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Understanding gendered challenges of noncommunicable diseases in the slums of India

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Chapter 1

Introduction

*When I was a child
I went to a Catholic school
Where
We wore iron-cripsed school uniform
Very shiny black shoes
Clean white socks
My friends
They went to school without slippers
Without breakfast
In the eyes of the child
We are no different
- Lily*

1.1 Aim of the thesis

Occupying 12.2% of the world's geographical area, it was estimated in 2015 that one billion people live in slums (UN-Habitat, 2015). Efforts to curb slum settlements and improve living standards led to a decrease in the proportion of the urban population living in slums between 2000 and 2014 – from 39% to 30% - yet the absolute population living in slums continues to increase (UN-Habitat, 2016; United Nations, 2015). In developing countries, there was an increase in the number of people living in slums from 767 million to 828 million between 2000 to 2010, and this number is projected to increase to 889 million in 2020 in the absence of control measures (UN-Habitat, 2010). The aggregation and formation of slums in the urban centres of most low- and middle-income countries (LMICs) will continue in the wake of globalisation, neoliberal economic policies and urbanisation (Davis, 2007). Alongside the varied implications of slum formation for policy makers, this rapid urban growth yields new levels of health risks for its residents.

Noncommunicable diseases (NCDs) have transitioned from a silent epidemic to an established pandemic. People with NCDs face long periods of disability and a diminishing quality of life over time. The World Health Organization, (2005a) labels cardiovascular diseases (CVD), cancers, chronic obstructive respiratory diseases (COPD), and diabetes as the four major categories of NCDs. Three of the top five leading causes of disability-adjusted life years (DALYs) globally are NCDs, and in 2016, NCDs accounted for 61.4% of global DALYs, compared to 28.0% for communicable, maternal, neonatal and nutritional diseases (Abajobir et al., 2017). The gap in the burden of NCDs between high- and low-income countries is closing, with the fastest rises in NCD prevalence now occurring in poorer countries (WHO, 2011). Two thirds of cancer deaths, 80% of CVD and diabetes death and 90% of COPD deaths occur in developing countries (Fuster, Kelly, &

Vedanthan, 2011). The situation of NCDs in LMICs is compounded by the fact that morbidity is occurring at a younger age as compared to individuals in higher-income countries (Dhillon et al., 2012).

The changing burden in developing countries from infectious to NCDs has been ascribed to a number of factors of economic development. These include: a shift in diets towards processed foods high in fats and sugars, changing norms such as a higher proportion of women smoking tobacco, and sedentary lifestyles and reduced in physical activity (Hancock, Kingo, & Raynaud, 2011). This higher prevalence of NCD risk factors in LMICs can affect the patient, family and society as a whole. In a review of household expenditures due to NCDs, Singh and Kumar (2017) found that patients and families can be burdened with out-of-pocket (OOP) payments in health systems lacking subsidised healthcare services. The costs of treatment can lead to the use of savings and loss of physical assets or property, which, combined with the loss of income due to sickness can pull families into a spiral of poverty. A conceptual analysis by Bloom et al. (2012) highlighted that NCDs are not just an economic concern at the individual level, but also have macroeconomic implications. They estimated that the global economic output loss due to NCDs and their risk factors would amount to US\$ 47 trillion over the next two decades: an amount sufficient to eradicate global poverty. Abegunde and Stanciole (2008) analysed the macroeconomic effects of cardiovascular diseases, stroke and diabetes, finding that the loss of physical capital reduces labour productivity, decreases access to factors of production and increases the use of personal savings, all of which serve to reduce national GDP.

The prevalence of NCDs in developing countries requires an urgent response. The health systems in LMICs however, are inadequately prepared to face the demands of NCDs and their risk factors. Healthcare infrastructure, predominantly organised for the treatment of infectious diseases, now has to reorient itself towards NCDs. The limited infrastructure and access to public services in slums have led to their typical association as fertile grounds for the spread of disease (UN-Habitat, 2010). Indeed, traffic accidents, respiratory infections and premature deaths due to air pollution, and communicable, vector- and water-borne diseases have all been linked to the destitution of urban infrastructure in slums (The Economist Intelligence Unit, 2015). Yet, there is evidence that the association between slums and non-communicable disease is incomplete.

Studies have shown that resident slum populations possess a high prevalence of non-communicable diseases (NCDs), such as diabetes (Ayah et al., 2013) and hypertension (van de Vijver, Oti, Agyemang, Gomez, & Kyobutungi, 2013). Cross-sectional surveys in slums in Bengaluru and Delhi reported hypertension prevalence as 12% and 17.4%, respectively (Gowda, Bhojani, Devadasan, & Beerenahally, 2015; Panesar, Chaturvedi, Saini, Avasthi, & Singh, 2013). The presence of NCDs in slums has debunked arguments that these conditions predominantly associate with individuals of higher socioeconomic classes. In some Indian slums, it has been reported 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 et al., 2013).

