

# VU Research Portal

## Understanding gendered challenges of noncommunicable diseases in the slums of India

Lumagbas, L.B.

2017

### **document version**

Publisher's PDF, also known as Version of record

[Link to publication in VU Research Portal](#)

### **citation for published version (APA)**

Lumagbas, L. B. (2017). *Understanding gendered challenges of noncommunicable diseases in the slums of India: Towards a perspective on communal care*. [PhD-Thesis - Research and graduation internal, Vrije Universiteit Amsterdam].

### **General rights**

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

### **Take down policy**

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

### **E-mail address:**

[vuresearchportal.ub@vu.nl](mailto:vuresearchportal.ub@vu.nl)

## **Chapter 6**

# **NCDs and their risk factors in Indian slums: the communal care perspective**

### **Abstract**

The epidemic of non-communicable diseases (NCDs) and their risk factors in the slums is an urgent issue that further aggravates the vulnerable condition of slum residents. In India, this situation is exacerbated by the limited health infrastructure locally available to slum residents. In view of this situation and the limited literature on the subject of NCDs in slums, this study aims to identify and explore the practices of social relations and networks in slum settlements that have been developed to confront NCD risks. Three explorative in-depth interviews were held together with 12 individual interviews with members of the community. Field observations in the slum were also recorded for several months, and data were analysed using the grounded theory approach. The findings show that rudimentary networks have emerged that are attempting to mitigate NCD risks within the limitations imposed by the environment. Actions to support one another in both the social and health domains appear to emerge from the shared experience of living in the slums. These actions take the form of care or informational support that also serve to enhance elements of social capital, such as trust and reciprocity, among members of the networks. The findings also suggested that the care provided through these networks is superseding provision in local health facilities because it is responsive to non-health needs. Thus, it is argued that the ethics of this care should provide the basis for strengthening the features of slum networks that are addressing NCD risks.

## 6.1 Introduction

There is a growing recognition among policy makers and academics for the need to address the risks posed by NCDs to slum dwellers. Occupying just 4% of the world's surface, slums are home to almost one billion people, with 25 million more people added to this number every year (UN - Habitat, 2004). The destitution of their built environment is fertile ground not only for infectious diseases, but also for NCDs and their associated risk factors. Cross-sectional surveys in slums in Bengaluru and Delhi have reported hypertension prevalence as 12% and 17.4%, respectively (Gowda et al., 2015; Panesar et al., 2013). In Indian slums, there is growing evidence that the epidemiological transition has progressed to a point where chronic conditions are starting to afflict the poor more frequently than the rich, compounding the burden already posed by infectious diseases (Bhojani, Beerenahalli, et al., 2013; Gupta, Singh, Seth, Agarwal, & Mathur, 2015). This 'indication of a reversal in the socioeconomic gradient for certain chronic conditions in India' holds implications for policy makers given the higher burden NCDs would impose on the urban poor compared to India's wealthier classes (Bhojani et al., 2013, p. 312).

Understanding the risk factors for NCDs in slums also depends on considering the social patterns of slum life and their influence on health. For example, an analysis of national-level data by Stroope (2015) found that social seclusion was associated with a higher rate of hypertension for women in India, while the husbands of secluded women were associated with a lower rate of hypertension. This pattern is also seen in the USA, where severe social isolation in elderly African American women was associated with a three-fold higher mortality over five years of follow-up (LaVeist, Sellers, Brown, & Nickerson, 1997). The empirical evidence for the influence of social relationships on health has been posited as a relationship where lower levels of social integration are deleterious to health, and higher levels are advantageous up to a threshold point (House, 2001). Thus, while social integration

may be an individual- and community-level determinant of NCD risk, it may also offer a mechanism to mitigate NCD risk in slum communities.

There are a number of hypothesised ways that social support and/or social networks can positively contribute to better physical, mental and social health, as shown in Figure 1 (Heaney & Israel, 2008). Supportive relations [arrow 1] can directly improve health and well-being by offering individuals companionship, intimacy, a sense of belonging, and self-assurance (Berkman & Glass, 2000), however they can also have indirect effects [arrows 2 and 4] through the greater access to contacts or information that facilitate problem solving. There are the benefits of heightening social capital within networks [arrow 4], so that general levels of trust and norms of reciprocity are strengthened (Ferlander, 2007): interventions to this end at the community level have been shown to increase community competence and capacity (Eng & Parker, 1994; Minkler, 2001). Research has shown that the effect of stressors – such as major life transitions (birth of a child, death of family member, etc.) – can be buffered through enhanced access to individual or community resources [arrows 2a and 4a] made available by social networks (Bohren, Hofmeyr, Sakala, Fukuzawa, & Cuthbert, 2017; Hodnett, Gates, Hofmeyr, & Sakala, 2007), and it has been speculated that a network could reduce the frequency with which stressors occur [arrow 3] (Heaney & Israel, 2008). Finally, there is evidence that social networks affect health-related behaviour [arrow 5] such as treatment adherence (DiMatteo, 2004), seeking help (Starrett, Bresler, Decker, Walters, & Rogers, 1990), giving up smoking (Palmer, Baucom, & McBride, 2000), and weight loss (Wing & Jeffery, 1999).

