as something that lasts and has its impact on the body for a longer period, that it cannot be managed single-handily and essentially requires professional attention. This implies that men distinguish common health problems from illnesses. In this context, a man said:

'It's not an illness, but an indication that the body needs rest when you do heavy work.' Hence, the question of judging the worth of care does not apply in the case of common illnesses that can be cured normally without professional assistance'. **[user of clinical care]** 

As most of the men in this study consider only one form of informal care (over-thecounter drugs) as being effective, they try to assess the quality of professionals as good or bad by comparing with other forms of informal care. The general perception of men is that professionals do not conduct their treatment on the basis of a superficial analysis (as informal healers do), rather based on a variety of technologies. Furthermore, professionals can show patients the specific affected area internally and its healing status post-treatment, which informal healers cannot. This assures men that they are undergoing correct treatment, thus in a way making professionals superior to informal healers. As remarked by a man:

'At least we know for sure through TV [scanning monitor] that something is wrong with the body, but there [informal healing], we do not even know whether we are actually ill.'

[user of medical care]

#### **Expected Outcome of Therapies**

Men who are in work consider that time is best spent earning money and fulfilling families' requirements, since they are the main source of income. As said by a man:

'Meagre or no income when I am sick disrupts other aspects of life such as food, clothing, shelter, education etc. in the family.' [user of medical care as perceived to have efficacy]

Therapies that cannot guarantee a quick recovery render men more vulnerable. This, in turn, puts them under stress, making it difficult to manage their financial position during sickness. As a man said:

#### 'I worry if I stay ill for long how my family will pay the costs of the situation.' [user of clinical care]

Since different informal therapies (other than counter over-the-counter drugs) are considered time-consuming, with no indication with regard to the duration required for recovery, it appears natural that men seem less inclined towards such informal therapies, as observed by us during the study period. They gather such experiences by observing the situation of their wives or other female members of the family who usually approach informal healers, while their own experience with

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formal health care is that doctors usually indicate a tentative duration of recovery. As a man commented:

'You will hear them [healers] often saying "I have done my duty... Now you have to wait patiently till it is cured and have faith in God". Such things you won't hear from doctors... My doctor usually says: "Within ten days you will get well, if not, come again".'

[denounces informal healing as believed to have poor efficacy compared to clinical care]

Another reason why most men prefer formal care is that they believe it provides effective healing without causing further deterioration after an initial improvement. Compared to formal care, informal therapies for chronic illnesses can lead to frequent relapses, making men unfit for work aside from further hampering their livelihood. As one man shared:

'Frequent illness will not let us start [working] and subsequently we will be kicked out from the workplace. So, we prefer to seek medical care that ensures full recovery besides preventing us from becoming sick within a short span... We can get back to work feeling more energetic... and can avoid being absent.' [user of clinical care, considered as having good efficacy]

For some men, investing both time and money in a treatment (having already incurred economic losses) with no guarantee of a quick recovery can demotivate them totally to avail of that therapy. Men, therefore, need an assurance that the therapy is worth the effort. As a man said:

'They [healers] test our patience and this is what we lack.' [strong admirer and user of clinical care]

# DISCUSSION

This study examined the health-seeking behaviour of men and women residing in an urban slum in Kolkata, India, by exploring the underlying perceptions affecting differences in their therapeutic choices. Previous findings had highlighted that gender differences manifested in men being more inclined towards formal health care, whereas women were more inclined towards alternative health care (Al-Krenawi & Graham, 1999; Vlassoff, 1994). Instead, the present analysis shows that both men and women make simultaneous use of formal and informal care. Yet, the key findings of this study show that they do so in different ways and have different motivations for their choices. Women's behaviour of mixing both formal and informal care indicates that they want to take care of their illness, but at the same time, they are keen on retaining their socio-cultural ethos, as reported in another study (Drummond et al., 2011). This health-seeking behaviour of women can be related to their lower (perceived) position in the community than men, as a result of which they have to face socio-cultural hurdles in terms of mobility, code of conduct, maintaining family prestige (by behaving well) and maintaining secrecy about their health problems.

Our study reveals that women benefit more from social support, as acknowledged in other studies (House et al., 1985; Rogers, 1996; Srivastava, 2007). Such social support is initiated through social integration with informal practitioners, who are distant kin or residing within the same neighbourhood. As shown in prior literature (Danigelis & Pope, 1979; Kushner, 1985) our study also confirms that such social association is developed through gender roles of maintaining social ties with close-knit kin (natal and consanguineous kin) (Curran & Saguy, 2001) and another type of social relationships (neighbours and friends) (Moore, 1990).

Choices stem from financial stresses that women face both at familial (depending on their husbands for money) and institutional levels (high consultation charges and expensive medications) while seeking medical care. Our study reveals that men often avoid acknowledging health problems of women even when they are serious, as is found in other studies (Retherford, 1975; Waldron & Johnston, 1976). Men who are guided by gender stereotypes in their views, according to which health is not considered as a core issue in life, think women are too sensitive to pain (Doblyte & Jiménez-Mejías, 2017). By consequence, they tend to dismiss and underestimate women's need for professional intervention. Men's judgement and control over women's health is directly linked to their financial autonomy. Failure to persuade husbands often makes women turn towards informal health care. Women are forced to stick to informal care, even knowing it can be less effective. If absolutely necessary, they try to seek formal care that is inexpensive. This finding supports other studies that have shown poor and disadvantageous women are less likely to utilise formal health care services compared to affluent women (Martinez & Lee, 2000) because of convenience, affordability and socio-cultural compatibility (Sudhinaraset etal., 2013; Shewamene et al., 2017).

The inability to participate meaningfully in formal health care use is also due to information asymmetry as regards how to adequately utilise health benefits. Women prefer door-to-door information on health benefits, as pointed out by another study (Sharma et al., 2009). In India, a major share of expenditure on health care is being borne out-of-pocket by the poor. This has resulted in after-treatment disasters such as selling or mortgaging assets and spending from savings, thus further worsening the poor's financial conditions. Other findings point out that ignorance among the

poor about free treatment and the complex and cumbersome procedures to obtain exemptions constrain the access of the poor to formal health care services (Ghuman & Mehta, 2006).

Unlike women, men in the study area do not have to conform to societal gender stereotypes. Therefore, they have more freedom and flexibility in making their choices among therapies. However, their gender role is associated with higher adherence to formal health care. This might be explained by the fact that men identify themselves and are recognised as the earning members of the family. As a result, they cannot risk staying at home for long periods of time due to illness. These reasons drive men to choose formal care that primarily allows them to work (and helps in reducing the risk of circumstantial problems) by curing them fast and completely. As a consequence, the effectiveness of the cure constitutes the main lens through which men judge the value of the care received. Men's choice for selfcare is motivated only by cost-effectiveness. Illnesses are initially taken care of by using drugs from drug stores. Men's judgement regarding choices of therapy is only based on time and treatment efficacy, needs that are both met by formal health care. During clinical encounters, men are more likely to communicate less and prefer quick diagnoses. This response might point towards masculine ideology, according to which men are neither meant to show nor expect emotions and sympathy (Addis & Mahalik, 2003), unlike women. Illness-related questions asked by clinical professionals make men comfortable; hence making professional care more preferable. This way, they feel can escape discussions about other social aspects, which are a potential consequence of the sympathetic exchange of words.

Another aspect of men's unease related to informal healing is its indigenous concept of treatment, which is not scientific, is not aligned with medical or scholarly discourse, and include the application of rudimentary technology in health and healing, thus putting a question mark against the efficiency and reliability of treatment. However, further research is needed to ascertain how physicians in these two healing domains validate their therapies and to examine the actual accuracy of diagnosis in these two therapy domains.

Finally, when it comes to male/female choices of physicians and therapies, we found that women are sometimes moving back and forth between informal and formal health care or utilising both. Instead, men are generally static as regards their treatment choices. The reason might be that women bear more cultural demands, social responsibilities and economic consequences, whereas men bear only economic stressors. In order to adjust to these multiple factors, women state an ample number of reasons for making therapeutic choices compared to men. This may have implications for examining the appropriateness and suitability of treatment provided to women as compared to men. Further research is needed to assess the

reasons for this apparent inconsistency or possibly perceived complementarity in using formal and informal therapies.

To conclude, it can be said that the notion of shortage may be a broader concept, which men and women residing in the urban slum of Kolkata experience and negotiate in a different way when it comes to the health care usage. Their very existence in society as immigrants exposes them to multi-faceted shortages in every aspect of life, the negative effect of which is also seen in their health-seeking behaviour. This suggests that medical adherence is secondary to the prevailing health care problems. Rather, policy approaches should be directed more towards effective communication, material access and awareness of social class in order to enhance users' adherence.

# CONCLUSION

We find that both men's and women's choices of treatment are related to their daily interactions with society, which create either a favourable or unfavourable condition for seeking a treatment. Both men and women utilise informal and formal therapies, but often move back and forth between the two domains to adjust to their economic situation and socio-cultural norms. However, men believe in a complete cure so as to avoid endangering their gender role; women place more of an emphasis on avoiding social and economic penalties and therefore improvise by adhering to poor-quality therapies. These findings can by no means be generalised to other contexts, and even generalisation to other slums should be made with caution, as every slum settlement presents a unique religious, ethnic, linguistic, socio-cultural and socio-economic composition. Furthermore, the focus of this paper is on gendered health experiences. It is therefore possible that other traits influencing health care-seeking behaviour and interacting with gender have not been addressed in the present study.

# DECLARATION

#### Ethics approval and consent to participate

Because of the non-clinical and non-invasive nature of the study, this research has thoroughly followed the ethical guidelines for social science research in health framed by the National Committee for Ethics in Social Science Research in Health (NCESSRH) (Shah et al., 2000; Risenga et al., 2013; Jesani & Barai, 2000). Oral consent to participate was obtained from all the participants. The Institute for Social and Economic Change (ISEC), India, has followed the study throughout and guaranteed the ethical suitability of the adopted methods in the local Indian context. Ethical approval for the study was obtained by the ISEC's Ethics Committee.

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#### Chapter 5

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The Gendered Experience with Respect to Health-seeking Behaviour



# **CHAPTER 6** General Discussion



# **GENERAL DISCUSSION**

The studies described in this thesis sought to learn more about how slum dwellers view their own health, how they deal with illness, who they involve in decisionmaking, and who they seek out for care, all of which play an important role in determining how they make use of any available health care services. Slum health and well-being studies have thus far focused primarily on the impact of infrastructural barriers, built-in environmental influences, and social determinants on specific health problems, such as maternal and child mortality in slums, the prevalence of chronic illnesses, and general health care expenditure/utilization in the public and private sectors. However, a small study attempted to investigate how slum dwellers perceive the holistic concept of health and respond to illnesses in terms of their health-seeking behaviour and the reasoning for their actions. The thesis's major section began by emphasising the importance of lay viewpoints in understanding how slum dwellers conceptualise their health and illness. Following that, the general concept of illness is regarded in terms of the progression of how and when illness is recognised, who participates in its treatment, how illness is treated, and at what stage and in what manner healthcare is utilised. Most significantly, the research aims to uncover the ways in which the ecosystem created by habitus and capital shapes all of these processes. Bourdieu says that capital has more than just economic forms. It also has cultural, social, and symbolic ones. Agents or groups of agents try to get capital over time so that they can use it to help others or make more capital in different ways. In their daily lives, agents want to be healthy and have a good life. In the strict Bourdieuan sense, what the families think of as health is not a single, independent field. People use professional health care, spiritual healers and herbalists, and religion, among other things, to try to improve their health. Still, thinking of lay health practises as a field helps us think in terms of relationships and see that there is a structured system of social positions that depend on each other for power and resources in the field. Bourdieu's definition of "capital" is the resources that people bring to social interactions or the results of those interactions. These resources can be used on purpose or by accident, and they can be used in ways that are economic, cultural, or social. We have used Bourdieu's ideas in new ways, especially capital forms and habitus, to understand how local actors (people who live in slums) work for and get access to health. The study also looked at how men and women in the urban slums responded to health services and how they differed in terms of how well and how often they used them. The emic viewpoints from the slum residents themselves on their complete health and illness experiences and the meanings that the slum residents attached to the illness and the sort of care that they sought were gathered through the collection of primary data. In this chapter, the main findings of the research are summarized, followed by theoretical and methodological discussions. Conclusions and recommendations for health policy and public health, as well as ideas for community efforts and future research, are discussed in the final section of the chapter.