The clinical presentation of NCDs in slums follows from a high prevalence of risk factors, and whilst a lot of the projected rise in NCD risk in LMICs can be explained by population growth and longer life expectancy, this would not be valid in the cases of slums with limited healthcare infrastructure. There is also little evidence indicating the influence of slum residents' unique situation in the prevalence of these risk factors i.e., being an urbanised population living in poor infrastructure. The higher burden NCDs impose on the relatively poorer populations of slum communities thus presents a question to policy makers of what can be done. The question can only be answered by understanding NCDs and their risks in slums. It is a necessary first step in determining the types of solutions that could be applied in these contexts. The growing awareness that slums are localities of NCD and risk factor presence yields little knowledge on the impact of NCDs on the lives of residents of slums (Garg et al., 2014). Moreover, compared with the mainstream study of NCDs and their risk factors, NCDs in the slums have been minimally studied. This thesis aims to contribute to filling this gap.

The primacy of research into slums and NCDs has been affected by the popular association of NCDs as diseases of affluence. A further hindrance has been the lack of accurate census data describing the populations and conditions of slums. Researchers and policy makers have made use of proxy measures to describe slums in the absence of or incompleteness of robust data. Using geographical systems in their analysis of slum health, Diez Roux et al. (2010) concluded that these proxies were inadequately representative of the actual situation of slums, created a distorted image of NCDs that lead to ineffectual policies and programmes. This begs the question of how the relationship between slums and NCD risk factors can be explored.

The Social Determinants of Health (SDH) were proposed by Michael Marmot (2006) to understand the link between health status and the conditions in which people are born, grow, live, work and age. The SDH can influence the onset of communicable and NCDs through a multitude of individual- and societal-level factors, for example, income level, social status, the labour market, presence or absence of a welfare state and others. The SDH have shifted attention away from thinking of diseases as pure physiological deviations, and SDH research on NCDs was critical in debunking the myth of NCDs as diseases of affluence and finding that they disproportionately affect the poor (WHO, 2008). Looking at the SDH provides one way of delineating the link between NCDs and their well-established risk factors, such as smoking, obesity, alcohol abuse and poor diet. One could ask whether the high risk of hypertension in slums is the result of unhealthy behaviours or the stress of the lived reality (Marmot, 2004). Yet, the attention on risk factors often yields unclear courses of action for policy makers. As an example, research in Indian slums has linked the high prevalence of obesity in women separately to their lack of physical activity (Anand et al., 2007), and unhealthy diet (Misra et al., 2011).

Further, whilst key themes within the SDH seem relevant to an analysis of the slums – e.g., social exclusion, early child development, health systems, globalisation, urbanisation (WHO, 2008) – how could these be individually or collectively tackled by social policies? Raphael et al. (2012) demonstrated the ineffectualness of programmes aimed at alleviating the negative effects of NCDs on low socioeconomic status (SES) citizens and communities in Canada, and a review by Krumeich and Meershoek (2014) expressed the difficulties in translating the SDH into actionable policies, particularly ones responsive to the needs of low SES communities. Recognising the lack of policy-oriented research alongside the rises in slum formation and NCD prevalence in LMICs, there is an urgent need to explore the relationship between slums and NCDs, taking account of the social factors that shape this dynamic. The main research question of this thesis asks:

How do NCDs and their risk factors within slums affect the lives of residents?

This thesis aims to derive an understanding of the presence of NCDs in slums, and to explore the burden it imposes upon slum residents' lives. Field studies were conducted inside a slum in Chennai, India along with nearly seven months of ethnographic observation to supplement the research. The insights into the impact of NCDs in slums may be bound to the Indian or Chennai context, however, the research looks to contribute to operationalising the SDH in the context of slums for actionable policy for governments of LMICs.

*Ideas, removed from
our material reality,
are dead ideas.
- Lily*

1.2 Theoretical concepts

This section, presents the concepts and theories used in this study. This starts with a definition of slums, followed by working conceptualisations of NCDs, SDH, treatment adherence, embeddedness, ethics of care, social networks, and gender. Taken individually, each of these concepts is intricate. This section, hence, provides a description of each concept whilst the conceptual framework highlights their connection to one other as used in this thesis.

1.2.1 Slums

For the past 200 years, slums have been considered as the place or location for the majority of the urban poor (Davis, 2007). As a living space, they are characterized by the absence of many amenities, including clean drinking water (Rydin et al., 2012) and water for general purposes like cleaning, bathing and washing (Joshi, Fawcett, & Mannan, 2011), inadequate sanitation (Satterthwaite, 2016) and solid waste management (Satterthwaite, 2003), and unreliable sources of electricity leading to increased fire risks (UNEP, 2011). In addition, houses can be dilapidated, vandalism is widespread, and services, such as schools, roads, health services and other social infrastructure are either absent, sub-standard or remote. The insecurity of land tenure in slums (Tanaka, 2009) makes the risk of demolition or displacement a constant threat, and slums can often be situated in highly dangerous places, such as reclaimed areas (Galea, Freudenberg, & Vlahov, 2005), rubbish dumps, slopes (UN-Habitat, 2003) and flood-prone areas, due to become increasingly vulnerable as climates change (Chatterjee, 2010). Finally, noise and air pollution pose further dangers in urban slums, and the lack of material and economic resources highlight the deprivation of residents.