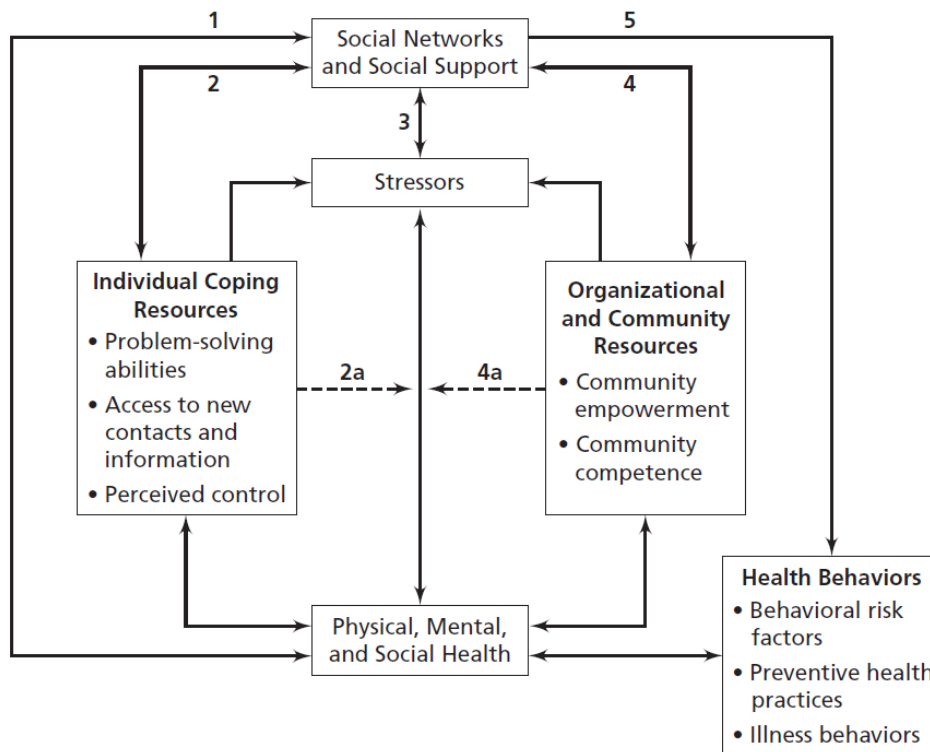


Figure 1. Conceptual model for the relationship of social networks and social support to health – numbered arrows explained in the text (Heaney & Israel, 2008). Two-sided arrows denote relationships of reciprocal influence, for example, health status can influence the extent to which a social network is maintained.

The interventions that target social networks can i) strengthen existing social network linkages, ii) develop new linkages, iii) enhance networks through community helpers, and iv) enhance networks via participatory problem-solving processes (Heaney & Israel, 2008). As globalization and urbanization in post-colonial countries contribute to slum settlements, the invisibility of slum residents' needs is rationalised through the idea that slums are synonymous with transience, criminality, disease and poverty (Dasgupta, 2013; Sengupta, 2013). By taking social interactions and social networks in slums as focal points of the research, there is the opportunity to identify linkages – and the practices within them – that currently meet some NCD-related needs. These linkages may provide an amenable

means for policy makers to mitigate NCD risk factors. The objective of the study is thus to explore the interactions maintained by slum dwellers in the face of NCDs and their risk factors.

## **6.2 Methods**

### **6.2.1 Study Design and Ethics**

As the study intends to present and explore the views, ideas, and actions of slum dwellers regarding the challenge of NCDs and their risk factors, qualitative methods were used (Hammersley & Atkinson, 1995). Through the collection of qualitative data, we could see and gain access to the practices, words, actions, and other signs that delimited the social space of the participants (Simon & Dippo, 1986). It gave us an opportunity to take a closer look at the various perspectives, the underlying structures of their situation, and the historical and material condition of the participants (Creswell & Miller, 2000). This enabled us to delve into the phenomena in the slum context (Baxter & Jack, 2008).

The study protocol received ethical approval from the Institutional Review Board of The Balm Institute in Tamil Nadu, India. We informed community leaders about the research, and started the data collection only after their approval was received. The purpose of the research and the procedures of the in-depth and group interviews were all verbally explained to the participants. Due to the low educational level of the participants, verbal consent was solicited rather than written consent. Likewise, interviewees were informed that they were free to end the interview at any time and could refuse to answer if they felt uncomfortable. To maintain confidentiality, interviews were held at a time and place convenient to the participants. No identifying information was collected.

### **6.2.2 Setting and Participants**

We conducted a field study in the slum communities in Chennai, Tamil Nadu, India. Chennai is highly urbanised; zero percent of the district population is classed as living in rural areas (Directorate of Census Operations Tamil Nadu, 2011). A total of 18 participants were invited to interview on different occasions. The criteria for the selection of participants were (a) being a resident of the slum community for a minimum of three years, (b) more than 18 years old at the time of the interview, and (c) willing to share insights on the topic. Some of the participants were recommended by the community leaders, but most voluntarily approached the researchers for interview.

### **6.2.3 Data Collection**

The data-collection strategy was semi-structured, iterative and flexible (Hardiman, 2004). Interviews were guided by the circle-in approach, where general notions identified during data analysis were refined over time through the personal experiences of interviewees and their interpretations (Guba & Lincoln, 1994). For example, starting with how participants view their health, illness, and treatment, they were subsequently asked to describe their experiences of health and illness. Following this, they were asked about their experiences of NCDs, the difficulties they have encountered with them, their risk factors, and how they have sought to manage these. Finally, participants were asked for suggestions about what could be done to counter NCDs and their risk factors in the community. Amendments were made to the interview guide based on the preliminary analysis of an initial interview.