### THE MAIN FINDINGS OF THIS THESIS

# The meaning of health does not exist on its own. Instead, it is thought of in terms of existential insecurity and how to deal with it through socio-cultural worldviews and religious remedies.

For the participants' health construct, the existence of undetermined (uncertain) through finite (certain) means was decoded as living with a perpetual threat to the survival of the participants' health meanings. Because of the continually changing environment, people are plagued by existential uncertainty. However, the capacity to find meaning in suffering, to make responsible decisions, and to make the best of a difficult situation is still present. This awareness drives individuals to connect health meanings not only to disease and its treatment, but also to uncertainty management, in which they strive to make sense of life by shielding and buffering themselves from the hazards they confront. When it comes to dealing with this kind of existential ambiguity, it is a social endeavour. Existential uncertainty is something that people say they try to deal with by investing in a cultural and religious worldview as an important source of meaning when they realise that the future life of their mind, body, and self is in danger (Dwan & Willig, 2021), uncertainty about the availability of a relationship that is necessary for psychological survival (Brothers, 2011), and the kinds of practical uncertainty that come with a limited lifespan (Zeiderman et al., 2015). Participants trust their body's language until they can figure out how their body reacts to illness, how much they can follow a routine before they get tired, and how long they think they can do chores before their body stops working as well as they want. That is not to suggest that slum dwellers do not make efforts to improve their bodies' efficiency, as evidenced by their preventive and therapeutic measures.

#### Acknowledging illness does not mean that slum dwellers are willing or able to use healthcare facilities, as utilization is affected by a complex interplay of human agency, disclosure implications, and the socio-cultural context.

To sum it up, the manner in which slum dwellers' approach to seeking and selecting healthcare services encapsulates the manner in which they articulate their sentiments about being ill, the confidantes they pick, and the helpful and disconfirming social and cultural exchanges to which they are subjected. Discussing disease with others is a critical stage in health-seeking behaviour because it helps to identify the best course of action (whether to conceal it, consult a specialist, visit a clinic, begin self-medicating, or wait for new symptoms). The outcomes of this study reveal that the association between disclosure and the traits of illnesses is situational and appears to be incongruent across genders. Men have a smaller pool of confidantes because they tend to put off disclosing their feelings or prefer not to.

Accepting a confirmation of an illness is often put off or ignored in order to protect one's employment and income, to maintain one's status in the family or society by maintaining one's masculine persons, and to live a normal life as long as possible. Among men, timely reporting is primarily linked to preventing and coping with biological issues that they have already encountered. At various stages of illness, women seek out a variety of confidantes, a behaviour that may be influenced by a variety of culturally mediated support systems. Lack of knowledge about the nature of the illness, fear of stigmatisation or emotional loss due to social exclusion and identity crises, financial crises associated with healthcare expenses, and difficulties coping with the adverse conditions of the slum are some of the reasons for delaying or not disclosing. Providing women with therapeutic experiences of disclosing ailments, increasing their confidence in combating unknown physical difficulties, minimising negative repercussions from recurring owing to delay or non-reporting, and avoiding future societal sanctions are all connected to early disclosure.

### Social, cultural, and economic capital inherent in slum neighbourhoods influence and determine urban slum dwellers' healthcare needs, as well as how they access, seek, and receive care.

Understanding how our participants interpreted and responded to their own experience of well-being, we used Bourdieu's ideas of habitus, capital, and field (Bourdieu, 1986). According to our research, respondents' conceptions of when to seek curative and preventative primary care, as well as their embodied actions during treatment, were all affected by the amount and type of capital in their slum neighbourhood. In the study, it was determined that the habitus or built environment's influence on health behaviour was one of the most significant factors. Priority setting in both Kolkata and Bangalore slums was influenced by the respondents' perceptions of the urgency of the requirements and the visibility of the benefits related to an improved physical environment. The majority of respondents selected to address their daily troubles as their priority and play an important part in delaying or even acknowledging their health problems because of the unavoidable and continual struggle with infrastructure. When faced with a decision between two options, people are obliged to adapt to and accept the conditions of their life. It is as a result of this that the need to invest in imagined health may seem inapplicable and even absurd, which has become the popular understanding in terms of health behaviours. In our study, we discovered that the three types of capital had distinct patterns of influence on people's perceptions of their healthcare needs and their perception of their ability to choose where they received care. To put it another way, economic capital increased the likelihood of seeking medical attention, social capital had a mixed effect, and cultural capital is a collection of societal ideas, religious beliefs, contextual experiences, and distinctive world perspectives that are used in daily life as coping mechanisms for health practises.

# Despite the fact that both men and women make use of formal and informal care, the methods they use and the reasons they have for doing so differ.

As we discover, men and women's treatment preferences are shaped by their daily interactions with society. For example, women and men react differently to physical and social components that influence their willingness to seek therapy, which is why these differences are apparent in our study. Because of the traditional socialization of women, who are more likely to engage in nurturing, caregiving, and self-treatment activities, they have a greater need for a wider range of healthcare services (including both clinical and alternative treatments). However, to make sure that norms are followed, women need to set up channels and make sure that the method of treatment they want and the norms they follow match. For instance, the way masculinity norms influence women's acceptance of men's authority in treatment decision-making for female-related illnesses drives them to seek more accessible and socially acceptable informal healthcare. Men are more likely to avoid or be unable to do health-related activities when they are stressed out in everyday life. Men have very few choices when it comes to health care. For minor ailments that do not interfere with their day-to-day activities, men choose over-the-counter treatments, but for serious illnesses that necessitate immediate medical attention, they prefer professional care. Men are more concerned about economic stressors like losing a job or having to pay for their families' expenses, and they think that these stressors are linked to their underlying illness and how it affects them and their lives (paying too much attention to mundane illnesses that can be ignored and paying attention to more important issues of daily life or ignoring severe symptoms that may hinder livelihood). Approaching clinical treatment as a predetermined decision is associated with a strong conviction in the efficacy of medicine and rapid healing, as well as with gender role expectations and social conceptions of masculinity.

# INTERPRETATIONS OF THE MAIN FINDINGS

The sub-sections below are arranged in accordance with the study questions and correspond to the chapters in the thesis.

# Meaning giving to holistic understanding of health and illness (Addressing Research questions 1,2 &3)

In Chapter 2, this study focused on how Kolkata and Bangalore slum dwellers viewed their own health and well-being, the causes they believed led to their good health and illness, how they defined and explained being healthy, the preconditions and causes underlying health and illness, and the type of treatment sought to avoid or minimise social sanctions and financial losses. Until now, no research has been done in the Indian slum context to investigate the direct perspectives of slum dwellers on the health consequences of living in an urban slum.

Many studies show that people who live in poor neighbourhoods are more likely to get sick and live shorter lives (Marmot et al., 2020). Deprived neighbourhoods are characterised by a sense of hardship and pain that is sometimes exacerbated by a lack of resources and a lack of social support, which can make them question their own existence. It is common to describe existential uncertainty as a feeling of having a low level of confidence in and control over many parts of one's existence (Penrod, 2007). The current study examined how slum dwellers' experiences of existential doubt are expressed through narratives about their daily lives. These narratives centre on issues and anguish that are not conceptually contained within the individual body's limitations. For the most part, participants' statements fit two or three conceptions, which indicates that they are from a diverse background and have a diverse understanding of health. As a result, the constructs are not fundamentally at odds with one another; rather, the participants link them to one another in various ways. These narratives about their minds and bodies "feeling troubled" or "not working" are reflections of their experiences of social hardship, unfair treatment, and an apprehensive anticipation of the future, which we interpret as indications of their anxiety. In contrast to the medical viewpoint, they do not make a distinction between the mind and the body. Most of the time, when asked explicitly, "what is health?" the urban poor tend to concentrate their response on illness. In their narratives, well-being or ill-being are connected with the context of their daily hardships. As a matter of fact, they have a proclivity to explain illness, and more specifically, not only physical well-being but also mental vitality, contentment, and tranquilly of the mind. The insularity with which slum dwellers approach healthcare comes to represent the reluctance of a social reality in which uncertain waiting is engrained in an irregular situation and ambitions for the future are restrained by a lack of resources. Illness is seen as a part of poverty, while health is seen as a way of coping with adversity. Individual and interpersonal domains of life and deprivation (Darghouth et al., 2006) are mentioned by the participants, who speak about stressors such as social, economic, and familial pressures that impose pain and suffering in the form of illness on them. Ignoring illness, feeling miserable, or giving up on life was natural and convivial for the majority of them, or, to use Bourdieu's phrase, they had created a virtue out of need (Bourdieu, 1977). According to Pierret (1995), health is a main concern for middle-class people, whereas manual labourers and small-scale farmers regard health as a tool to be used in the course of their work. Like d'Houtaud and Field (1984), we found that slum dwellers spoke of health "more negatively, socially and instrumentally" in our research.

The construct of health as mental and physical well-being that resulted from this study is unique to the urban poor. Men who are the primary breadwinners in their families place a high value on the role and tend to focus on their mood by referring to peace of mind, which in reality connotes stability (e.g. regular wage, thus stable life). Indeed, they do not use the term "health" in a positive sense. Their definition is

more pessimistic and includes their precarious lives, unreliable income, frequently no income at all, and unemployment, among other things. They describe feeling helpless and lacking peace of mind in their poverty-stricken environment. In this construct, the participants who place a strong emphasis on peace and well-being, but in a positive way, are typically older residents. They define health as a state of being characterised by social support, state benefits, and a positive relationship with family members, despite the fact that they are dealing with several issues.

The urban poor tend to give more structural explanations for illness by emphasising their living situations, which they see as the root cause. Many investigations, such as those conducted by Herzlich (1973), Helman (1981), and Blaxter (2003), have concluded that illness is external to the individual. Among these, Herzlich's (1973) observation that respondents made a clear distinction between illness-the negative notion—and the positive concept generated by ways of life was also noted in our study. The reasons supplied by the urban poor are structurally aligned with the health product/consequences framework, as well. However, it is noteworthy that, in contrast to the findings of much research conducted on a varied range of individuals (e.g. Pill and Stott, 1982; Blaxter, 1983; 2003, etc.), germs or infection were not identified as the primary perceived cause of illness in our study. While Blaxter (2003), Helman (1981), Pill and Stott (1982) and others have stated that the medical model of disease has infiltrated the lay perspective, this was not the case in our study, according to the findings. Despite the fact that many of the participants, particularly women, utilise health care for a variety of ailments, it appears that medical terminology and the medical perspective have not permeated the participants' lay perspective. The most frequently cited explanation corresponds to the health-product/consequence conceptual framework, in which participants explain by focusing on social factors, particularly meeting basic needs, economic difficulties, working conditions, low and irregular income, and healthcare access, as opposed to medical factors. When it comes to content, this construct differs from Pierret's. According to her findings, which suited the health-product explanation (Pierret , 1995), the interviewees "considered health as an objective to be accomplished, but they thought that obtaining it depended on numerous things." This concept, which means "outcomes of a set of causes', is very common among middle-class people. It has been found to be linked to a view of health as an end in itself, not a tool (Pierret, 1995). Our participants, on the other hand, perceive a healthy body as a tool rather than as an end in itself. Instead, they view health as a tool and link poverty inextricably with poor health, both of which are incorrect (actually illness). In contrast to other constructions, a sizable proportion of participants who describe health as a product explain it exclusively by emphasising health as a result of such elements, particularly the structural one. Here, poverty experiences are fundamental. The explanation based on health as a result of economic considerations is more prevalent among benefit-dependent poor respondents. Access to healthcare is critical for people who

are uninsured to define themselves as healthy. The findings of Shilling (1993), Pierret (1995), d'Houtaud, and Field (1984) are consistent with those of other researchers who have found that manual, poor, or working class people's orientation towards health, illness, and the body is as if it were a tool, capital, or a means of doing their jobs, rather than as an end or an objective to be achieved. In many ways, the findings are consistent with those of prior studies, such as Shilling's comparable distinction between "means to a goal" and "an end in itself" for different classes, the study conducted by d'Houtaud and Field (1984), and Pierret's (1995) health construct, among others. In particular, the health of men and people who work in families is very important because they are thought to be the main breadwinners. Because they work in manual jobs, their bodies must remain strong and healthy in order to ensure that the family is well taken care of. This emphasis on the need for a healthy male earner is supported by family members in general and specifically by the female respondents. Women are regarded as being at the bottom of the totem pole, following their husbands and sons in importance. Health is cited by participants as a tool to ensure mobility, the ability to perform daily duties, and the ability to meet their own demands, in addition to breadwinners. With the construct, "health means having strength and the ability to do anything; working and completing everyday tasks." They explain health as "the absence of illness", which is consistent with the health-as-a-tool construct. People in our study didn't think of health in terms of fitness, vitality, energy, an end in itself, or behaviour. Instead, they thought of health as a product or consequence.