The lacking infrastructure and access to public services in slums have led to their typical association as fertile grounds for the spread of disease (UN-Habitat, 2010). Indeed, traffic accidents, respiratory infections and premature deaths due to air pollution, and communicable, vector- and water-borne diseases have all been linked to the destitution of urban infrastructure in slums (The Economist Intelligence Unit, 2015). Yet, there is evidence that the association between slums and communicable disease is incomplete. Studies have shown that resident slum populations possess a high prevalence of non-communicable diseases (NCDs), such as diabetes (Ayah et al., 2013) and hypertension (van de Vijver et al., 2013). Cross-sectional surveys in slums

in Bengaluru and Delhi reported hypertension prevalence as 12% and 17.4%, respectively (Gowda et al., 2015; Panesar et al., 2013).

Although slums take many names around the world (e.g. squatter, tambakan, favela, inner city, skid row, ghetto, bandas de miseria, bustee, estero, shanty town etc.), unifying characteristics have led to common conceptualisations. UN - Habitat (2003) defined slums as a place of human squalor marked by lack of services, poverty, debasement, criminality, and environmental degradation. On this definition, slum discourse is approached from two angles – the material and the communal aspects. On the material condition of the slums, Vlahov, Boufford, Pearson, and Norris (2010) asserted that the UN characterization of the slums is inadequate, arguing that slums can be further characterized by a lack of sunlight, poor ventilation and built on hazardous land unsuitable for development. The debate has highlighted the different usage, meanings, terms, and signification of the word slum, and its contestation and loaded connotations have led authors to advise discretion in its usage (Gilbert, 2007; Davis, 2007). This notwithstanding, the attention on slums' material and physical conditions is disproportionate to the dearth of literature on slum dwellers' lived experiences.

Contrary to the deprived image of slums in terms of deprivation, slum residents create bonds that tie the community together (Carchedi, 2008). Friendships amongst neighbours and relatives can become the foundation of social support networks that promote a positive identity and social cohesion. Thus, people in slums also have the opportunity to create trust, establish social networks and cultivate social capital (Pearson, Pearce, & Kingham, 2013). These bonds generate resilience amongst slum dwellers (WHO, 2005), offering avenues for inclusion and empowerment. On slum's communal aspect, Kalyan (2014) in review stressed that slums are not just about people's physical and material reality, but also concern the individuals who are living within these conditions. Slums as lived spaces and slums as a community of people are two facets of the same reality. Failure to account for these intricate and intertwined facets of the slums leave behind an appreciation of the role of slum residents in shaping their environment, which could subsequently undermine the way in which NCDs and their impact on slum residents is understood. In this regard, the context of Indian slums provides the material, historical and physical conditions in which the interaction and impact of NCDs and risk factors in the lives of slum residents are explored. Hence, it brings to the fore an understanding of NCDs from the slum residents' perspective.

1.2.2 Non-communicable diseases

Non-communicable diseases (NCDs) are characterized by long duration and slow progression. Individuals with NCDs are often burdened with extended periods of disability and a dwindling quality of life. WHO categorizes cardiovascular diseases (CVDs), cancer, chronic respiratory

diseases, and diabetes as the four major categories of NCDs (WHO, 2013). Risk factors for NCDs are classified into behavioural, physical, and biochemical groups. Alcoholism, smoking, diet and physical activities are behavioural risks, whilst, weight, height, blood pressure, and heart rate are identifiable physical risk factors. Finally, biochemical risk factors include blood glucose and cholesterol levels. NCDs have become the leading cause of death worldwide with 40 million people dying of such causes every year accounting for 70% of all deaths (Forouzanfar et al., 2016). Currently, three of the five leading causes of disability-adjusted life years (DALYs) globally are NCDs, and in 2016, NCDs accounted for 61.4% of global DALYs, as compared to 28.0% for communicable, maternal, neonatal and nutritional diseases (Abajobir et al., 2017)

1.2.3 Social Determinants of Health

The Social Determinants of Health (SDH), both as a concept and as a framework, is used to understand the social dynamics and impact of NCDs. Compared with the biomedical view of illness, SDH offers a wider perspective on the causes of diseases, such as social exclusion, employment conditions, gender equity, globalisation and urbanisation (WHO, 2008). It has identified multiple factors associated with the prevalence of NCDs in resource-poor settings (Marmot, Friel, Bell, Houweling, & Taylor, 2008) and established the mutually reinforcing association between poverty and NCDs, which leads to a downward spiral of impoverishment, aggravated illness, stigmatization, and social exclusion (Henderson et al., 2005). Hence, the SDH move beyond individual, clinical, physiological and behaviour factors towards a recognition of the socioeconomic and environmental elements influencing people and their health.

Some issues have been raised against SDH as a framework with a broad interpretation for the causes of disease. One methodological difficulty experienced is in operationalising SDH for measurement (Chaix et al., 2011). Another criticism pertains to the translation of SDH into actionable policies at the local or national level (Krumeich & Meershoek, 2014). These difficulties have been borne out into NCD policies and programmes that are unresponsive to the needs of very poor communities (Bolay, 2006; Subbaraman et al., 2012). Recognising these limitation, the social dynamics surrounding health were taken one step further and the focus was transferred to social networks, as evidence has shown their impact on health (Heaney & Israel, 2008) and their importance to the lives of residents (De Wit & Berner, 2009). As such, social networks can provide distinctive insights into the dynamics of NCDs in the slums.