The interviews were conducted in phases. The first phase comprised an explorative in-depth interview (P1) with two women and one man to gain preliminary insights into residents' perspectives on issues. One of the participants had been living in the community for more than 30 years, while the other two interviewees were born in

the community and had lived there for more than 25 years. The second phase comprised 15 interviews (P2) with slum residents that built on the foundations of the previous phase, following the interview approach mentioned above. All interviews were recorded with participants' consent. Field notes also formed part of the data collected. We had the chance to live in the slum for several months and integration in the community opened opportunities to experience the "structures" and "trends" (Willis & Trondman 2000, p. 395) that permeate the slums. This provided what has been described by Willis and Trondman (2000) as a 'concrete sense of the social' (p. 395) of living in a slum.

#### **6.2.4 Analysis**

We transcribed the recorded in-depth and group interviews. Applying a grounded theory approach, we used inductive coding to cluster the statements of the informants into thematic labels, and these were refined iteratively over the course of the interviews. We stopped holding interviews when saturation of data was reached. Member checking was used to check the robustness of the coding. Two main clusters of themes emerged and will be discussed consecutively in the results section: health and social needs, and caring networks. Following this, the relevance of these insights will be discussed against the literature and suggestions for policy interventions will be presented in the discussion section.

### **6.3 Results**

#### **6.3.1 Health and social needs**

A key theme from the discussions with slum residents was their unmet health and social needs. Although residents recognised risks in their lives, they often found the



limits of their situation or environment inhibited an appropriate response. W2 (P2), who works as a cleaner in a hotel in Chennai, said:

*It is tough to stop eating. You see I work during the evening. In the morning, when I arrive from work, I prepare the food of my husband and children. Then I sleep. Then when I need to do other chores, I do it all when I do not have work. But when I go to work. It's work, cook, sleep, and work again. I cannot expect to lose weight. I want to. I have been trying to because I want to have another child. But it's hard. I work at home. I work at the hotel. I am just so tired that food is a relief.*

Men also found it difficult to address their health risks alongside their livelihoods. While many women were homemakers or worked within the slums (e.g. on food stalls), men were more commonly observed working outside the slums and using transport more frequently as a result. Opportunities for 'male' jobs (e.g. labour) were highly competitive, and the demands of the work could affect their risk of developing NCDs. M1 (P2) is a fisherman and his wife is a cleaner. He shared his experiences:

*We needed alcohol, not only because we want to have fun. We go to the sea in the evenings. We stay there the whole night. To keep ourselves warm, we drink alcohol. It is necessary. It is really very cold. Hot drinks are not enough. When I don't have a catch, alcohol relaxes me.*

For many slum residents, there are limited support structures – formal or informal – that offer respite in their care for NCDs. This can place a large burden on direct family members or those suffering a disease. E1 (P2) is elderly and openly shared the fears she holds for her child. She said:

*My daughter started to have mental problems after marriage. She was always beaten. Then, the husband left her, taking everything. Everything.*

*After that she was no longer herself. If do not look after her, she will just wander away. We go to private doctors to help her. If she takes her medicines, she is back to her old self. But if she missed taking her medicines, she just wanders around. One time she removed all her clothes while walking on the street. I fear for her. As her mother, I am really afraid, especially now that I am already old.*

The health needs of slum residents can be compounded by the failures of public health facilities. Ergler, Sakdapolrak, Bohle, and Kearns (2011) found that cost, long waiting times, and lack of affective care experienced in public health facilities were the leading reasons behind poorer citizens' preference for private care. Participants in the interviews expressed similar sentiments. E3 (P2) said, *'I do not go to the general hospital for my diabetes. The doctors they don't see you well. They are always hurrying. They don't even ask how are you'*. Together with one of the slum residents, the researcher visited the outpatient clinic of a local public hospital where half a day was spent queuing before a doctor became available. The process began by waiting in line in order to be assigned a number that organised consultations in sequence, and these numbers were only distributed for a restricted amount of time. The second task was to wait for the number to be called, before then gaining a chance to see a doctor. While waiting in the hospital, the sheer number of patients placed heavy pressure on doctors' consultation time. After the consultation, W5 (P1), who accompanied during the outpatient clinic visit, noted, *'You are lucky. You are treated well'*.