# Choice of Confidantes and strategising illness disclosure (Addressing Research questions 4, 5 & 6)

Recognizing or accepting disease does not necessarily translate into disclosure and seeking assistance. In Chapter 3, respondents' narratives demonstrated that disclosure is entwined with slum dwellers' social worlds, their daily lives, and their experiences with their health conditions, and that these diverse roles impact how they view themselves and are regarded by others. Since the disclosure process is ongoing and constant, it can be described as a part of their daily routine. Slum dwellers do face disclosure limits in our study, which have a detrimental effect on how they think and talk about their illness, their coping practises, and psychological adjustment. This demonstrates the significance of stigma beliefs as a common cultural phenomenon that influences the choice and utilisation of healthcare services. Negative preconceptions about various chronic, mental, and sexual health conditions are pervasive.

It is proposed here that one aspect that has been missed or understated in previous studies on urban slum health is fear of disclosure. Fear manifests itself in a variety of ways, however it is suggested here that it can originate with health professionals in certain cases, while more perceived fear originates with personal

relationships in others. For example, slum dwellers expressed having a high level of trust in an individual, whether it is their spouse, family, kin, peers, or individual health practitioners, but may not consult with all of them on specific health issues, preferring instead to engage in selective disclosure, as that individual may be viewed as a representative of, and conduit for, a larger system of practises and institutions that entails social risks such as family and community rupture. Numerous potential punishments for disclosure have been identified, including fear of job loss, reduced social contacts, and social rejection. As a result, self-esteem is weakened, as is fear of institutionalisation, fear of judgement, dread of the unknown, and shame.

Gender plays a crucial role in our study and has an effect on how we discuss fear and selective disclosure. Similarly, to previous research (Benson et al., 2015), neither men nor women showed a one-size-fits-all approach to disclosure. Our study discovered that men and women disclose differently to various audiences, ranging from nondisclosure to selective and/or partial disclosure. As a result, men and women are impacted by the reactions of others to their disclosure. Hence, they create a variety of disclosure strategies and consequently adopt a variety of roles. When women make decisions about whether or not to tell, their socio-cultural background plays a bigger role than their immediate surroundings, according to our findings. Men are more concerned about the structural stigma that comes with telling. As a result, men and women develop their own distinct sets of privacy standards. Disclosure is a critical part of the illness experience for women in our study, even though the decision and method may differ by gender. Women are more prone than men to divulging private information, and they believe that making these disclosures has beneficial consequences for them (Petronio & Martin, 1986). Disclosure is a way for individuals to share information about themselves with others, specifically about their chronic illness and their current health condition. Barned et al. (2016) say that women use preventative disclosure to control and manage the impressions that other people make about them. They also do this to ease the psychological discomfort that comes with identity concealing and make it more socially comfortable (Kaushansky et al., 2017).

Our study analysed remarks made by women and men regarding how they weighed the decision to reveal illness-related information. Numerous choices must be made regarding the audience, the content, and the amount of information supplied during the process. Steuber and Solomon (2011), for example, conducted a study on how couples deal with infertility and shared their findings with others. When it came to the topic of infertility, husbands were less inclined to divulge information, and they judged the topic to be less acceptable. Men in the study reported more feelings of self-doubt and uneasiness at the prospect of exposing this knowledge than women. Infertility, like mental illness, has the potential to be stigmatised. In our findings, both men and women had to negotiate complex social groupings and maintain various amounts of autonomy in the decision to disclose their health status. As was the case in numerous other studies, the pattern of disclosure was influenced by contextual and relational factors, prior experiences, and anticipated outcomes (Greene and Faulkner, 2002; Gronholm et al., 2017; Siu et al., 2012). It's possible that when women choose to share sensitive information, they need to feel safe with the person they're talking to. Males, on the other hand, need to feel that the situation is safe enough for them to do so (Petronio & Durham, 2008).

A number of studies have already examined the disparities between men and women in disclosures (Petronio, 2002). Remarkably, according to our research, both men and women are more likely to divulge confidential information to women from the outset. That is to say, establishing disclosure criteria is influenced by the gender of the discloser, but confidantes' own gender also played a role in the process of disclosing information. Women are more likely than men to turn to female relatives and friends for help in disclosing their illnesses, rely less on their spouses for this purpose, and report more benefits from this type of communication than men do. In terms of usefulness, each disclosure technique associated with a certain illness differs depending on the situation, the apparentness of the illness, the proximity to the listener or the qualities of the relationship, and the perceived receptiveness of the listener. For example, women debated whether or not to disclose to a specific, chosen person (females from the natal household, female kin and female in-laws, or folk healers), taking into consideration the social ramifications of their decision. Certain topics, such as reproductive health, domestic conditions, mental health, and sexually transmitted illnesses, are considered sensitive, and their disclosure may result in social withdrawal if not shared with the appropriate confidante. According to the participants, the social norm of not discussing genital ailments with the opposite sex was often cited as a socially unacceptable practise that immediately causes them to approach the female members by default. The social acceptance and marriageability of women may depend more on their physical appearance than on that of men (Alonso, 2010; Agbo, & Chukwuemenam, 2011), so illnesses associated with physical disfigurement are more harmful for women. The participants, both female and male, said that discussing genitals, especially in the context of illnesses that affect these body parts, is considered taboo and culturally undesirable between women and men, probably due to the association of such body parts with sexual interaction in adulthood. There are a variety of factors that influence men's decisions to disclose their illness, including the expected reaction of the recipient (Greene and Faulkner, 2002), the type and severity of the illness, the impact of the illness on the workplace, any potential stigma associated with the illness, as well as the availability of practical or social support. A person's low self-esteem may have developed as a result of being ridiculed for displaying signs of depression or anxiety in the past. Because men's illnesses aren't talked about freely at home and in society, they may feel compelled to keep their condition a secret out of fear of social ostracism (Admi

and Shaham, 2007; Benson et al., 2015; Lambert and Keogh, 2015). According to the findings of the study, men reported that if they made more regular disclosures, they would receive a variety of reactions, ranging from scepticism to unwanted counsel. As a result of their male identity, men often have their voices rejected or muffled while speaking about their illness. This is made even more obvious when men claim that they did not feel truly listened to. Male culture has a binary concept that states that a man can either be a strong man or a weak man, depending on his circumstances. This polarity tells men to be quiet and not disclose their disease to others, since men who admit they are ill and disclose their condition are considered weak by society (Kvigne et al., 2014). Our study discovered that men have a difficult time managing disclosure decisions. To protect their sense of self and avoid having fun with their friends, men have to balance their masculine identity and the upholding of dominant masculine norms when they decide whether or not to tell someone about their feelings. Ill men's identity management is highlighted in this study, which expands the research on the subject (Courtenay, 2000; Charmaz, 1994). Having a chronic illness makes it more difficult to meet masculine norms and follow masculine cultural rules, which makes it more difficult to make disclosures. The desire not to offend dominant masculine norms suggests that when these norms are breached, a sense of guilt is experienced. The fact that males put their health at risk in order to uphold traditional gender roles may be a result of this internalised conflict. Additionally, this means that males will choose to remain silent in order to preserve their masculinity. These males stated the desire to take action in order to traverse communication difficulties by adopting disclosure methods. By sharing in a way that did not compromise their male identities, participants may have been engaging in agentic activity. Given the apparent conflict that exists when making disclosure decisions, it is understandable that men would develop ways to help them manage the process of disclosing. For instance, Munir et al. (2006) discovered an approach that patients with chronic illnesses frequently employ: conducting a costbenefit analysis to determine whether or not to reveal it in a given situation or to certain people. These individuals are attempting to forecast whether or not exposing themselves and disclosing information about their disease would be beneficial enough to deal with the possibility of more disclosure. Men in our study prefer to strike a compromise between competing needs to acquire benefits from disclosure while also avoiding negative repercussions from sharing, as has been observed in other studies (Petronio, 2000). As Kelly (1996) explains, people's reactions have a big impact on the disclosure of disease since the perceived reactions from confidantes determine whether or not the disclosure is beneficial to the teller. Secrets can sometimes be more useful than divulging them, depending on the anticipated reactions and expenses involved in keeping them hidden. There are others who will conduct an evaluation of the issue, weigh the advantages and disadvantages, and come to the conclusion that public disclosure should only be made when absolutely essential (Barned et al., 2016). For example, men, for example, will open up about their condition if the circumstances are right, particularly to their spouses and medical experts, as well as to others who are experiencing a similar situation and with whom they can empathise. Silence and disclosure have been directed at specific audiences (such as spouses or clinical professionals) and situations (such as venting extreme emotional distress), frequently in order to keep the illness hidden from certain people (peers, colleagues, and frequently kin) or deemed insignificant for self-management (minor ailments). When people are in a safe and supportive setting, they are more inclined to open up about their illnesses (Slepian et al., 2015). According to Munir et al. (2006), men are more willing to share their innermost thoughts and feelings with others who share common interests and experiences. Positive experiences with the disclosure of chronic illness information boost the discloser's self-confidence and capacity to communicate effectively with others. In order to learn about and feel more comfortable with the illness, it's helpful to find commonalities with other people who have the same condition.

# Conflicting experience of health and habitus in two different neighbourhood (Addressing research question 7&8)

Slum dwellers' general health and related practises were examined further in Chapter 4 as a result of the habitus that influences objective conditions like availability to good, embodied activities as well as symbolic beliefs and ambitions. As well as attempting to determine the composition of a person's capital (such as their financial assets or social networks and cultural norms and skills), the research also seeks to understand the obduracy of poor lifestyle choices based on class and the underlying habits and dispositions that encompass these choices. It has been proven that the built world has an impact on people's health, in addition to the socioeconomic and cultural capital that a neighbourhood possesses. Bourdieu's conceptual framework (Bourdieu, 1979, 1990) highlights how the enabling, restricting, and discriminating nature of habitus in connection to health produces distinctions in poor neighbourhoods' complicated concepts of healthy behaviours or lifestyles. Material or infrastructural aspects, like the quality of housing, the environment, and how easy it is to get to services, as well as social aspects, like community cohesion and crime rates, are all factors in the amount of capital (Bridge, 2002; Cotter, 2002; Dorling et al., 2007; Macintyre, Ellaway & Cummins, 2002). Our findings further demonstrate that the volume of capital that forms the pattern of habitus (Abel & Frolich, 2012; Hoeeg et al., 2020; Oncini, 2020) causes numerous commonalities but also major disparities in the ways that the urban poor perceive health among themselves and among their neighbours. We developed a comparative understanding of the neighbourhood and the volume of capital that differed in the research sites of the different cities and expressed different health seeking behaviours in each of the cities under investigation. According to the findings, respondents are aware of the reasons why they are unwell or poor and frequently have suggestions for how to improve their circumstances. They express their gratitude for their good health. As previously indicated, risk avoidance and healthy behaviour are constrained by a lack of economic capital. According to our findings, social capital of the habitus—such as social support, social networks, and social capital—has the potential to either improve or worsen health-related outcomes. Neighbourly cohesiveness, diverse and resource-dense social networks in Bangalore's slums have been shown to have a favourable influence on social capital. It is through heterogeneous social networks that information may be disseminated more widely, resulting in the production of the knowledge required, not just about health conditions and diseases but also about the healthcare system as a whole. People living in Kolkata's poorer neighbourhoods have less social capital, which means they are more like acquaintances. Slum residents have more bonding social capital and ask for responses or connect with a socially mediated health care provider. As a result, behavioural standards that are consistent with traditional village norms can be more easily recognised within informal social networks, which in turn influence people's behaviour decisions even further. The result was a restriction in intra-group norms or knowledge of health-care resources in the habitus that makes external circumstances interior and renders alternative ways of being unimaginable or 'not for people like us', thereby creating a virtue out of necessity. Practicing various coping strategies (such as an attitude of avoidance, low self-esteem, and feeling of resignation) to manage healthcare exclusion and negotiate care in alternative healthcare spaces such as traditional and spiritual healing centres, and community health centres, among others, is mediated by slum dwellers' symbolic and informational resources for action such as values, behavioural norms, and knowledge related to religious and supernatural mechanisms, which are acquired mostly through social learning.