1.2.4 Embeddedness

Embeddedness is used in this thesis as a heuristic to investigate NCDs and the related experiences of individuals in slums. Adopting the embeddedness approach stems from the

assumption that the experiences of the individual are not removed from the material, social and physical reality in which the person is situated. It serves as a guiding epistemological principle to understand slum residents' experiences, as based on their need to make sense and meaning of their condition. Hence, rather than seeing individuals' experiences in the slums as context-independent and guided by a calculation of costs and benefits, embeddedness emphasises the role of social relations and the context of which they form part to describe an individual's behaviour (Granovetter, 1985). For example, an 'embedded perspective' would disregard the notion that all individuals, regardless of context, act in the interest of reducing health risks. Instead, it would recognise the fact that individuals' behaviour can be influenced by the likely choices of other individuals, which highlights the importance of social and cultural norms in defining action. Alongside this, embeddedness intends not to reduce observed phenomena in the slums to distinct and tangible objects of society, but rather seeks to understand the coherent whole. This guides the research away from singular explanations of slum residents' experiences or theoretical impositions concerning their behaviour, and seeks continuing articulations of individuals' conditions so that the relationship between context and individual are maintained (Merleau-Ponty, 1996).

Embeddedness critically informed the ethnography as both a means to minimise bias, and to solicit information from slum residents in a manner that can better appreciate the influence of social and contextual factors in their experience. Whilst the understanding of slums and NCDs sought in this thesis aimed to be independent of theoretical assumptions, these concepts 'make operational' the process of quantitative or qualitative measurement in the slums. The presuppositions that these concepts or frameworks impart on the data based on their use are intended to be countered by the ethnographic observations that remain 'embedded' in the slum context. For example, to study NCDs and their risk factors in the slums, the Social Determinants of Health (SDH) is used to provide a broad perspective on the causes of disease that can account for contextual and social factors. Nevertheless, SDH is viewed as a sensitising concept that is suggestive of 'directions along which to look' (Bowen, 2006). It draws attention to particular features of social interaction, and serves as a starting point for building an analysis (Bowen, 2006).

1.2.5 Gender

Although sex and gender are often used interchangeably in health literature, they are distinct concepts (Inhorn & Whittle, 2001). Sex refers the physiological differences between male and female, whilst gender is a social construct distinguishing the distinct social roles and expectations between men and women. Gender is, thus, culturally specific and may vary considerably between and within countries. In health, gender is crucial in understanding the impact of diseases. It is not just the example of women being disadvantaged in a patriarchal

society, but about being a man or woman in a society whose gendered roles may constrain their agency. Gender can affect their pursuit of a healthy life, and the extent that this impact is still being resolved.

1.2.6 Treatment (non-)adherence

How closely patients follow a prescribed treatment regimen dictates how well they may respond to that treatment. Treatment adherence protects patients from further complications of disease (Osterberg & Blaschke, 2005), or at least from further deterioration (Conthe et al., 2014). Studies show a significant association between treatment adherence and better quality of life (Simpson et al., 2006) as well as lower mortality, and this is especially true for patients suffering from chronic diseases which typically require prolonged periods of medical care (Desai, Mahajan, Sewlikar, & Pillai, 2014; Wild, 2012). Given these factors, non-adherence to treatment is incomprehensible to many health professionals (Dunbar-Jacob & Mortimer-Stephens, 2001) due to the reduced benefits. In their survey, Berben, Dobbels, Engberg, Hill, and De Geest (2012) found that treatment non-adherence not only undermines the effectiveness of treatment, but also leaves the patient more vulnerable to further complications, faster deterioration and lower health-related quality of life.

Due to the self-evident benefits of treatment adherence, non-adhering patients are often subjected to prejudices or negative perceptions. They are considered to be exhibiting dangerous behaviours that require correction or modification (Kagee & Van der Merwe, 2006). The problem of treatment non-adherence however, is not solely about the patient and their calculated benefits; it is a complex issue that needs to be approached from patients', doctors', and health professionals' context and life narratives.

1.2.7 Social networks

A social network is a web of social connections and relations established over time, with the connections potentially serving functions, such as in the provision of social support (Heaney and Israel 2008). The concept of social networks was developed through work undertaken in a Norwegian village by Barnes (Barnes, 1954), which looked for a description of social relations outside of typical social units such as families or colleagues. In the early stages of life, an initial network is intimate-familial, but over time, other relationships are established that extend beyond familial networks into spheres of relationships such as work, school, hobbies and other linkages that create more complex and diversified networks. The structure of social networks is usually understood through the dyadic relationship between the individual of interest and other people in the network (Israel, 1982). Figure 1.1 presents the conceptual model for the

relationship between social networks and social support to health. It demonstrates and suggests a number of hypothesized ways in which social networks can positively contribute to better physical, mental and social health.