Alongside their health needs and the insufficient care structures, some residents highlighted their lack of social relations. From their testimonies, the lack of ties to the community was a source of stress and discomfort. W3 (P2), a homemaker, said:

*There is no life after marriage. Before, I was happy. Free. Always laughing. Now, there is no life. I spend my entire days inside the house cleaning, cooking, washing and taking care of my family. I only go out to pick my son*

*from school, or when my husband can accompany me. I cannot go out by myself any more.*

Sujatha et al. (2003) found that homemakers in slums work more than eight hours every day. The contribution of women's (unpaid) contribution to the family can be overlooked, yet the social seclusion it creates can increase their dependence on their husbands. Social isolation was a recurrent theme in the slums, and the separation from the community can have implications for NCD risks, either for the secluded individuals themselves or the recipients of their care. O (P2) works as a cleaner and is her daughters' sole carer. At the time of interview, O was obese, hypertensive and had medication for diabetes:

*My husband left me for another woman, leaving me with our children. I have to work. My children, they are still very young. I cannot think about blood pressure and sugar. I am afraid for them. If I worry a lot, I feel dizzy. I cannot work. So, I don't concern myself with this. I am afraid not for me but for them. What will happen to them if I do not work? You have to understand life is difficult. There is no other way.*

There is evidence in the slums that the residents' difficulty in addressing their health needs can be exacerbated by their unmet needs in the social domain, and vice versa. The mutually reinforcing physical and mental stressors play a significant role in the presence of NCDs in the community. The following section explores the caring networks in the community that have attempted to mitigate NCD risks and fill the gaps left by the formal health system.

### **6.3.2 Caring networks**

Although there were slum residents who cared for themselves or received help from family, other members of the community had adopted the practice of caring for their neighbours. M3 was a retired government employee living alone as his

wife had left him. He was very thin and had had a cough for more than three months. His neighbour, W4 (P2), was the one checking up on him and ensuring he was eating every day. W4 said: *'He was not like this before. After his wife left, everything changed. He is no longer interested in living. His cough. It has been so long. I accompanied him to the doctor. He seems not interested in getting well'*. The act of looking after your neighbour was a common experience among the participants, as repeated by W7 (P2): *'My family and some of my neighbours were the ones who were helping me. They cooked my food. They help me get back'*. Yet in some cases this neighbourly act of caring had evolved into a tacit arrangement that was upheld by members of the network. W6, who was born in the slums and hospitalised for a long time, suggested this idea, saying: *'That time I was in the hospital, my family, friends and neighbours would take turns in taking care of me'*. Similarly, M4 (P1), whose mother was undergoing chemotherapy at the time of the interview, was able to rely on this arrangement for the care of her mother: *'Every time my mother goes for chemotherapy or I go to work and leave my mother behind, I rely on my neighbours. I have to ask them to watch over her. My sister is not here. My father is working. I know that I can trust them to help us'*.

During the collection of data, we established a friendship with four homemakers who were living on the same floor in a tenement building. Every day, one of the authors (LL) would pass by their floor and have a chat over snacks with them. Initially, although the wives were friendly towards each other, there was some inhibition towards us. As LL gained their friendship, the women became more candid and opened up, and LL learned that H1 was relatively new to the community. She had moved to the slum three years ago while the others have been living in the community for more than a decade. During one of the discussions, the group were worrying about H2 as her husband beat her and was constantly checking on her. In fact, as H2's husband wouldn't allow her to speak with the group, they planned to find a way that they could continue meeting, even for just a few minutes. They agreed that they would not talk when she answers the phone, and as soon as her cell phone would ring, they would immediately lower their

voices. Alongside the emotional support that they provide to each other, the group also exchanges information on how to lose weight, how to cook a particular dish, where they can get the cheapest vegetables and other topics related to their health. On one occasion, the group prepared a small meal for the sisterhood that had formed among us. H1 said: *'We are sisters. Life is difficult but we now have each other'*. The significance of *the sisterhood* and the relationships the group had established in the slums appeared instrumental in the group's lives, as it was a reliable source of both informational and affective support. Another informational support arrangement was observed in the practices of W8 (P2). She explained:

*After the operation and I started to recover, I knew that I can do something. And I think it is true. Now that I know some doctors and nurses in the general hospital, I had been referring them so they would not wait too long. Like the other day, I accompany Y in getting her medicines. I told her that she can get a discount card. She just need to ask. She is an elderly. She is supposed to get it. But you have to ask. You see, we help. It is not much but we help in the way that we can.*

The practice of providing this information to others didn't appear conditional on any reciprocal action on the part of the receiver, as it didn't among the female group described above. These acts of goodwill extended beyond information, as we observed that it was common practice for women to share and exchange salt and tomatoes with their neighbours without expecting a commitment to repay. Over time, the reasoning behind these actions was understood to derive from the common experience of the slums, and possessing an ability to act when other residents displayed a health or social need was highly valued. This is well illustrated by the comment of M4 (P1), who shared: *'You know, I wish nothing like cancer happens to anybody. But I hope, when it happens, they can have somebody, like my neighbours. It is not just money. It is being there'*.

## 6.4 Discussion

Although the conditions of the slums and scarcity of resources do not provide much hope or many opportunities to those living there, some rudimentary networks have emerged that are attempting to mitigate the limitations imposed by their environment. Actions to support one another in both the social and health domains appear to emerge from the shared experience of living in the slums. When a person has a health or social need and this need is recognised by others in their network, a response is given that doesn't seem bound to any kind of conditions or contract. That support networks should arise among individuals inhabiting and sharing a context is supported by Thoits (1995), when he stated that 'the most effective support-givers may be *similar others* – that is, individuals who themselves have successfully faced the same stressful circumstances that the victim is currently facing' (p. 67).