#### Motives for Differential Healthcare seeking across gender (Addressing Research questions 9, 10 &11)

Healthy behaviour is anything an individual does or does not to maintain their physical well-being and fitness. This allows them to manage their social, physical, and biological environments to their own liking (Adaramaja & Ogunsola, 2014). It also means making choices from the options that are available and how easy it is for humans to make certain choices over other choices (Shehu, 2005). Improvement and maintenance of health are achieved not just through the advancement and application of health science, but also through the efforts of individuals and their sensible behavioural choices, which are sometimes impacted by cultural norms and expectations (Brabers et al., 2016). The way men and women in urban slums look for health care is one of the most important things that has helped determine 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. In general, society is segregated between female and male gender groups. People who fall on either side of the classification have very different roles and responsibilities in society. When it comes to everyday living, women and men are exposed to a wide range of different

circumstances that can have a profound impact on their well-being, both negatively and positively. However, the varied responsibilities expected of men and women, as well as the social pressures placed on them, have a substantial impact on their health. Because of their gender's distinct societal duties, women are more likely to seek medical attention than men. According to a study conducted in Canada, women use more medical services and spend more money on healthcare than men on average. According to Thompson et al. (2016), a study of more than 7,000 patients across Canada's 10 provinces found significant gender differences in health-seeking behaviours, with women reporting more visits to their primary care provider for physical and mental health concerns compared to men. In a similar vein to prior findings, gender was found to be a major predictor of attitudes toward obtaining help in Chapter 5, with women expressing more favourable attitudes toward receiving help than men. The number of healthcare services used by women was found to be higher than that of men, despite the fact that no significant disparities were found between the sexes in terms of the wide range of treatment alternatives that women and men sought out.

Indian healthcare is characterised by a pluralistic environment in which numerous, largely competing options for health care are available. There are wide variances in demographic, socio-cultural, and socioeconomic characteristics among slum dwellers in India, which predispose them to different health-seeking behaviours, some of which result in needless loss of life and disability as a result of ineffectiveness and/or inefficiency. Our research tried to gain a better understanding of the complexities of structural determinants as well as the causes of inequalities in choice and utilisation of health-care services in greater depth. Individuals do not all have the same opportunity to seek and receive health-care services on an equal basis. The selection and use of health care is a complicated undertaking. Manoeuvring elucidates how men and women living in difficult social and economic circumstances choose and engage with healthcare providers as part of a continual process of reflexive social monitoring. Manoeuvring theory is an experimentally based theory of a significant domain (Corbin and Strauss, 2008). That is, it tries to explain a specific social practise in a specific setting. The process of manoeuvring in our results indicated an underlying mechanism that was present across both men's and women's care-seeking, and it also explained the majority of patterns of healthcare utilisation. A number of studies have looked into the role of enabling factors in explaining inequalities in health-care utilisation between men and women (Green & Pope, 1999; Dunlop et al., 2002). In particular, it should be noted that women have a greater need for health care, which is approximated by their lower health status (greater morbidity, lower perception of health, poorer health-related quality of life, and a higher sense of social impairment than men), a different social construction of illness (roles, attitudes, beliefs, and behaviours of men and women once they are sick or concerned about ill-health), which results in different processes for seeking health care, and differences between men and women (Macintyre, 1996).

As a result of their upbringing as nurturers, females have additional health demands that are not met by men, and they feel more restricted in their ability to access health-care resources. In part, this is due to culturally determined social roles and the lower social value put on women, which make it difficult for women to access health care facilities during the day. Women's health-care seeking was motivated by knowledge of the potential hazards of morbidity and a desire to have a better health outcome, according to the findings. Bertakis et al., (2000) found that even after accounting for other variables, women still used healthcare facilities at a higher rate than men, which they attributed to the fact that women have different reproductive and particular health needs. Many of the women who took part in our study were motivated by feelings of anxiety and uncertainty to carefully explore the range of health-care alternatives available to them and to make efforts to try to find a suitable provider. Because of this, some women have chosen or avoided specific providers, such as conventional and alternative medicine as a first point of care, or avoiding clinical doctors from the start. If a threatening situation arises during the healthcare-seeking process, women may abandon informal healers and seek formal care. There were three primary behavioural stages involved in seeking healthcare: investigating possibilities, making a decision, and managing the interaction with the healthcare provider. First, the individual sought support from her social group in order to enter into the sick role and establish appropriate behaviours, sought information and advice about services from her social network; and gained an understanding of access to alternatives, while also considering the social and economic consequences of health actions for the household. Second, families are involved in purposefully selecting one or more potential providers by identifying their health and health-care requirements as well as evaluating the suitability of available providers. The third phase, managing the health-care interaction, included a variety of actions and techniques aimed at improving the patient's experience of health-care and ensuring a favourable result. Women reconstructed events and used them to shape subsequent health-seeking decisions and behaviours. Manoeuvring is often thought of as a single, linear process, but it is actually a series of 'cycles' of manoeuvring in which women make decisions and use health care services, and then use what they learn from the process to guide their future choices. More than that, the direction of movement was frequently reversed, and families reverted to earlier phases as they re-evaluated their status in light of new experiences, or as social or economic circumstances altered. Adapting to changing experiences and conditions frequently necessitated reconsidering techniques and making modifications to choices, which in turn influenced later health care-seeking decisions, ultimately resulting in a mixed usage of both official and informal healthcare. There were real social and economic barriers that made it hard for the families in the study to

get the care they needed. People's perceptions of how easy it was to get different types of health care were partly based on their class consciousness and how poor they thought they were. Helplessness is associated with lower socioeconomic status, which correlates to Varma's (2004) understanding of the term "aukaad", which states that lower socioeconomic status persons confront difficulties moving beyond their given limitations. On the other hand, manoeuvring demonstrated that women's health practises were not completely restricted by their socioeconomic circumstances and cultural meaning: some women opposed or rejected the medical advice of their healthcare provider and took alternative action instead. This means that medical knowledge and health treatment are subjective, flexible, and susceptible to negotiation. Other people's suggestions and suggestions weren't always taken at face value. To keep some control over the healthcare encounter, families questioned clinical diagnosis and recommendations and sought a second opinion through negotiation. Manoeuvring, we propose, is a sort of self-monitoring and is tied to the grand theory. According to Giddens (1984), when people engage in social activities, they have an impact on the systems and structures in which these activities are possible. He refers to this as "reflexive monitoring of action." Reflexive monitoring is the ability of people to keep an eye on their own and other people's actions, as well as the environment in which they happen, and change them. People who change their behaviour have both intended and unintended consequences in terms of how the social structure stays the same or how it changes (Giddens, 1984). If the social structure restricts health care-seeking to a certain level, it relies on how easily or difficult it can be contested. This includes access to "resources" inside that system. Agents can move around in the social world in accordance with prevalent norms, which makes them aware of their capabilities within a system, but they can also challenge or reproduce certain aspects of that system when manoeuvring. This is the closest analogy to Giddens' reflexive monitoring of action. The research presented in this chapter sheds light on manoeuvres that demonstrate how reflexive monitoring works in the context of obtaining health-care services. Women who challenged medical advice or sought a second opinion changed the dynamic between them and their providers, as well as the actions of women to whom they would give advice in the future. When women didn't seek help because of poverty or "aukaad," social norms that kept women from getting the care they needed were repeated. Alternatively, using an agency to negotiate quality or results with a provider posed a fundamental challenge to the encounter and altered the structure of the interaction. These may have had an immediate, micro-level effect, but taken together, they have the potential to have a long-term impact, such as when women share their "successful" interactions and actions with others in their social networks. Women who took part in our research expressed their dissatisfaction with the care they received, the way they were treated, and the attitudes of the people working in health facilities, particularly those in the public sector. Mistreatment when seeking medical attention is prevalent, and it occurs at all levels of interaction with healthcare systems (Bohren et al., 2015). An investigation by Mannava et al. (2015) into the attitudes and behaviours of health care providers toward service users in low and middle–income countries revealed a variety of organisational and individual factors that influenced the attitudes and behaviours of health care providers toward service users. We found that many of these echoed the experiences of the women who participated in our study. Evidently, unfavourable structural and cultural factors not only limit choices, but they also make socially and economically disadvantaged populations more vulnerable to discrimination and mistreatment by healthcare professionals, as has been demonstrated.

Despite the fact that men have greater access to healthcare in terms of physical, economic, and cultural accessibility, they nonetheless fall behind women in our study. To put it another way, men visit public healthcare facilities far less frequently than women because they lack the necessary confidence to seek health care, which is shaped by dynamics rather than solely medical considerations. There was a connection between the fear of discovering their health problems (financial hardship), the notion of masculinity, and the effectiveness of treatment. Men prefer to use over-the-counter medicines to treat their symptoms. According to several previous studies (Alavi et al., 2011; Cherniack et al., 2008), females are more likely to self-medicate than males. However, contrary findings were revealed in our investigation, which were verified by other studies conducted in various regions of India (Selvaraj, Kumar, and Ramalingam, 2014), such as the fact that males were more likely than females to self-medicate (Zhao & Ma, 2016). For male participants, finances are a significant problem, and they believe that the cost of transporting themselves to a medical facility is prohibitively expensive. As a result, many are turning to over-the-counter medications and other non-medical methods of health care that are less expensive than going to the doctor. As a result, many people who took the survey said they questioned "what is the need" when one can get by just fine with a trip to the drugstore and a few medications. At the heart of these impressions is the belief that the men knew more than the women, which reflects macho scripts about their own talents or expertise once more. When it comes to excellent health, money is a hindrance. However, as many participants noted, there are government hospitals with lower rates than private ones, making basic healthcare accessible to everybody. Having a multitude of serious health concerns that necessitate competent healthcare from private hospitals is the only situation in which financial constraints might be a hindrance to getting medical treatment. Further, the people who took part in the study were afraid because they knew their psychological awareness of being breadwinners and how that would affect their jobs, which men aren't allowed to talk about in social situations. In doing so, they are going against the stereotype of males as courageous and strong, and they are infringing on their right to be the head of the household.