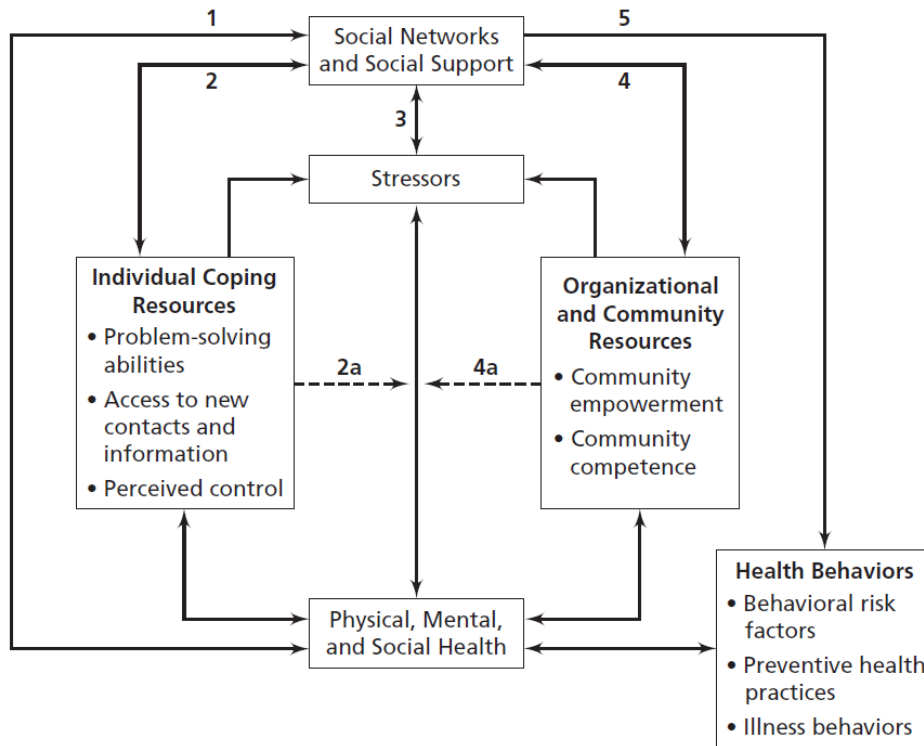


Figure 1.1. Conceptual model for the relationship of social networks and social support to health (Heaney & Israel, 2008)

Social relationships and the social support these provide are known to impact health, however the influence of social networks on health, particularly in the slums, has received less consideration. The limited literature stresses distinct characteristics of social networks that can bring about beneficial results, such as intensity, close proximity, density, and reciprocity (Heaney & Israel, 2008). Sluzki, (2010) noted in a review that as chronic illnesses can isolate patients, there could be opportunities for the creation of new networks. He cited, as an example, the observed networks of elderly people without family and who live in their own home: the elderly establish a close relationship with their primary healthcare providers or carers in these circumstances. Other concepts explored in this thesis – namely, treatment non-adherence, ethics of care and gender – also provide access to slum dwellers’ perspectives and experiences of NCDs, and these viewpoints are integrated into a deeper understanding of slum’s social networks.

1.2.8 Ethics of Care

Ethics of care is founded on the significance and centrality of human relations in human life. Whereas men often appeal to abstracted ideals, Gilligan (1982) concluded from her empirical

studies that women are more concerned about protecting and nourishing relationships when they have to make moral decisions. Her findings and discussions paved the way for an alternate explanation for moral decision-making – the ethics of care. In health, ethics of care is normally associated with the dyadic relation between the patient and the primary health care provider. Nursing has advanced and articulated ethics of care both in theories and in practice. The recognition of the patient’s and the care provider’s personhood, the nourishing of the relation, respect for each other, acceptance of the context and a more holistic approach to care are crucial in the care relation (Botes, 2000; Gastmans, Schotsmans, & Dierckx de Casterle, 1998). This does not mean however, that caring relations only take the dyadic form, as ethics of care are both personal and political concepts that can move beyond dyadic relations to communal interactions (Kittay, 2011; Tronto, 1993).

1.2.9 The conceptual framework

The study aims to elucidate and understand the complex interactions between NCDs and their risk factors, as well as the lived experiences of slum residents in India. The conceptual framework guides the study, making explicit what will be examined and how these concepts link to a more enriched understanding of NCDs in slums. Whilst the concepts are used differently, as explained below, they each offer a theoretical lens through which an understanding of what is happening is built (Figure 1.2). Four concepts permeate the entire investigation – slums, gender, embeddedness and SDH – whilst three – treatment non-adherence, ethics of care and social networks – provide relevant theory during separate studies. These groups are considered in sequence below.