There are features of the slum's supportive relationships that provide both direct and indirect benefits. The unspoken agreements shared between a network that ensure homes are maintained if a person is sick directly benefit members, but they also serve an alternative means of cultivating social capital. Social capital 'refers to features of social organisation such as networks, norms and trust that facilitate co-ordination and co-operation for mutual benefit' (Putnam et al., 1993, p. 35). The network thus protects against stressors (in this case, the inability to maintain a household when one is sick) that are deleterious to health, while the acts of caring themselves may enhance the empowerment, participation, sense of common purpose and belonging, reciprocity, trust, and safety dimensions of social capital, as posited by Forrest and Kearns (2001). These types of networks seem a substantive means through which to attempt to mitigate NCD risk factors in the community, given that they are often – and sometimes unwittingly – serving that purpose.

Conceptions of social networks, such as 'a specific set of linkages among a defined set of persons' (Mitchell 1969, p. 2) or 'the web of social relationships that

surround individuals' (Heaney & Israel 2008, p. 190), although not explicit, assume a sufficient set of relations such that 'the characteristics of these linkages as a whole be used to interpret the social behaviour of the person involved' (Israel 1982, p. 65). Social networks create dynamics that are protective of their members, yet the slum networks observed often involved just two or three persons, so their practices may not be as insulated – or produce effects as large – as networks comprising five to ten individuals. Interventions designed for social networks or support relationships can aim to i) strengthen existing social network linkages, ii) develop new network linkages, iii) enhance networks through community helpers, iv) enhance networks through collaborative problem-solving processes (Heaney & Israel, 2008). The effects of social networks on members' health have been explored both through their quantitative features (e.g. number of linkages, frequency of interaction) as well their qualitative elements (e.g. perceived meaning and quality of interactions). Quantitative explanations of network effects – e.g. the network's benefits to health increase alongside the number of linkages – have produced conflicting results, while qualitative features illustrate a more consistent trend in protecting health, especially the intensity of relationships and their reciprocity (Israel, 1982). Thus, although networks in the slum community are currently small due to restricting gender norms, interventions that focus on improving the quality of these linkages are more likely to have a positive effect on health than targeting quantitative characteristics.

The findings discussed above yield considerations for policy and theory, such that the strengthening of positive features of slum networks could benefit their members and the wider community. Observing the slums, there were features of the community dynamics that would facilitate engaging and developing their inherent networks. These include their friendliness to outsiders, their generosity in sharing basic foodstuffs (such as salt or tomatoes), the safety within the slums, and the absence of hierarchy between different slum families. Building on these positive features, the following section proposes opportunities – arising from the

analysis of slum interactions – to enhance existing social networks in the slum community in order to mitigate NCD risk factors.

#### **6.4.1 Implications for policy and reframing care**

The following sections explore two mechanisms through which networks have had a positive effect on health in the slums, and discuss how these could be strengthened to offer greater health protection and comment on the implications of gender for theory and practice. These mechanisms relate to pathways 2 and 4 in Figure 1 in Heaney and Israel (2008) that theorises the relationship between social networks and health. Pathway 2 shows the reciprocal effects of social networks on an individual's coping resources and vice versa; an example being the greater access to contacts and information that networks can provide. Similarly, Pathway 4 indicates that networks can improve members' ability to garner community resources that relate to protecting members' health. Strengthening these pathways, through intentionally building networks and enhancing social support in communities, has been shown to improve practices of reciprocity (a form of social capital) that increases a community's competence and self-determination (Gupta et al., 2015). Initiatives targeting these mechanisms are suggested in Table 1. An interesting aside that arose from the analysis of the social networks was to observe an alternative ethics of care in the slum communities. Thus, the final part of this section, on reframing care, reflects on the ethics of promoting such networks as an alternative framing to the models of formalised care in the community, and argues that care provided through informal networks is more responsive to the health needs of the community than care currently offered in public health facilities.

##### ***Pathway 2: Improving access to individual and community resources***

The results provide a number of examples whereby networks or dyadic relationships among slum residents include tacit arrangements to help other



members of the group when someone experiences a social or health need. An example is the response of W7 during her pregnancy: *'My family and some of my neighbours were the ones who were helping me. They cooked my food. They help me get back'*. The practices of these networks have evolved as ways to alleviate some of the hardships associated with slum life, and they potentially already provide some tangible health benefits to its members. The meetings of these networks also constitute forums for information exchange, as evidenced by the gatherings of H1 and friends who discussed cooking, losing weight and each other's wellbeing. There is an opportunity to build health information and NCD risk factor monitoring capacity within these networks. Exchanging information in this way will heighten the ability of network members to solve problems related to both health and social life. Women's networks in other slum communities have similarly been observed serving this function. In a qualitative study of women diagnosed with TB in an Indian slum, Khan (2012) noted that:

Women did attempt to improve their life situations and rarely could one witness passiveness and complete helplessness despite the enormity, severity, and continuity of their sufferings. Women were adept at making complex decisions and at negotiating, varying, and shifting expectations for themselves, at the same time doing what they felt they must for themselves and their families. (Khan 2012, p. 14)

The impact of this informational support can be heightened if the existing network ties are strengthened, given that the exchange of new ideas will be facilitated by greater mutual empathic understanding (Heaney & Israel, 2008). In addition, developing new connections within groups can further empower members through the access gained to more contacts and information. There would be an opportunity to incrementally merge or increase the size of groups to help in this regard. There was evidence of supportive networks among both men and women in the slum community, however, it was observed – as is consistent with previous research – that women's networks were typically stronger and more responsive

than men's or mixed-sex networks. Ensuring that every member of the community, irrespective of gender, has the opportunity to forge or join a supportive network might be a fruitful policy for minimising community-wide NCD risk.