A man's ideas and actions reflect how he sees himself in relation to the rest of society. Manhood can be threatened or impaired by illness. Scholars, like Amoo (2018) and Amoo et al. (2017), say that masculinity shapes the way society is and how people look for health care. Socialization into the male hegemonic culture begins early in life (Amoo et al., 2018), and it is visible in men's use of basic healthcare facilities in various countries (Craig et al., 2008). Our study, like others, discovered a reoccurring topic enmeshing "typical masculine behaviour" as a reason for men's delaying obtaining health treatment during times of illness (Galdas et al., 2005). Cultural and patriarchal norms and beliefs, according to the findings, continue to play a critical role in shaping the health-seeking behaviours of men in the long run. Global discourse on men's health-seeking behaviour and masculinity has been highly insightful when evaluated from a variety of angles. The majority of Indian societies, including those in the study slums, are highly patriarchal. Gender dynamics and power relations are intertwined with the concept of masculinity, which is a dynamic rather than a fixed reality. Also influencing their decision to seek health care are socio-economic, cultural, and political issues, which are accompanied by gender socialisation and gender dynamics. While men's masculine identities are always shifting, Courtenay (2000) claims that their ideas and behaviours around health issues are negatively influenced by their conceptions of patriarchy and masculinity. Finally, Courtenay (2000) claims that health-related behaviours and beliefs are recognised strategies for creating and validating gender, which is particularly essential. Masculinity is shown in our study results by avoiding or neglecting health care and supporting harmful behaviours. Because traditional masculinity continues to be the dominant identity for our male participants, healthcare is strictly regarded as a feminine construct, in which females, who are typically described as weaker vessels, require health care services on a regular basis, whereas men are resilient and do not require health care services or are not frequently referred to as having "fallen ill" (Seidler et al., 2016). This demonstrates how socially constructed gender stereotypes like as masculinity, which typically describe men as tough and brave, affect men's attitudes and prevent them from obtaining quality health. Defining masculinity and gender in the context of health is problematic since males are less likely than women to seek medical attention before symptoms worsen and necessitate an emergency room visit. Lubega et al. (2015), Men's Health Forum (MHF, 2008), and Khan all corroborated this finding (2004). The males in our study prefer to seek therapy that is less time-consuming in terms of recovering their sense of masculine identity and, consequently, their capacity to function as men in order to avoid violating rigorous hegemonic norms at the earliest possible opportunity. However, because they tend to be self-reliant and strong, they often choose to use formal health services as their first and last choice when self-medication and alternative medicine have failed and their health has worsened. Clinical care is considered to be the most successful way of treatment for males because alternative treatments may assist in managing illness but do not provide a cure. The use of many procedures in the treatment of sickness, as well as the short amount of time it takes, generated positive perceptions, which tipped the scales in favour of seeking clinical care. Men responded that providing for their family was a significant component, and that their role as financial providers was key to their identity. They also stated that taking time off to visit a doctor on a regular basis takes money away from their family's finances. Finance might be seen as the disappearance of a significant source of power (Perkins, 2015). This study supports previous research indicating that the provider position actually encourages men to seek healthcare services in order to return to work faster and reclaim their status as breadwinners (O'Brien et al., 2005).

# THEORETICAL AND METHODOLOGICAL REFLECTIONS

#### **Theoretical reflections**

Using the Arthur Kleinman Explanatory Model of Illness (EMIs) (Kleinman, 1981) as a guide, the study explores the concepts of comprehensive health, giving meaning to it, and health-seeking behaviour in the context of comprehensive illness among slum residents in urban Indian settings. The study's application of the EMI concept provided insights into how cultural meaning systems and ideas about health and illness in the broader context influenced the participants' health-seeking practises and treatment choices.

The standard formulation of Kleinman's theory states that explanatory models are created from five topics: The aetiology: the time and method of development of symptoms, the pathophysiology: the disease process; the course of sickness, including how bad it is, how long it will last, and how the patient will act as a sick person; and treatment, which measures are likely to be effective, how they work, and what their side effects are (Kleinman et al., 1978). There are different kinds of explanations that do not fit with a certain kind of explanation. Explanatory frameworks are sets of assumptions about what kinds of causes and causal principles are relevant to a certain kind of thing. It is based on categories that are characteristic of biomedical explanation that the notion of explanatory models is established. Medical anthropology suggests that sickness explanation frameworks differ substantially both within and across cultures, but relatively little research has examined whether and how causal models of individual illnesses differ across diverse explanatory frameworks. One significant difference between illness explanatory frameworks that have been extensively discussed by anthropologists is the distinction between those that attribute illness to physical causes and those that attribute illness to psycho-social causes. This distinction has been discussed extensively by anthropologists (Foster, 1976; Murdock, 1980; Shweder et al., 1997). Even while there may be possible physical reasons that have either been rejected by or lie outside the purview of biomedicine, the physical explanatory framework that is most often mentioned is "biomedicine." When compared to physical explanatory

frameworks, which attribute illness to a disruption of a bodily or physiological process, psycho-social explanatory frameworks attribute illness to thoughts or emotions (either one's own or those of another person), which are typically the result of social influences. One such example comes from the Zande people of Central Africa, who believe that illnesses are brought on by the witchcraft of envious or angry neighbors (Evans–Pritchard, 1937). Susto is a common cause of illness in Latin American societies in which a terrible emotional circumstance leads one's soul to leave one's body, causing one to become unwell (Rubel et al., 1985). Many alternative medicine practitioners in the United States and other industrialised countries believe that sickness is caused by negative thinking and other psychological issues (Whorton, 2002).

When the explanatory models were first developed, they were aimed at gaining a better understanding of the clinical interaction, which is a rich source of information regarding the patient's and his or her family's perspectives on sickness and their wider belief systems. According to D'Andrade (1992), the cultural meaning system of a community is generated by the individuals' cultural schemas that are shared by the entire community. When confronted with both familiar and unfamiliar situations, these schemas guide individuals' actions and provide them with a sense of what they should and shouldn't do. Individuals' views and beliefs about signs and symptoms, the causes of illnesses, and their perceptions of health services and their quality were influenced by the conceptions of health and illness held by the broader community. Our research on health and illness experiences employs a variety of framing techniques. It is proposed that the explanatory frameworks for certain kinds of phenomena, such as describing health and illness, are related to specific cognitive domains by drawing a distinction between psycho-social and physical explanatory frameworks. As a result, we developed a selection approach that may serve as a guide to the types of factors that should be included in illness explanations. For this reason, we kept it open to participants who can address the topic of whether phenomenon of health and illness fit under the cognitive domains of psychology, the mind, folk-biology, or the body in order to provide a more complete account of health and illness.

Many studies have used the EMIs parts of this model as a whole to explain how people make sense of health. In this study, the parts of the model are used separately to look at how people make sense of their own health and how they make decisions about how to practise medicine. In fact, as stated in previous research, we did not follow any fixed entities or single constructs of an explanatory model (Kirmayer & Bhugra, 2009). Instead, we thought it was a fluid, multilayered, and complex construct that could change based on a number of factors, such as the relationship, the neighbourhood, and the types of capital available. Chapter two, for example, examines culturally dictated processes of making meaning of one's health and illness through the examination of socially built individuals' perceived vulnerabilities and severity of the health status quo. In-depth information was gathered from this evaluation about participants' awareness and understanding of signs and symptoms as ascribed by social expectations of the ill role, and as processed and filtered by cultural values and contextual considerations. In Chapter three, the option to disclose disease is evaluated by eliciting individuals' perceived barriers and anticipated benefits to adopting specific confidantes. If not chosen properly, these confidantes can have a favourable or negative effect on their future course of action. In chapter four, the neighborhood's social, cultural, and physical characteristics have been looked at to see how everyday life experiences that are linked to health are framed, understood, and built by structural forces. This helps to understand the context or neighbourhood that influences the decisions of slum dwellers and determines their behaviours in the pursuit of better health. Further, in this chapter, cues to action are evaluated through an investigation of the aspatial dimension (volume of social, cultural, and financial capital) of prospective access to health-care services and resources. This provided insight into the information participants possessed about illness and the sources of that information, whether internal (symptoms, prior experiences) or external (quality infrastructure, degree of mutual trust and connectedness as close knit kin to support one another during times of crisis, availability of services and financial support to provide a "leg up"), that largely influenced the exaltation of quality healthcare access. Chapter five expands on casual attribution in utilising certain health care-seeking methods by including gender perspectives. Restrictive gender norms for men and women that lead to limited options as a "normalised" practise in some health-seeking behaviours and the selection of particular medical services for disease were revealed as a result of this research.

#### **Methodological reflections**

The study's research objectives and questions were shaped by the theoretical notion discussed above, Kleinman's Explanatory Model of Illness (EMIs). This idea helped shape the design of the data collecting trajectory, including the decision to undertake in-depth interviews (IDIs). In order to make the EMIs components operational, they were transformed into questions and probes that were included in the topic guides. During the in-depth interviews, these topic guidelines were utilised to collect data. The research was carried out in two separate cities in India in order to better understand how inequalities in different forms of capital and neighbourhood influence health-seeking behaviour in different parts of the country. Pilot interviews were conducted in the first round, and the findings were used to fine-tune the topic guidelines for primary data collection, which included in-depth interviews.

The study locations were purposefully chosen in order to collect both core and periphery viewpoints on urban slums. As a result of the purposeful recruitment strategy used to recruit study participants, it was possible to identify a diverse group

of participants, which comprised slum dwellers of various genders and ethnicities, as well as people of various religions and ethnicities. For this study, the use of IDIs to gather data unearthed new views on health-seeking behaviour and provided in-depth information on the subject. Qualitative and phenomenological methods were used to capture the narratives, followed by a deep investigation of the concerns through IDIs, which tapped into each method's strengths and widened the scope of the findings. There were no new findings after the saturation points were reached, which means that the people who took part and the data that was collected were enough for each topic and gender.

Not only throughout the planning and data collection phases, but also during the analysis, the EMIs framework guided the research. They presented emic insights into the slum dweller's knowledge of health and illness, as well as how their neighbourhood social and cultural setting affected their own logic in terms of action (Kleinman, 2020). When it comes to structuring people's health opportunities and choices, cultural capital plays an important role. Slum dwellers have access to a variety of culture-based resources that can be used to maintain and promote their health. These resources interact with social and economic capital in the formation of people's health chances and choices. Poor lifestyles based on social class, which express predisposed but seemingly naturalised patterns of thinking and acting, influenced the model of illness in terms of perceived severity and perceived benefits, as well as barriers to acknowledgment, disclosure, and access to healthcare services.

Data analysis was carried out using thematic analysis to generate inductive and abductive codes. The code development procedure entailed the researcher communicating developing codes with two supervisors situated in India and the Netherlands, and the process was repeated until no new codes arose. Following the development of codes, the next step was to code the data, which was then followed by code categorization and classification. The process of coding and categorising the codes into themes was repeated until no new themes or categories were identified. The majority of the themes highlighted novel notions that arose inductively from the data and reflected the components of the EMIs that guided the topic guides for data gathering. Beyond their own beliefs and perceptions, the new concepts of health and illness, how they experience illness, the level of confidence and confidante they choose to disclose, the neighborhood's influence, and the volume of capital influencing access to health services, self-medication, and treatment choice emerged as significant factors influencing individuals' health-seeking behaviour. These emerging conceptions indicated the need for additional theoretical concepts, as the challenges raised by these concepts could not be satisfactorily described by the previous theoretical concept. Additional theoretical notions, such as the culture-centred approach (Chapter 2), Bourdieu's concept of habitus and forms of capital (Chapter 4), were adopted to aid in the understanding of emergent concepts. When the Cultural Centred Approach concept was applied in conjunction with a Bourdeusian habitus and associated capital resources, it provided spaces for cultural voices to articulate their health needs and facilitated in-depth explanations of how slum dwellers understand and practise health and well-being while being mindful of material and symbolic constraints, alternative understandings and values, and differences between cultures.

### CONCLUDING REMARKS ON THEORETICAL AND METHOD-OLOGICAL REFLECTIONS:

We believe that this is the first study of its kind in public health that has used the theoretical concepts of the Kleinmen Explanatory Model of Illness to assess health-seeking behaviour among residents of urban slums in India in order to assess a comprehensive understanding of health and illness, as well as subsequent health seeking practices, among residents. As a result, the study was able to get a lot of detailed information about how the macro and micro level factors in the community work together to shape the health-seeking behavior that people do in their communities for both good health and bad health. The additional theoretical notions that were applied helped to widen the explanations of the individuals' actions, situations, and experiences beyond what they believed and perceived. The use of IDIs in studies of health-seeking behaviour is not novel from a methodological standpoint. However, the methodological trajectory of integrating lay views, narrative and phenomenological knowledge, and theoretically informed data gathering procedures in studies of health seeking behaviour is novel, particularly in the context of India's urban slums. Methodologically, this path provides a novel contribution to studies of health-seeking behavior. The incorporation of theoretical foundations into the data gathering guides and research procedures contributes to the credibility and validity of the study findings.