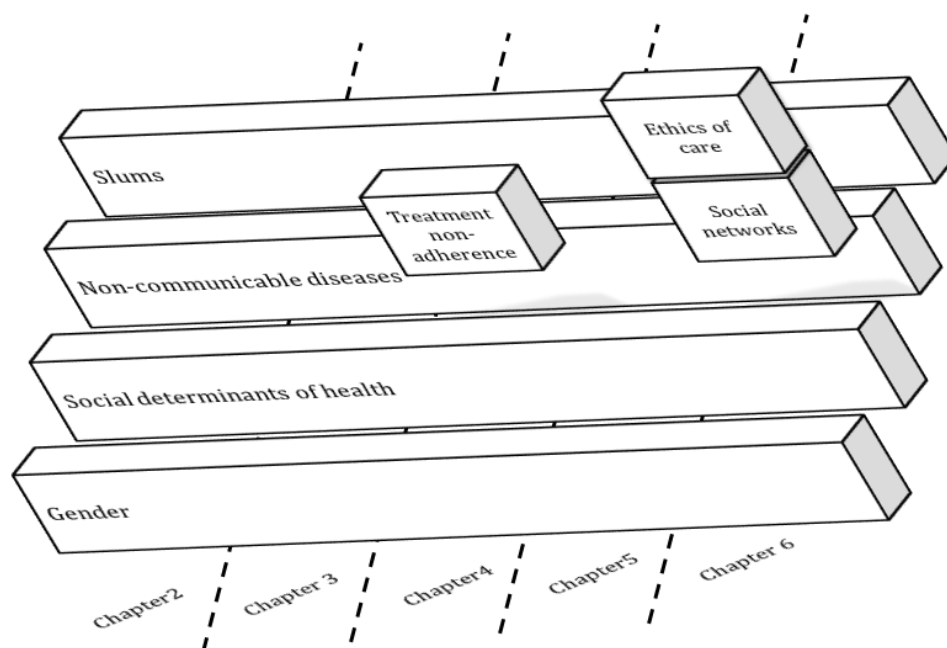


Figure 1.2. Conceptual framework visualising the relationship between concepts

The definition of slums provides the material, historical and physical conditions in which NCDs and their risk factors are investigated. It delimits the 'area of concern' of the research, guiding the methodological design – notably, the setting and study participants – in what should and shouldn't be considered relevant by the investigation. Following this demarcation, the notion of embeddedness is used to understand the experiences of slum residents as borne from the material, social and physical reality in which they are situated. Embeddedness serves as the epistemological basis for the knowledge claims of slum residents as they position their experiences of NCDs. Their articulation of NCDs, as well as the factors relevant to this understanding, offers the evidence through which the gap is bridged between NCD policies and their actual NCD concerns. The SDH thus offers the lens through which to understand NCDs and risk factors in slums. Whilst both NCDs and slums are established areas of investigation, their combination has been minimally studied, particularly on how it affects the lives of slum residents. The SDH sensitise the research, away from the limited perspective offered by the biomedical view of health and illness, and towards the complex, sometimes intangible connections of human life, such as gender, race, socioeconomic status and culture, which influence health status. In this regard, the SDH provide the starting points as to where the study should be looking with regards to NCD and risk factor understanding. Gender, in this research, emerged as an organic concept (Harding, 2004) permeating the issue of NCDs in the slums of India. The dichotomised gender roles observed in slums led to the identification of gendered NCD risk factor causal pathways, which have been inadequately considered in policy making for NCDs in slums. Further, it was recognized that current efforts integrate gender considerations into policies or programs have been ignorant of women's knowledge and experiences, relegating it to the shadow of men's perspectives. Thus, the influence of gender on the experiences of NCDs in slums was critically considered for the theoretical and practical insights this perspective generates.

The fourth chapter uses the above conceptualisation of treatment non-adherence to disaggregate this complex problem. The understanding, shaped by the holistic perspective of the research, recognises a multitude of factors influencing how closely patients follow a prescribed treatment regimen: individual, social and health system factors. The sixth chapter integrates two concepts into its analysis of NCD experiences in slums retrieved through interviews with residents: social networks and ethics of care. Recognizing the social aspect of disease presentation through SDH, the theory of social networks provides theory through which to understand the health protective effects of social support, as mediated through relationships or networks. Ethics of care emerged during the course of the study as a pertinent consideration to the actions of networks as they seek to address health-related needs. Thus, the ethics of care within the studied slum community is discussed, leading to an elaboration of the concept that serves as a future course of inquiry.

*To lay this world bare...
Is to allow us to rediscover the world in which
We live.
- Merleau-Ponty (1948)*

1.3 Research Design

In the first section, the urgency of the problems caused by NCDs and their risk factors in the slums was discussed. Given the orientation of healthcare infrastructure in LMICs towards infectious diseases, the rising burden of NCDs imposes further strain on weak healthcare services (Beaglehole et al., 2011a). Existing literature on NCDs in the slums is limited, and this lack of knowledge can lead to the development of policies and programmes that are incongruent with the actual health needs of slum dwellers. In the second section, the various concepts used in this study were presented. This section highlights the relevance of these concepts when presenting the design of the research methodology. It starts with the central research question and sub-questions, followed by the research approach and methodology.

1.3.1 Research questions

The main research question that directs this thesis is:

“How do NCDs and their risk factors affect the lives of the people in the slums?”

In view of answering this, five sub-questions were formulated:

- 1 *How do slum conditions influence the occurrence of NCDs and their risk factors?*
- 2 *How prevalent are NCD risk factors in slums of India?*
- 3 *What are the underlying factors that contribute to treatment non-adherence in the slums?*
- 4 *What are the responses of slum women in the face of NCDs?*
- 5 *How have residents responded to the challenges presented by NCDs and their risk factors in slums?*

Before discussing the studies that were guided by these sub-questions and the methodologies these used, the following section details the approach taken and setting of the research. The thesis is divided into three parts. Part 1 sets the scene of the research, identifying what is currently known about NCDs and slums, and why there is a need for further study. Part 2 shows the extent of NCDs and their risk factors in the slums. It seeks to uncover the prevalence of NCDs as well as confirm the falsity of the myth that NCDs and their risk factors are diseases of affluence

(Marmot, 2006; Diderichsen et al., 2012; Raphael, 2011). Part 3 focuses on the experiences of NCDs of people in the slums. This part of the research offers a view of NCDs in the slums drawn from the lived experiences of the people and examined in the light of their condition. It aims to generate evidence that is crucial to finding policy options responsive to slum dwellers health needs.