#### ***Pathway 4: Community competence and social capital***

Social capital has been defined as the 'resources characterised by norms of reciprocity and social trust' (Heaney & Israel 2008, p. 191). Access to these shared resources – such as, tacit knowledge, companionship or empathy – bestows a form of empowerment on the individual, which, as observed in the slum, is severely lacking among community members. The rare, literal examples of social capital observed in the slum community typically involved relationships of paternalism between residents and community leaders or politicians, who, in exchange for votes or future debts, could grant the residents access to (physical) resources. However, the acts of caring provided through the informal networks in slums may constitute a rare instance of social capital for residents. In this instance, they possess an 'ability to do something', or a small degree of agency through which they can act in support of another – the rarity of this feeling may in fact motivate the action. Expressed another way, the caring represents some freedom of choice and thus grants more control to residents and therefore less stress. By viewing the informal networks in the community as a medium through which social capital is cultivated among slum residents, an alternative set of opportunities arise with regards to minimising NCD risk factors. Previous research in the USA has linked community interventions that augment social capital through intentional network building with greater community competence for solving local problems (Eng & Parker, 1994; Minkler, 2001).

There is a high value placed on the infrequent opportunities that women have to interact with other women. These meetings provide the means through which an identity can be created that is separate from the one as a wife and mother at home. Khan observed a similar sentiment among women in another Indian slum:

*'Depending on the contexts, women sought help from kin group (such as during pregnancy/childbirth) or from other groups in order to be "away" from their kin, and in this process created solidarity despite differences'* (2012, p. 14). It was commonly observed that the journey to and queuing at the water well provided the only instance of social interaction for many women. Thus, creating additional spaces in the community that are safe for female relationships and networks to form would be key to raising the social capital of many women. The example of shrines is discussed in Table 1. Male slum residents, on the other hand, exist in highly competitive networks – as shown in M1's response – their role being to secure resources (jobs, money, food) for their family. As research states that networks of women are more likely to be close-knit, and hence sources of affective and instrumental support (Israel, 1982; Shumaker & Hill, 1991), there is a need to engage men in slums to move the role of networks away from a forum of competition to one of support. The structures of slums that surround daily life (poverty, immobility, lack of freedom of choice) mainly act to constrain individuals, so the instances of social capital that supportive networks provide should be a key argument used in recruiting men in the community. Male buy-in in slum communities is a crucial point for policy: their power over women has the potential to limit or prevent the launch of any such initiatives to strengthen social capital or networks.

Table 1. Suggested strategies to strengthen and develop existing slum networks for the mitigation of NCD risk factors

Intervention	Aim	Description
Peer-to-peer and buddy caring	Improving access to individual and community coping resources	Extending the practice of self-reporting NCD risk factors to the groups or peer-to-peer caring arrangements in the slum community could heighten health literacy, improve risk factor awareness and act as a social check-up mechanism for all its members. Adapting current practices in this regard would be best served using lay health workers, who can temporarily attend meetings, advise on self-reporting practices and lend materials. Various strategies have been employed to identify lay workers in the past (Eng & Young, 1992) but it is common practice that members of the community are asked to name individuals to whom they naturally turn for aid, advice and support. After the initial period of teaching, the lay workers can periodically visit groups and check the quality of information reported. Care must be taken that the information discussed does not become community gossip, and women in the community who experience significant social seclusion and oppression must not be isolated further.
Shrine building	Community competence and social capital	The building of a shrine provides added security to slum communities against displacement given the protection of religious monuments in India. They could also provide a space in which women can safely meet, and many shrines in India hold a room for exercise or meditation. Visiting places of worship is normal practice in Indian communities, and thus is conducive to the norms of the slum, meaning women can interact with less fear of sanction. The benefits of social interaction for health are well documented, yet balancing between the seclusion and mobility of women in slum communities is delicate given the health trade-offs for husband and wife – the more secluded the woman, the higher her blood pressure and the lower her husband's (Stroope 2015)

### ***Reframing care: Communal ethics of care***

An interesting aside that arose from the analysis of the social networks was to observe an alternative ethics of care in the slum communities. The implications described above call for a discussion of the ethics of providing, and advocating for, more care in the community, however the legitimacy of doing so also stems from a need within the community itself. Slum residents were often invisible to formal health providers – it was reported that visiting a public facility would require 10 hours in order to be seen by a doctor, and that prescriptions were written before any real consultation. The typical ‘ethics of care’ model stresses the relational aspects of human nature, in that our interdependencies are crucial to moral deliberation (Kittay, 2011), yet the disparity between the care provided in the slum community and the care offered in public health facilities was stark in terms of how each handled the carer–receiver relationship. The typical dyadic relationship between patient and provider, where each individual has equal ability to influence the other, does not exist for slum residents, and this is particularly true in countries where doctors are highly revered, such as India (Baru, Acharya, Acharya, Kumar, & Nagaraj, 2010). Providers exert undue influence over slum residents, and thus the ethical legitimacy of the relationship breaks down. As shown above, however, there is a model of care within slum communities that is appropriately addressing health needs – ‘communal ethics of care’.