# IMPLICATIONS

Recent years have seen an increased focus on the interplay between individual (e.g., food, lifestyle choices) and social/structural (poverty, service provision) factors in determining health and illness outcomes. However, while it is widely acknowledged that people who live in more destitute areas have poorer health, the exact mechanisms that are at work in this association are not well understood at this time. How much of an impact do "contextual" elements have compared to the "compositional" factors of the people who live in these areas? The findings of the study have raised fundamental questions concerning areas and locations as social spaces in which people live and interact with one another as well as with the rest of their surroundings. The findings confirm that there is a growing need for a better understanding of how people's identities, attitudes, behaviours, and relationships

are influenced by, and in turn shaped by, the environments in which they choose to reside. It is clear from our research that there has been a progressive change in emphasis away from studies of the subjective experience of the "sick role" toward studies of how people interpret the broader social determinants of health. This research shows that people living in slums are increasingly thinking about health in terms of more than just a single bio-medical model or a bad environment. This shows that lay ideas are important for a more complete understanding of health inequalities. This evolution has been accompanied by the building of a "richer, thicker depiction of lay ideas of health and illness' as opposed to the naive assumption that public and professional/expert views are inherently polarised. Rather than using the passive descriptor "lay beliefs", the findings of the study have been expanded to include the more persuasive descriptors "lay expertise" and "lay knowledge." Following the outcomes of the study, it is suggested that there should be a change beyond basic semantics by engaging with lay knowledge as opposed to just lay beliefs, in order to conceptualise a different, more "nuanced and sophisticated" role for lay knowledge. At the policy level, such efforts may have the ability to provide insights that can be used to complement, challenge, or act as a mirror, resulting in a different order of knowledge being generated. This method has the potential to merge policy expertise with the democratic engagement of laypeople in a practical way, raising the level of input of lay knowledge while simultaneously reflecting on the public health field.

There are many different types of ailments, and none of them are the same. To give only a few examples, some illnesses are stigmatised, although others are not; some illnesses are contested, whereas other illnesses are not; and some illnesses are considered disabilities, whereas other illnesses are not. That these inequalities exist for social reasons rather than biological ones is significant because it is one of the major ingredients in concealing or disclosing disease and seeking proper medical treatment. This research discovered that admitting illness has cultural implications and repercussions that are not reducible to biology or the poor status quo of slum residents alone, and these cultural meanings and consequences impose additional burdens on those who are afflicted by them. An overarching conclusion drawn from this line of research is that there needs to be more attention paid to interventions that are more aligned with social and cultural contexts rather than exclusively focusing on biomedically fixing slum inhabitants' health, bringing about changes in their physical conditions, or building capacity. For example, slum men's negative attitudes about acknowledging or treating their illnesses are shaped by norms of masculinity, so there should be policy efforts to improve the health of men as well as women and children. This should be done by building on men's strengths rather than making them seem bad or toxic in terms of their health behaviours. Taking advantage of the fact that many men are already attempting to care for their individual health and well-being is critical, as demonstrated in our study, where men do not completely ignore illness but instead take over-the-counter medications or seek clinical care based on their perceived susceptibility to the illness. Public health policies must create and implement multisectoral health and well-being policies that take into account the influence of social, economic, and cultural issues, as well as male norms, on the health outcomes of men in order to improve their overall well-being. Men's hegemonic authority over women and other men has a number of unintended repercussions, and the public health system should take steps to eliminate these unintended consequences through evidence-based programmes and outreach initiatives. Medical and health care professionals in countries should also be trained to comprehend masculinities and men's health needs and include them in their diagnostic, referral, and treatment methods. Again, this should be done with careful consideration given to the location of funds and resources in order to ensure that everyone has access.

It is far more difficult to treat and manage an illness if it is associated with a social stigma. For example, female participants were reluctant to disclose or seek treatment for fear of being mistreated by health care practitioners or being publicly identified with a contaminated ailment because of the stigma connected with women's sexuality. Instead, they sought treatment from traditional healers who were culturally competent in understanding and maintaining the level of concealment that was required. As a result, a viable integrative paradigm for Traditional Medicine and Healing (TMH) tailored to the specific needs of the Indian slum population should be actively explored in health policy. Furthermore, both stigmatised diseases and contested illnesses should have policy ramifications that should be considered. In addition, the framework for health stigma and discrimination can be used for different health problems to illustrate the drivers, facilitators, intersecting stigmas, and manifestations of stigma and discrimination. When dealing with a particular marginalised community or a group with which they are familiar, researchers, physicians, programmers, and policymakers should determine which characteristics of each of these domains are most important for their work, and then apply the framework to their work. The framework, we hope, will enable the standardisation of measures, the comparison of outcomes, and the development of more effective cross-cutting interventions. The framework can also be used by researchers to find research topics, look into multiple health issues, and look into how different identities, social inequalities, and health problems are linked. Using the framework, physicians, programme implementers, and policymakers can better address the needs of their patients, communities, and society as a whole while also improving health outcomes. For instance, by identifying which stigmatising factors need to be addressed, as well as the specific interventions or policies that should be implemented to combat these factors and the changes in specific outcomes over time that can be measured using implementation science approaches, we can better tailor and apply the framework.

This study adds to the increasing corpus of research on healthcare consumption in Indian urban slums by illustrating how neighbourhood characteristics influence and manifest diverse healthcare consumption behaviours. The study looked into the pros and cons of using conventional therapies against complementary and alternative therapies. Although the concept of choice has not been disregarded in the sociological literature on healthcare, the concept itself has not been sufficiently interrogated in the slum environment where this phenomenon occurred, as revealed by this study. Even more importantly, there has been minimal examination of the ways in which slum inhabitants make choices, as well as the social structures that influence their decisions. In the study, it was demonstrated that having the proper information is just part of making a meaningful choice; it is also important to have the right support, confidence, and the ability to participate in collaborative decisionmaking. Seeing how people use different kinds of capital is a big part of paying attention to not just how many health-related resources people have, but how well they can connect material and non-material resources so that their own or group benefits are maximised. It's also crucial to take into account the normative pressures that characterise modern cultures. Among them are not only expectations towards specific healthy behaviours, but also the very fundamental matter of choice-making in urban settings, as many participants reflected on the fact that they had "no option but to select" given the amount of capital they had. As a result, choice has unquestionably become a significant factor in health inequality. This means that policymakers, in the context of capital and health-related capabilities, need to take into account the following: 1) the range of options for any individual is constrained by the total amount of different forms of capital he or she has to work with; 2) contexts and people's abilities to "play" their capital most effectively and; 3) the non-material aspects of the social structure.

This study's findings have revealed some of the mechanisms through which the possession of economic, social, and cultural capital influences the utilisation of healthcare services. Slum residents should be encouraged by the government to acquire a sense of ownership over their personal capitals. While accumulating economic wealth may be more challenging, creating resource rich social networks and acquiring favourable cultural heath capital and educational credentials may be encouraged. However, it is likely that this will not be enough to provide individuals with the resources they need to navigate complex health systems. This is because the social field in which the capitals give people advantages when it comes to getting health care is set up in a certain way, and what really matters are the relative differences in the amount of capitals the people living in the slums own. According to this interpretation, even if those who are "close to necessity" manage to accumulate significant amounts of social and cultural capital, their levels of capital will not be sufficient to provide them with the advantages enjoyed by those who already have substantial quantities of these capitals. The way we see it, this interpretation is in

line with Bourdieu's focus on the structure of the social field and fits with our findings that the composition of capitals at the individual level is just as important as the amount of capital. Interventions would have to focus on the conditions under which the correct form of capital enables the use of health services, in terms of policy terms.

### **CONCLUDING REMARKS ON STUDY IMPLICATIONS**

The significant conclusion of this study contributes to the increased knowledge of the need for innovative methods to address the factors that contribute to the bad health and well-being of Indian urban slum dwellers. It emphasises the importance of facilitating meaning-making processes as a means of promoting health and well-being in various slum environments. This information is critical for policymakers, public health practitioners, and anyone concerned with urban slum dwellers' quality of life. Everyday context impacts the health implications of slum dwellers' experiences, and their local culture of health practises serves to define their way of life. In everyday life, people make meaning by negotiating between their own interests and social morals and their ability to participate in living situations, which can be affected by their health. The meaning-making of health and its subsequent practises is anchored in habitus and is influenced by differences in the volume and structure of capitals, which are in turn related to differences in levels of healthcare utilisation and utilisation of resources. Individuals who face the challenges of maintaining good health demonstrate how health is woven into the fabric of everyday life as the social and material conditions in which they live generate distinct tastes, priorities, and lifestyles, which are then transformed into social practises and become an individual's "choice of necessity" in ordinary living. As a result, the activities of people with a limited pool of wealth are restrained to what is absolutely necessary, resulting in adaptation and acceptance of this requirement. Demonstrating a desire to be and act like everyone else in the neighbourhood necessitates the creation of a setting that meets whatever requirements they believe are necessary to feel like a regular person. Due to the health difficulties that needed to be addressed, tensions between being a meaningful social member and addressing personal requirements resulting from the health condition surfaced constantly. In order to achieve what was important to them, their meaning-making processes involve practical steps in managing personal needs that clash with more important societal needs every day. This causes meaning-making processes. As part of their existential meaning-making in healthcare, the slum residents were continually challenged to explore how to follow their personal beliefs and interests in the midst of their common everyday conditions. Thus, the findings of this study can be used to shape context-specific interventions aimed at: 1) strengthening slum dwellers' health-related decision-making in relation to their "choice of necessity" in daily life; 2) reiterating the importance of looking beyond economic factors and considering their immaterial, socio-cultural factors when examining access to healthcare; 3)

build existing social networks to serve as role models for beneficial health behaviours within peer groups; develop measures to alleviate stigma and aversion to associated normative behaviour so that slum dwellers can effectively disclose and care for their health; 4) provide comprehensive, inexpensive multi-sectoral therapies to ensure that slum dwellers receive the essential health benefits they require to care for their own and their families' health; 5) advocate for gender-sensitive ways of healthcare provision that involve rather than marginalise slum males, which can have a beneficial effect on the relational character of health practises and gender dynamics at the household level; and 6) policy can emphasise the importance of narratives by giving slum dwellers a voice and giving them a place to make meaning out of their situations in order to improve their well-being.

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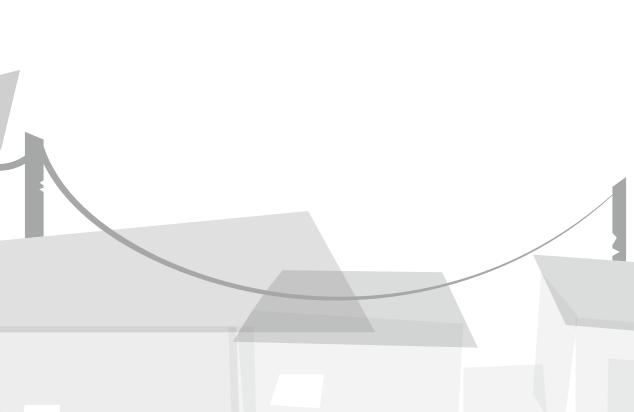
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## Summary



#### 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 healthrelated 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-thecounter 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 multisectoral 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.

Summary



## Valorisation



## VALORISATION

The purpose of the valorisation addendum is to describe the scientific and societal impact of this thesis. This chapter presents a summary of the societal significance of the thesis's presented work. This societal value will be expressed in terms of the practical relevance of the study's findings, the stakeholders for whom these findings are significant, and practical implications of the findings.