1.3.2 Research Approach

The philosophy behind Transdisciplinary Research (TR) guided this thesis. TR is anchored on the epistemological tenet that “being-in-the-context” allows experts and societal actors to formulate and co-create knowledge (Regeer & Bunders, 2009). It formally recognises various forms of knowledge, including experiential, and sees its value in the creation of policies (Bunders et al., 2010). Translating the TR approach into action, we adopted mixed methods in the collection of our data. It allowed us to gather data using various methodologies, which in turn, provided us with a wider coverage of the issue and a more in-depth perspective of the relation between NCDs and their risk factors and the lives of the people in the slums. Through the quantitative data, we were able to gather information that allowed us to describe and see the extent of the prevalence of NCDs and their risk factors. Through the qualitative data, we were able to access and delve into the meanings behind the actions and narratives of the people. Thus, the starting point in designing the research was prioritising knowledge co-creating opportunities. This influenced the decision to reside in the slums for six to eight months and undertake ethnographic observation alongside the fieldwork used in the studies. The observations recorded with slum residents intended to deepen the understanding of the situation as the context could validate experiential claims made by individuals as authentic articulations of their circumstances (Merleau-Ponty, 1996). Slum dwellers’ embeddedness highlights the situated-relational condition of slum residents. As the person is perpetually located in a situation of constant relation to the world, the foundation of knowing is set and the individual’s relational nature is affirmed. Hence, the combination of robust academic knowledge and experiential knowledge drives the search for a holistic understanding and integrative solutions for the slum context.

1.3.3 Setting and study population

In 2017, India is projected to be the world’s fourth-fastest growing economy (World Bank Group, 2017). Rises in exports and higher government spending have reversed the economic downturn caused by the global financial crisis. As India’s economy continues to grow, the ensuing trend of urbanisation concentrates a vast number of people inside a very small geographical area. This overcrowding of urban centres causes the development of slums. The Census of India indicates that 20-25% of the urban population live in slums, which is equivalent to 62 million people. NCDs

(CVD, diabetes, cancer, and COPD) are now the leading the cause of mortality and morbidity in India, and their long duration of treatment can pose great financial burdens, particularly for the relatively poor slum populations. In view of these contextual and temporal features, India is a good candidate to: 1) explore and explain the connection between slum conditions and NCDs because of its increasing urbanisation; and 2) conceive programmes targeting slum health since as India's continuing economic growth relies on healthy populations. Chennai, in the state of Tamil Nadu, is one of the most progressive states in India: as a centre of culture and arts, but also the locus of economic growth in the state. Chennai was chosen as the setting of the research given the following unique features of the city:

- It is highly urbanized- none of the population is classed as living in rural areas
- Chennai has the largest slum population in Tamil Nadu – 10,79,414 persons are reported to be slum dwellers in Chennai.
- As much attention is given to infectious diseases in the slums, limited attention has been allotted to NCDs in the slums.
- High involvement of the local government in policies and projects designed to improve the quality of life of the people.

1.3.4 Research methodology and studies

The research used mixed methods to analyse the impact of NCDs on slums in multiple ways. Mixed methods research investigates questions using different data sources and design elements so as to bring different perspectives to bear and triangulate findings (Patton, 2005). Five studies were conducted in this thesis (Table 1.1), supplemented by a period of ethnographic observation in the slums. The first was a literature review of both quantitative and qualitative research, whilst the second study analysed quantitative data to describe characteristics of the study population and their association with NCDs. The third and fourth study used mixed methods, whilst the final study is purely qualitative. The qualitative data aimed to identify the underlying reasons behind NCD risk factors associations in the slums. Each of the studies was guided by a sub-question linked to the overall aim of the research. These research sub-questions and their methodologies are discussed below.

Table 1.1. Use of methodologies in the research by study chapter

Chapter	Research sub-question	Methods	Data Analysis
2	How do slum conditions influence the occurrence of NCDs and their risk factors?	Literature review	Root cause analysis
3	How prevalent are NCD risk factors in slums of India?	Quantitative survey (n = 240)	Logistic regression (SPSS 21)
4	What are the underlying factors that contribute to treatment non-adherence in the slums?	Mixed methods: survey (n = 240), in-depth interviews (n = 4) and focus group discussions (n = 5)	Quantitative Data: Logistic regression (SPSS 21) Qualitative data: Grounded theory
5	What are the responses of slum women in the face of NCDs?	Mixed methods: survey (n = 425), in-depth interviews (n = 3) and group interviews (n = 10)	Quantitative data: Prevalence (SPSS 21) Qualitative data: Grounded theory
6	How have residents responded to the challenges presented by NCDs and their risk factors in slums?	Qualitative: explorative (n = 3) and individual (n = 15) interviews, field notes	Grounded theory

Part 1: The current context

Research sub-question: How do slum conditions influence the occurrence of NCDs and their risk factors?