Communal care ethics differs from traditional care ethics (Held, 2006) as it takes the community as the context in which care is expressed, as opposed to within the provider–patient dynamic. It considers the connected relationships of the people in the slums as its central tenet. By asking, *‘How can I help within the limits of my own capacities?’* communal care ethics acknowledges the personal capacity to care and the limits imposed on individuals by their conditions. It calls to attention both to their limitations and their capacities to help, without denying what they hope – the possibility of reciprocal care in the future. The ‘communal ethics of care’ possesses other important differences from the traditional model. First, there was recognition in the slum community that, given the environmental constraints, residents could often only help their neighbours or friends by ‘just being there’. Caring, in the traditional model, is usually borne of inclination – I care because I want to – or virtue – I care because I must. The ethics of care within slums appears to be something closer to ‘I care because I can’. There is a potential in these relationships for reciprocity of respect and influence that does not currently exist within the care ethics framework of the weak local health services. Where a medical consultation promotes vertical relationships of paternalism, the complementary communal care occurring in slums appears to provide legitimate benefits while also being empowering.

Although still nascent, the argument for further exploring the framing of communal ethics of care in slums follows from the position that such community-based care initiatives inscribe little on community practices compared to many other interventions developed outside the slum context.

Equally, there are opportunities for improving health and mitigating NCD risk factors within slum networks, when local health systems have failed to appropriately respond to residents' health and social needs. While the limited number of members in current networks poses a challenge to the proposed actions, developing a cluster of small networks that enhances horizontal social relations and provides access to new resources and social capital for its members holds promise. Further research is required to refine communal care ethics and understand the basis of these caring relations, alongside a practical need to test the association between stronger slum networks and health-related benefits.

## **6.5 Conclusion**

The influence of social relationships on health is an unexplored area in slum settlements. The communal care observed in slums' horizontal social networks are an overlooked social practice with the potential to mitigate NCD risk. These networks provide both direct and indirect benefits to members in the form of caring actions and greater trust, as respective examples. Health and social needs are being addressed through the practices of these networks in a way that is voluntary and independent of any expectation of future payback. The ethics of this 'communal' care differed greatly from care provided by local health facilities, the former achieving norms of reciprocity and respect and the latter being paternalistic. Ensuring every member of the community, irrespective of gender roles, has the opportunity to forge or join a supportive network might be a fruitful policy for minimising community-wide NCD risk.

## References

- Baru, R., Acharya, A., Acharya, S., Kumar, A. K. S., & Nagaraj, K. (2010). Inequities in Access to Health Services in India: Caste, Class and Region. *Economic and Political Weekly*, 45(38), 49–58. Retrieved from <http://www.jstor.org/stable/25742094>
- Berkman, L. F., & Glass, T. (2000). Social integration, social networks, social support, and health. *Social Epidemiology*, 1, 137–173.
- Bhojani, U., Beerenahalli, T. S., Devadasan, R., Munegowda, C. M., Devadasan, N., Criel, B., & Kolsteren, P. (2013). No longer diseases of the wealthy: prevalence and health-seeking for self-reported chronic conditions among urban poor in Southern India. *BMC Health Services Research*, 13(1), 306. <https://doi.org/10.1186/1472-6963-13-306>
- Bohren, M. A., Hofmeyr, G. J., Sakala, C., Fukuzawa, R. K., & Cuthbert, A. (2017). Continuous support for women during childbirth. *Cochrane Database of Systematic Reviews*. <https://doi.org/10.1002/14651858.CD003766.pub6>
- Dasgupta, S. (2013). Permanent Transiency, Tele-visual Spectacle, and the Slum as Postcolonial Monument. *South Asian Studies*, 29(1), 147–157. <https://doi.org/10.1080/02666030.2013.772826>
- DiMatteo, M. R. (2004). Social Support and Patient Adherence to Medical Treatment: A Meta-Analysis. *Health Psychology*, 23(2), 207–218. <https://doi.org/10.1037/0278-6133.23.2.207>
- Eng, E., & Parker, E. (1994). Measuring community competence in the Mississippi Delta: The interface between program evaluation and empowerment. *Health Education Quarterly*, 21(2), 199–220.
- Eng, E., & Young, R. (1992). Lay health advisors as community change agents. *Family & Community Health*, 15(1), 24–40.
- Ergler, C. R., Sakdapolrak, P., Bohle, H.-G., & Kearns, R. A. (2011). Entitlements to health care: Why is there a preference for private facilities among poorer residents of Chennai, India? *Social Science & Medicine*, 72(3), 327–337. <https://doi.org/10.1016/j.socscimed.2010.09.042>
- Ferlander, S. (2007). The importance of different forms of social capital for health. *Acta Sociologica*, 50(2), 115–128.
- Forrest, R. and, & Kearns, A. (2001). Social Cohension, Social Capital and the Neighbourhood. *Urban Studies*, 38(12), 2125–2143.
- Gowda, M. J., Bhojani, U., Devadasan, N., & Beerenahally, T. S. (2015). The rising burden of chronic conditions among urban poor: a three-year follow-up survey in Bengaluru, India. *BMC Health Services Research*, 15(1), 330.
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 105–117). London: Sage.
- Gupta, P., Singh, K., Seth, V., Agarwal, S., & Mathur, P. (2015). Coping Strategies Adopted by Households to Prevent Food Insecurity in Urban Slums of Delhi, India. *Journal of Food Security*, 3(1), 6–10. <https://doi.org/10.12691/jfs-3-1-2>