## RELEVANCE

Slum residents are extremely vulnerable to health and environmental dangers. They tend to settle around waste management facilities like landfills, sewage treatment plants, and industrial operations. Slums are also characterized by a hostile built environment, including poorly designed and unsafe living conditions; shared shelters, access to quality water and piped water supply; safe and clean sanitation, proper waste disposal, and restricted access to healthcare. All of these lead to high rates of illness and injury among the urban poor. Overcrowding, filth, air pollution, and contaminated water and food allow infectious diseases to spread in these locations. Drugs, alcohol, abuse, crime, social isolation, residential instability, and violence worsen slum inhabitants' mental health. At the community level, the health burden and disease morbidity factors among slum dwellers require immediate and concerted attention.

Over 93 million people live in slums (Census, 2011). Most families affected by urban development in India live in slums being resettled or rehabilitated. Examining slums and their inhabitants' lifestyles could help identify the most critical regions in need of assistance. Urban slum poverty, starvation, infectious diseases, and lack of clean water and sanitation contribute to India's high infant mortality rate. The challenges that plague India's whole slum population have thus far eluded the Indian government's control. To improve the health and well-being of the urban poor, urban health development programmes must surmount various obstacles. Some of these factors include the inadequacy of the physical environment and the lack of government assistance for health in slums, as well as a lack of identification, which inhibits the urban poor from having a legal voice. Efforts to enhance the health and well-being of the urban poor are hampered by a number of institutional and sociocultural impediments, such as cultural challenges to improved health for everyone and dysfunctional and uneven governance structures. Population increase, environmental deterioration, and global warming all contribute to the problem and work against a solution, so aggravating the current circumstance. Without gains in urban health, particularly for the urban poor, the Millennium Development Goals cannot be achieved.

Efforts should be undertaken to support and strengthen a comprehensive and needbased urban healthcare system. Volunteers and community health workers can help urban poor engage in self-care and environmental stewardship. The foundation of urban health programmes should be preventative and promotive care. The urban poor have an urgent need for primary care services that are both affordable and of good quality. It is necessary to develop public sector primary care facilities, but it is also crucial to support private providers, non-governmental organisations (NGOs), and community-based organisations (CBOs) that provide healthcare. In this context, governments should consider public-private partnerships. Expanding access to public healthcare for the urban poor requires a focus on both primary care and community-based referrals to secondary and tertiary facilities. Social health insurance and other inventive health care funding could reduce patients' out-ofpocket and catastrophic expenditures. Finding locally-tailored solutions to enhance urban poor access to healthcare involves operational research to establish effective community-level healthcare service models.

Strengthening social capital is vital for promoting health. Social capital can only be fully comprehended in its context for obvious reasons. The increased mobility and transient nature of urban poor habitations pose a danger to the sense of community, which is often strong in economically stable urban neighbourhoods and to a lesser extent in rural ones. Due to their proximity, urban dwellers may have quicker access to institutional help networks, but informal networks may be strained. Due to their economic and social disadvantage, individuals are more prone to become victims or criminals (stealing, trafficking etc.). This causes residents to feel insecure, which harms their emotional and psychological health. Food insecurity is just one of the numerous ways that poverty affects people's lives negatively, and it can lead to riots and even civil conflict. People's well-being often suffers as a result of migration and poverty due to the loss of culture, language, medical systems, and social structures. Since slum dwellers can't stand up for themselves, it's necessary to invest in the area's social capital so more people can get part in health efforts. Through social networks, people can obtain access to opportunities and resources. Resources are in social network architecture, not the person. Race, religion, nationality, or languagebased relationships are essential to many people's social expectations. Possibilities for upward mobility and good health can be boosted by acquiring access to various forms of capital, such as education (human capital), wealth and assets (financial capital), and social networks (social capital). Both social capital and cohesiveness are based on the idea that networks are useful and that network norms establish expectations of behaviour that benefit individual and communal goals. Collective social capital may indirectly improve health by boosting communities' ability to collaborate on health concerns (Kawachi et al., 2008). However, social capital alone is not enough to positively influence health and health behaviours. Poor communities can't be helped without additional government funding and public services. Instead,

it can be an indispensable instrument for maximising the value of existing resources and increasing the availability of new ones.

#### TO WHOM ARE THE RESEARCH RESULTS OF INTEREST?

This study aimed to explore how people in urban slums evaluate their own health, the factors that drive these perceptions, and how these beliefs affect their health-related behaviours and access to treatment. These findings are significant to public health researchers, clinical physicians, community health workers, informal health care providers, civic groups, faith-based organisations, and social workers. Non-specialists may find the findings useful. These results may provide light on the etiological pathways that should be considered when designing place-based public health interventions in a variety of complicated slum environments by think tanks and policymakers.

Our research showed that many of the urban poor choose to get health care from informal healthcare providers (IHPs) like spiritual and religious healers, shamans, and unlicensed medicine dealers. Among the urban poor, reliance on the more accessible and affordable informal providers is on the rise (Onwujekwe et al., 2011). This is due to a number of factors, including the limited availability of health insurance (Okoli et al., 2019) the necessity of making out-of-pocket payments for healthcare (Aregbeshola & Khan, 2021), and the uneven distribution of healthcare facilities and services in urban slums (UN Habitat, 2012). Our research indicated (Chapter 5) that traditional healers are culturally sensitive and have similar views on illness as their patients (Simwaka et al., 2007). They use a holistic approach, taking a patient's social life, relationships, external surroundings, and spiritual health into account (Simwaka et al., 2007). Drug dealers and unlicensed practitioners are popular for similar reasons; they are easy to go to, don't need extensive travel, and are often less expensive than conventional medical care (Courtright, 2000; Munthali et al., 2014). Since traditional healers are better familiar with culture-specific health challenges and traditions, their relationships with patients and their families qualify them to act as an alternative to conventional health care specialists. Given that traditional healers act as physician, counsellor, psychiatrist, and priest, it will be challenging to alter their traditional role in society (Soodyall & Kromberg, 2016).

At this point, the thesis provides health care practitioners and policymakers with a valuable perspective on what is relevant in health systems. What is more crucial is instilling in slum dwellers the habit of seeking medical care when they are ill. For this flexibility in providing healthcare experts, whether for clinical or informal care, they must be made available. We discovered that slum dwellers readily substitute health and well-being in the first place or deny its existence when they are forced to do with fewer resources. To encourage individuals to seek preventative or primary care, it is

necessary to provide them with inexpensive and culturally appropriate healthcare. Formalizing informal practitioners (IPs) is a strongly contested concept. While many organisations, particularly those representing formal providers, are wary of IPs, the reality is that IPs represent a substantial share of providers and that efforts to eradicate or ignore them have failed. Regardless of a nation's approach to IPs, it is essential to comprehend both the rewards and risks of their care in order to make prudent choices. In nations without comprehensive health care coverage, such as India, patients are sometimes restricted to attending providers whose rates they can pay. Because IPs are generally inexpensive, they are frequently the provider of choice for non-life-threatening conditions.

Our research shows that self-care is common at both the micro and macro levels (Chapter 4). On a smaller scale, people follow cultural norms and practises, such as taking concoctions and herbal remedies and praying to gods and spirits, as a way to stay healthy and get better. At the macro level, these include the larger socioeconomic and cultural contexts of a person at the family, community, and societal levels, as well as the demand and supply sides of the health service delivery system. Families are responsible for thorough self-care for mild ailments, decision-making on illness disclosure and health-seeking behaviour, and social and emotional support during illness and when seeking care. At the community level, social and moral support, lay referral mechanisms, and physical and psychological care support comprehensive self-care. At the micro level, people's health behaviour is negatively influenced by their belief in sickness aetiology; for example, those who believe cancer is caused by karma do not seek treatment; those who believe jaundice or leprosy is caused by luck do not practise proper cleanliness or limit alcohol use. Low levels of illness acceptance and treatment adherence are linked to high levels of fatalism. Family can negatively impact self-care by deferring self-care, procrastinating seeking care, receiving lower-quality care, failing to keep medical appointments, failing to comply with medical recommendations, and prematurely discontinuing long-term therapy. The best community-based self-care initiatives are those that draw from both beneficial lay and traditional self-care practises for a revitalised approach to individual health and wellness.

The thesis also indirectly argues that community health workers should promote and strengthen the informal network (Chapter 4) to address the unplanned and unscheduled needs of the poor, reduce the economic shock caused by health expenditures, and maintain the balance of other basic needs. Formal network expertise can be used to provide scheduled and structured care services (Wacker & Roberto, 2013). Self-care can boost community engagement and social cohesion, which can help a low-resource neighbourhood through a crisis. Our findings reveal that collective action and solidarity are considered desirable but only within the context of small, trusted circles (Chapters 3 and 4). But, how can this solidarity and collective effort be strengthened for the adoption of self-care in an ethnically diverse slum? The Learning Network for Health and Human Rights shows that small-scale individual acts, such as shared health and human rights education, can contribute to the common good (Douwes et al., 2018). Given the increased demand for care among community-dwelling individuals, the model suggests more people may engage in informal caregiving in the coming years, leading to the creation of vast and diverse care networks encircling the ill and dependent. Informal caregivers, such as family, relatives, friends, and neighbours, should be encouraged to indirectly implement self-care in the home of a person who requires support with activities of daily living and instrumental activities of daily living. This could be in the form of transportation to and from medical appointments and social events; companionship; emotional support; or help setting up professional medical treatment (Triantafillou et al., 2010).

Our findings remind policymakers that obtaining lay knowledge by giving slum dwellers a voice can provide an alternative way to understand social pattern of health and illness (Chapter 2). How some groups or classes of people get sick while others stay well requires the creative application of multiple disciplinary perspectives and methodologies in close collaboration with laypeople. This thesis argues that social science research largely excludes lay information from etiological discussions. Instead of trying to figure out what causes bad health, research focuses on lay explanations to figure out why different kinds of explanations are given. Blaxter (1992) also says that there haven't been many systematic attempts to combine epidemiological studies on social differences in health and research with lay people's biographical views on health and illness. This is strange because these two types of research have a lot to offer each other in terms of making study results more generalizable and valid and answering questions that one or the other leaves unanswered (Ferrarotti, 1983). There is more and more evidence that public health researchers, no matter what their specialty is, need to take into account the etiological views of lay experts.

## WHAT CAN RESULT FROM THE RESEARCH FINDINGS?

As stated previously, the purpose of the research presented in this thesis was to get a better knowledge of lay perceptions of health and illness from the perspective of urban slum residents. There were no projected physical products, services, processes, operations, or commercial activities. It is difficult to discover direct applications for this type of research. As our thesis demonstrates, the potential contributions of lay knowledge to our understanding of health and disease patterns are broad and varied. On the basis of common knowledge, our research seeks to develop more rigorous and exhaustive explanations for patterns of health and illness in modern urban poor neighbourhoods. The basic argument of this thesis is that laypeople develop 'expert' knowledge distinct from but comparable to that of public health professionals through a more or less systematic process in which experience is compared to life events, circumstances, and history. We are not arguing that "professional expertise" should be devalued. However, we propose that a much more reflective understanding of the formation of professional and amateur knowledge is required. Equally crucial is a broader awareness of how varied forms of knowledge can increase our understanding and guide policy. The "borderland" between "science" and "opinion", where many public health challenges exist, is a crucial venue for assessing the validity of this type of democratic or public research.