The first part of the research, in Chapter 2, is a literature review aiming to trace the causal pathways of NCDs and their risk factors in slums. Through the use of root causal analysis (RCA), topics identified in the literature relating to NCDs in slums, their risk factors and the social components of disease were dissected. RCA is an analytical tool that, through a process of iteratively “asking why”, can organize topics into hierarchical trees by distinguishing symptomatic problems from deeper causes (Okes, 2009; Wagner, 2014). Topics were categorised into four larger themes that are representative features of slum contexts: scarce clean water, low education, lack of physical activity, and transportation (UN-Habitat, 2003). The social determinants of health (SDH), which established the association between diseases and socioeconomic conditions (Marmot, 2006), was used in exploration of NCD causal pathways in

slums. The SDH provides a lens through which to identify the causes of the causes, i.e. the “the social conditions that give risk to the high risk of non-communicable disease” (Marmot, 2005, p. 1102).

Part 2: The prevalence

Research sub-question: How prevalent are NCD risk factors in slums of India?

Against the high burden that NCDs impose around the world, the prevalence of NCDs and their risk factors in slums have been minimally studied. Several factors account for this situation, including: the lack of accurate census data covering slum areas (Neuwirth, 2007); limited disaggregated data between slum communities and other sectors of society (Manjrekar, Sherkhane, & Chowti, 2014), and; a lack of appropriate measurement methodologies for slums and other similar poor communities (Diez Roux, 2007; Diez Roux et al., 2010). This study aims to contribute to filling the gap in prevalence measurement in slums, whilst recognising the influence of gender in the association of risk factors. Previous research has highlighted the impact of gender on the prevalence of NCDs in slums (Anand et al., 2007; Yadav & Krishnan, 2008), thus identifying how NCD risk factors cluster by gender can reveal the causes of difference between men and women in NCD susceptibility. Understanding which risk factors affect by gender is important in the design of policies or programmes that intend to target entire populations.

Part 3. The insights and its analysis

The final part of the thesis focuses on residents’ narratives of their NCD and risk factor experiences. These experiences are used to understand the factors that lead to treatment non-adherence, being a woman in the slums, and how residents have responded to the challenges imposed by NCDs. This part of the thesis comprises three studies explored in greater detail below.

Research sub-question: What are the underlying factors that contribute to treatment non-adherence in the slums?

Sabaté (2003) stated that just 50% of patients in developed countries are adhering to treatment, with this figure expectedly to be lower in developing countries. Yusuf et al. (2011) found in their cross-sectional study that only 3% of CVD patients in India are actually taking their secondary medications. Actual measures of treatment non-adherence are lacking, particularly in slums, but there is an increasing recognition for the role of social and contextual factors in treatment (non-)

adherence. Given the unique contextual features of slums, the study aims to discern the underlying reasons that motivate treatment non-adherence through residents' perspectives.

Research sub-question: What are the responses of slum women in the face of NCDs?

The inclusion of women's concerns in clinical studies regarding CVD only began in the 90's (Inhorn & Whittle, 2001). Before that, women's CVD events were understood through the lens of men's CVD experiences, which resulted in the development of treatment procedures that were inappropriate. Women's NCDs are often correlated with their menopause (WHO, 2002), which has contributed to the marginalisation of women's NCD concerns. This study aims to identify the responses that women in slums show towards their NCDs and risk factors, in order to better understand the specific demands that these diseases make on them.

Research sub-question: How have residents responded to the challenges presented by NCDs and their risk factors in slums?

There is a growing recognition among academics and policy makers for the need to address the risks posed by NCDs to residents of slums by both academics and policy makers. By viewing the ways in which residents have responded to these challenges, the aim of the study is to identify avenues for exploration that may currently serve NCD-related needs. In particular, interactions amongst slum dwellers as they confront NCDs and their risk factors are investigated.

1.3.5 Validity

Questions regarding bias and validity were addressed in each step of the data collection and analysis. The first to be addressed was personal bias, with the potential of the researcher's long involvement and engagement in slum issues influencing her values and interpretation. Although this prior knowledge was invaluable for conducting research in a specific setting, actions to address personal bias were taken through the continuous discussion of the project with other members of the research team and self-reflection. A range of strategies was adopted to enhance the validity of the research: triangulation of data was achieved through using multiple data sources and methodologies; member checking of the data was performed; corrections were made to interview notes by respondents immediately after finishing; transcripts were sent to respondents for their comments or edits, and; saturation of qualitative data was sought. Finally, the informal discussions with the members of the community together with ethnographic observations undertaken by the researcher enriched and validated actors' perspectives and meanings within the social structures in the slums.

1.3.6 Outline of the Thesis

This thesis is structured into seven chapters. The first chapter provides a description of the rationale and aim of the thesis, an overview of the theoretical concepts underpinning the research and the design of research methods. Chapters 2 to 6 are based on separate articles submitted for publication, which successively look to answer the research sub-questions detailed above. The chapters are organized into three parts. The current situation of NCDs in the slums is explored in Part 1 (Chapter 1). Part 2 (Chapter 2) highlights the prevalence of NCDs and their risk factors in the slums, whilst, Part 3 (Chapters 3-5) integrates the experiences of slum residents with regards to NCDs and their risk factors. Chapter 7 presents the conclusion and discussion of the results.

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