- Heaney, C. A., & Israel, B. A. (2008). Social networks and social support. *Health Behavior and Health Education: Theory, Research, and Practice*, 4, 189–210.
- Held, V. (2006). *The Ethics of Care: Personal, Political, and Global*. Oxford: Oxford University Press.
- Hodnett, E. D., Gates, S., Hofmeyr, G. J., & Sakala, C. (2007). Continuous support for women during childbirth. In E. D. Hodnett (Ed.), *Cochrane Database of Systematic Reviews*. Chichester: John Wiley & Sons, Ltd. <https://doi.org/10.1002/14651858.CD003766.pub2>
- House, J. S. (2001). Social isolation kills, but how and why? *Psychosomatic Medicine*, 63(2), 273–274.
- Israel, B. A. (1982). Social networks and health status: Linking theory, research, and practice. *Patient Counselling and Health Education*, 4(2), 65–79. [https://doi.org/10.1016/S0190-2040\(82\)80002-5](https://doi.org/10.1016/S0190-2040(82)80002-5)
- Khan, K. B. (2012). Understanding the Gender Aspects of Tuberculosis: A Narrative Analysis of the Lived Experiences of Women With TB in Slums of Delhi, India. *Health Care for Women International*, 33(1), 3–18. <https://doi.org/10.1080/07399332.2011.610541>
- Kittay, E. F. (2011). The ethics of care, dependence, and disability. *Ratio Juris*, 24(1), 49–58.
- LaVeist, T. a, Sellers, R. M., Brown, K. a, & Nickerson, K. J. (1997). Extreme social isolation, use of community-based senior support services, and mortality among African American elderly women. *American Journal of Community Psychology*, 25(5), 721–732. <https://doi.org/10.1023/A:1024643118894>
- Minkler, M. (2001). Community Organizing among the Elderly Poor in San Francisco's Tenderloin District. In J. Rothman, J. L. Erlich, & J. E. Tropman (Eds.), *Strategies of Community Intervention*. Itasca, IL: Peacock Publishers.
- Mitchell, J. C. (1969). The concept and use of social networks. In J. C. Mitchell (Ed.), *Social networks in urban situations: Analysis of personal relationships in Central African towns*. Manchester: Manchester University Press.
- Palmer, C. A., Baucom, D. H., & McBride, C. M. (2000). Couple approaches to smoking cessation. In K. B. Schmalings & T. G. Sher (Eds.), *The Psychology of Couples and Illness: Theory, Research, and Practice*. Washington, DC: American Psychological Association.
- Panesar, S., Chaturvedi, S., Saini, N., Avasthi, R., & Singh, A. (2013). Prevalence and predictors of hypertension among residents aged 20-59 years of a slum-resettlement colony in Delhi, India. *WHO South-East Asia Journal of Public Health*, 2(2), 83. <https://doi.org/10.4103/2224-3151.122937>
- Putnam, R. D., Leonardi, R., & Nonetti, R. Y. (1993). *Making Democracy Work* (STU-Stud). Princeton, NJ: Princeton University Press. Retrieved from <http://www.jstor.org/stable/j.ctt7s8r7>
- Sengupta, R. (2013). *Ecological Limits and Economic Development: Creating Space*. New Delhi: Oxford University Press.
- Shumaker, S. A., & Hill, D. R. (1991). Gender differences in social support and physical health. *Health Psychology*, 10(2), 102–111. <https://doi.org/10.1037/0278-6133.10.2.102>
- Starrett, R. A., Bresler, C., Decker, J. T., Walters, G. T., & Rogers, D. (1990). The role of



- environmental awareness and support networks in Hispanic elderly persons' use of formal social services. *Journal of Community Psychology*, 18(3), 218–227. [https://doi.org/10.1002/1520-6629\(199007\)18:3<218::AID-JCOP2290180305>3.0.CO;2-Y](https://doi.org/10.1002/1520-6629(199007)18:3<218::AID-JCOP2290180305>3.0.CO;2-Y)
- Stroope, S. (2015). Seclusion, decision-making power, and gender disparities in adult health: Examining hypertension in India. *Social Science Research*, 53, 288–299. <https://doi.org/10.1016/j.ssresearch.2015.05.013>
- Thoits, P. A. (1995). Stress, Coping, and Social Support Processes: Where Are We? What Next? *Journal of Health and Social Behavior*, 53–79. <https://doi.org/10.2307/2626957>
- UN - Habitat. (2004). The Challenge of Slums: Global Report on Human Settlements 2003–2004 *The Challenge of Slums: Global Report on Human Settlements 2003*. London: Earthscan 2003. *Management of Environmental Quality: An International Journal*, 15(3), 337–338. <https://doi.org/10.1108/meq.2004.15.3.337.3>
- Willis, P., & Trondman, M. (2000). Manifesto for Ethnography. *Ethnography*, 1(1), 5–16. <https://doi.org/10.1177/14661380022230679>
- Wing, R. R., & Jeffery, R. W. (1999). Benefits of recruiting participants with friends and increasing social support for weight loss and maintenance. *Journal of Consulting and Clinical Psychology*: American Psychological Association. <https://doi.org/10.1037/0022-006X.67.1.132>