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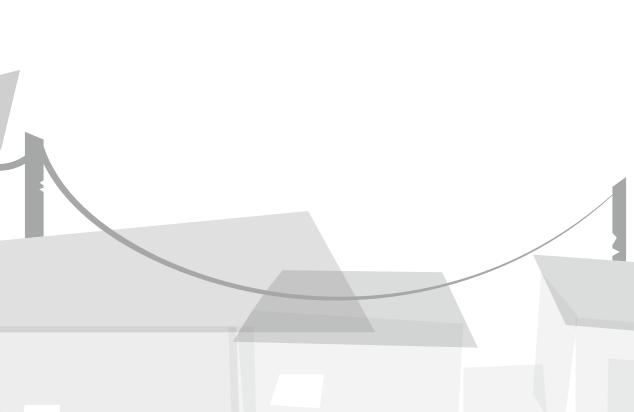
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Valorisation

V



# Appendix



# INTERVIEW GUIDE FOR INDIVIDUAL INTERVIEWS WITH SLUM DWELLERS

#### Introduce yourself to the study participant

- i. Explain the general purpose of the study: To learn about lay understanding of health and illness and the related health seeking behavior in the urban slums
- ii. Aim of the interview: To learn about general health and illness and decision and choices in healthcare practices
- iii. Expected discussion time: Aproximately1 hour
- iv. Why participant's cooperation is important: Your participation and cooperation is very important for the success of this study as we would like to learn from you; your opinions, perceptions and experiences with health and illness and health seeking behavior in general
- v. What if you don't want to be part of the study? Being part of this study is important but it is up to you to decide. If you do not want to take part in this study, it will not affect in any care or treatment you receive. It will not cost you or your family anything
- vi. What will happen with the collected information and how the study participants will benefit: The information collected will be used only for the intended purpose of meeting the requirements of the PhD candidate and for advising program implementers on how to improve healthcare services provision and uptake in urban slum areas of India
- vii. Use of tape recorder: To be able to keep a more accurate record of our discussion I am proposing to use a tape recorder; if you don't mind. Do you mind if I use a tape recorder? (Observe whether agrees)
- viii. Confidentiality: The information that we will discuss here today will remain confidential, no one apart from the research team who will know what you said and it can't be directly linked with you. This data will be published and shared with the scientific community but your name will not appear in any of these publications
  - a. Do you have any question?
  - b. Consent: Do you agree to take part in this discussion?

#### Section A: Background characteristics

- 1. I would like to know more about you and your family:
  - a. What is your name
  - b. What is your age?
  - c. What is your caste?
  - d. What is your religion?
  - e. Are you married?
  - f. What is your native place? If yes since how long you have been here?
  - g. What is the reason behind migration

- h. Have you been to school? If yes, up to which level?
- i. What is your source of income?
- j. What is your spouse's education level?
- k. What is your spouse's source of income if any?
- I. How many children do you have?
- m. Perhaps, you could now tell me a little bit about your family members. Who do you live with here? And how do you relate with them? (For interviewer: Names are not important but give number and fill in the table below)

S /N	Relationship	Age	Gender	Religion	Education Level	Source of Income
eg	Aunt	20yrs	Female	Hindu	Std 4	Petty trader
1						
2						
3						
4						
5						
6						
7						

- 2. Interviewer observe during the field visits: Housing condition, infrastructural condition of the slum areas such as water supply condition, sanitation and hygiene condition, drainage and sewers, healthcare facilities etc.
- 3. Listing and Ranking Technique based on needs

Slum Name and area(core/periphery)			
Need for Healthcare			
Housing			
Sanitation and water provision			
Solid waste management			
Sewage and drainage system			

#### Section B: Perception and lay knowedge on health and illness

- 1. How do you feel about your general health condition ?
- 2. As you have already told me that you feel that you are fit/unfit or healthy/ unhealthy could you please tell me a little more about this
  - a. What makes you think you are healthy/unhealthy? (probe: reasons for developing such feeling of being healthy/unhealthy)
  - b. How do you think a healthy person looks like ? (probe: reasons for why he/ she thinks so)
  - c. How will you define health and well-being then? (Probe: all the possible reasons of defining health)ss
  - d. How do you think an ill person looks like? (probe:reasons for why he/she thinks so)
  - e. What makes you think the illness has been caused ? (probe: all the possible reasons)
  - f. Do you think the neighbourhood where you stay have an impact on your being healthy/unhealthy? If yes/no can you explain how? (Probe: broaden the discusion to include all the physiological and psychological aspects of the slum neighbourhood)
  - g. Do you think your lifestyle and your behaviours have an impact on whether you stay fit or stay unhealthy? (Probe: for healthy and unhealthy practices, traditional norms & values, stress, loniliness, worry, social network, economic hardship, job insecurity, migration issues, pattern of diet etc. based on the responses)
  - h. What makes you think that in what ways these factors (Qn g. above) contibute in making you healthy/unhealthy? (Probe: according to the given response explore more on incidents, stories, consequneces, coping mechanisms etc.)

#### Section C: Etiology or causes of illness:

- 1. Let us continue our discussion by talking more about illnesses in your neighbourhood. What are the illnesses found in this neighbourhood? Probe:
- 2. What are the illnesses affecting adult people more? (Probe for all illness affecting adults in the community.)
- 3. What do you know about it? (Probe: local names, what they hear about it, all possible causes, reasons for such associations)
  - a. Which illnesses are issue of concern? Why? Probe:
  - b. Before you were diagnosed with an illness in the past, did you know that you might have been suffering from it? (Probe: If yes, how did you know, how it started, initial symptoms, symptoms that identify persistence of illness and which ones are most common?
  - c. What was the first thing you did after noticing the symptoms? Why? (Probe: for each action taken and the reasons behind)

- d. What about the role of evil spirits for example? (Probe: all traditional beliefs about the cause of illness)
- e. [Start like a story Vignette] Let us talk about such illnesses you think are usually not discussed and associated with stigma, fear and isolation. (Probe: all those illnesses)
- f. Why you think they are intentionally avoided and its disclosure can lead to such stigma, fear and isolation? (Probe: all the causes and consequences as per responses)
- g. Have you or anyone in your family experienced such illnesses?
- h. If yes, how did you/they feel when first diagnosed? Probe: (broaden the discussion reflecting on the gender-specific behaviour)
  - i. Was this the first time to hear about the illness or you already heard about it?
  - ii. Where did you hear about it? And what information did you have?
  - iii. What did you do when you were first diagnosed with the illness? Probe: did you tell your family/friends and other people about it or hide it? Why?
  - iv. Do you purposefully choose a person for disclosing a specific illness? Why (Probe: intentions, types of disclosant, consequences for disclosing)
  - v. How you coped up with the existence of such illnesses?
  - vi. In your opinion, what do other people in the family think about you because of having the illness? Why?
  - vii. Who was with you or helped you decide on the actions you took? Why did you involve this person? (Probe: relation with the disclosant, for all reasons and actions taken behind)
  - viii. What support did you needed from your family or friends to be able to seek care for your last illness episode? (Probe: what support was needed and who gave it, what support usually is expected during illness course)

#### Section D: Health-seeking behaviour (broaden the discussion reflecting more on gender-based health seeking behaviour built on the results found in pilot study)

- 1. Tell me about the process that you follow in your healthcare regime. (Probe: for all preventive measures, for each action taken for specific illness and the reason for doing so)
- 2. Before you went to the hospital, what other treatments did you use? (Probe: according to the type of treatment used)
  - a. Self-medication what type of medicine was used? What was the source of that medicine? Why self-treated first?

- b. Bought medicine from drug stores what type of medicine, who advised that medicine? Why buying drugs from the shop before hospital consultation?
- c. Use of traditional herbs which ones were used? What was the source? Who advised their use?
- 3. Now let us talk a little more about the use of traditional healer's services for treatments, what is your experience on this? (Probe: have you ever sought traditional services for your illness, how often you use the services? What made you to do so? What kind of services did you get?)
- 4. How was your consultation with the traditional /spiritual healer for your last illness episodes
  - a. What questions did the healer/prescriber asked you?
  - b. How were you diagnosed with the illness?
  - c. What did the healer/prescriber tell you about your illness?
- 5. What did the healer/prescriber explained to you on the use of the treatments suggested?
- 6. What opinions do you have concerning the whole consultation process? How else would you want it to be? What medicines were you prescribed to use? Probe: where did you get those medicines? How is it normally? How much did you pay for medicines? What do you think about those costs?
- 7. How long did you use the treatments? Why? (Probe according to response given: What made him/her to stop before finishing the dose? Or why he/she had to finish the dose?)
- 8. How are you feeling now after using the treatments you just described? Probe: what other medications have you used after the ones you just told me? Where did you get them? Why?
- 9. What do you think of the treatments that you were prescribed for your last illness episode? (Probe: about timing of the dosage, duration of the dose and number of doses? Perceptions of the effectiveness, side effects etc)
- 10. Where will you seek treatment if you get ill again? Probe: What medicine would you prefer using in treating you get ill? Why?
- 11. How does the cost of care and treatment with the traditional/spiritual healer for your last illness episode affected the welfare of your family? (Probe: How did you cope with this problem)
- 12. [Start like a story Vignette] What preparations were you to make before deciding to seek clinical treatments? Probe for medical costs (consultation and treatment; distance/transportation costs) other responsibilities that had to be met first (e,g looking after the family etc) and how they affected his/her decision to seek care?
- 13. How was it then you went to the health facility after using self-treatment/herbal treatment/spiritual healing/other traditional methods you mentioned? Probe:
  - a. What prompted his/her use of the health facility services?

- b. Who was involved in making decisions for seeking medical treatments?
- 14. Tell me a little more on the processes of seeking clinical care at the health facility?
  - a. How long do you have to wait before seeing the specialist?
  - b. What about medical costs consultation and treatment costs?
  - c. How long did you go with the same symptoms before being diagnosed with illness?
  - d. What instructions did the health care worker gave you on using medications? Do you understand well? How can you describe your relationship with the health care worker?
  - e. What is your opinion concerning the way consultations are made? How would you like it to be?
- 15. Tell me a little more about illness self-treatments at home? What challenges are you facing? (Probe: How does cost of care and treatments affect your continuity with the use of the recommended treatment?)
- 16. Do you face any lifestyle changes due to illness or for initiating treatment? Can you please explain again a little more on how you feel about the life style changes prescriptions? Probe: How are you managing with the life style changes prescriptions? What are the challenges faced and how do you cope with them?
- 17. How does the cost of care and treatment for illnesses affect the welfare of your family? (Probe: How do you cope with this problem?)
- 18. How do you feel about the treatments that you are using? (Probe: for personal experiences and feelings on the medicines used and lifestyle change practices; How is it helping you? Do you think there is need to continue using as was advised?)
- 19. Where is the other place that you went to seek care after initiating treatment? What type of service did you get? And what are the reasons for doing that? (Probe for any type of care eg. prayers, dietary restrictions, spiritual healing etc.)
- 20. What consequences one can get as results of having illness? (Probe: for social, economic and health consequences, for any specific illnesses according to response)
- 21. What do you think need to be done to help people when they are ill? Probe:
  - a. What can health care workers do to help people with illness to comply better with your choice of treatment regimen? probe for both continuity with treatments and life style changes
- 22. What support do you get from your family and friends in taking care of your clinically based lifestyle prescriptions? (Probe: Who is providing most of your care/support and what are the tasks that this caregiver carries out for you)
- 23. What do you think needs to be done for patient caregivers/family members to provide care when they receive medical prescriptions?
- 24. Is there anything concerning any illness that we have left /missed and you would like to share with me? What is it?

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## **CURRICULUM VITAE**

Moumita Das was born in Assam, India, on November 27, 1985. She is the daughter of Jatindra kumar Das and Gopa Das, and sister of Manali and Sujoy. She completed her secondary education at North Lakhimpur College, Assam. In 2006, she graduated with a degree in Anthropology from Gurucharan College, Assam. In 2009, she earned a master's degree in anthropology from Visva-Bhaarti University in Santiniketan, West Bengal, with a specialisation in social and cultural anthropology. In January 2010, she became a PhD student at the



Institute for Social and Economic Change in Bangalore and finished her pre-PhD coursework. In November 2011, she was accepted and began her PhD studies at the School of Public Health and Primary Care of the Faculty of Health, Medicine, and Life Sciences at Maastricht University as part of a student exchange programme. With her official appointment with Maastricht University coming to an end in 2015, she began working in several research and teaching positions. She began freelancing for a variety of qualitative faculty development programmes. She participated in numerous CSR projects. She also participated as an invited faculty member in qualitative research seminars. In addition, she taught Sociology, Public Health, and Social Work to postgraduate students. She and her husband, Dr. Ayanendu Sanyal, are happily married.