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

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# Summary

## Introduction

Noncommunicable diseases and their risk factors in slums, particularly in Indian slums, is an urgent health concern. The combination of the pandemic of NCDs and the unabated slum formation, which in low-middle income countries is predominantly observed, drive the exigency of this health issue. Currently, the direst effects of NCDs and their risk factors, such as higher mortality at a younger age, increasing prevalence of NCDs and their risk factors, and increased morbidity, are experienced in LMICs. Exacerbating the situation is the limited capacity of LMICs' health infrastructure in handling NCDs' demands. NCDs further strain the already stretched LMICs' health systems, which are still burdened by infectious diseases.

Unfortunately, despite its criticality, limited studies have been conducted on NCDs in slums. The following factors influence this situation. First is the myth of NCDs as diseases of affluence. Second is the difficulty of securing accurate census data. The third is the socio-political and economic controversies surrounding slums. All of these factors combined lead to the observed incongruence between policies and programs targeting NCDs in slums and the NCD experiences of slum residents. It leaves behind some of the most vulnerable members of society.

Motivated by the circumstances as mentioned earlier, this research looked into NCD prevalence and experiences of Indian slum residents. It aimed in understanding the extent of NCDs and their risk factors in the slums as well as explore the NCD experiences of slum residents; hence, bringing in the slum view on NCDs. In this regard, the primary question of the research was how do NCDs and their risk factors affect the lives of people in the slums?

## **Theoretical background and study objectives**

The material and physical condition of the slums coupled with the mortality and morbidity associated with NCDs and their risk factors are realities whose conceptual clarification is more often descriptions or characterisations of what is seen and experienced.

Briefly, NCDs and their risk factors are chronic illnesses characterised by long duration, slow progression disability, and continuous dwindling quality. Slums, on the other hand, are lived spaces that are marked by human squalor. NCDs in slums bring together two of the most pressing concerns in today's society. In the face of these complexities, the Social Determinants of Health (SDH) highlighted that the narrow perspective offered by the bio-medical view of diseases fails to capture the complex interactions among the individual, diseases and society. Hence, SDH challenged the bio-medical paradigm of diseases and offered a broader perspective of diseases with emphasis on the significance of the socio-economic-cultural and political dimensions of diseases.

In this regard, SDH served as the sensitising concept that directed the study's starting point. It helped the study in determining where first to look as it provided an initial supposition necessary in attaining the objectives of the study. Thus, being said, the primary objective of the study was to understand NCDs and their risk factors from slum residents' perspective. The primary objective was dis-aggregated further into three sub-objectives clarifying the connotation of 'understanding' NCDs in slums.

1. To know the prevalence of NCDs and their risk factors in Indian slums.
2. To explore how the experience of NCDs and their risk factors affect the lives of people in slums.
3. To contribute both to the limited literature of the subject matter and the development of policies aligned with Indian slum residents' actual NCD concerns.

In understanding NCDs in slums, its unique condition served as the platform for the shared commonality of experiences. The notion was established using the embeddedness or *being-in-the-world* concept of Merleau-Ponty. In adopting the concept of embeddedness, the sense and meanings of the concepts of social network, treatment non-adherence, ethics of care and gender were grasped within the formulations and meanings attributed to it by slum residents: thus, giving shape to what is NCDs and their risk factors from slum residents' perspective.

## **Methods**

With Transdisciplinary Research Approach (TRA) as the fundamental ethos driving the research design of the study, Mixed Methods was used in the study. Mixed Methods enabled us to translate TRA into action.

For the review, literature was drawn from both quantitative and qualitative categories. For the quantitative data, both the WHO STEPwise survey and the adapted Morisky and Greene survey were used. The STEPs survey was used for the surveillance and monitoring of NCDs and their risk factors in the community, while the adapted Morisky and Greene survey was utilised for treatment non-adherence. For the qualitative data, various methodologies were employed; semi-structured individual interviews, group interviews, focused-group discussion and ethnography. The extensive array of the family of methods under the qualitative research gave the study the opportunity to mark the social actions and practices of the participants as theirs. It sought to understand the material, historical, socio and physical context of the issue by making sense of the meanings through actual engagements with slum residents and their condition.

## **Results**

Considering the objectives and sub-questions of the study, the results were divided into three parts. In *Part 1*, slums, as lived spaces, are amalgam of sub-standard

living conditions. It implies that it is not just being a poor woman with low education. It means being a poor woman with low education who is living in dangerous living conditions such as lack of clean water; sanitation and other similar attributions. Considering this unique condition, little is still known how slum condition contributes to the development of NCDs. This is, despite the fact that SDH paved for a more inclusive and broader understanding of diseases.

In this regard, slum context showed not only the gravity and urgency of both NCDs and slums, but emphasised that the existing framework – SDH- used in analysing NCDs in slums require a re-framing of its lens to Slums –SDH. In order to address the intricate complexities and connections between NCDs and slum condition as well as the challenges it posits in the lives of slum residents, SDH lens must be reframed.

In **Part 2**, the high prevalence of NCD risk factors found in both men and women in Indian slums affirmed the observed trend – NCDs and their risk factors are increasing at an alarming rate in Indian slums. Our study found an important gradient – gender roles open gendered causal risk pathways for NCDs in slums. The dichotomised social expectations on gender roles explain, to a large extent, this phenomenon.

In **Part 3**, the experiences and insights of slum residents were explored. The study noted treatment non-adherence affects both slum men and women but women and the elderlies were placed in a more disadvantaged position because social infrastructures form part in limiting their capacity for decision-making, particularly in the arena of health and economics.

Women's experience of NCDs and their risk factors have been shadowed by gender ideologies. As much is known regarding their reproductive and maternal concerns, their NCD experiences were tied to men's experiences. In the past three decades, although changes have been made; the under appreciation of the fact that NCDs and their risk factors affect slum women across their life span still remains. Hence,

women describe fear in the face of NCD since they know it will happen, like a Damascene sword that can fall anytime. This fear was re-enforced by lack of care and respect shown to patients coming from slums by some healthcare providers. Nonetheless, some of the women stated that by helping each other, they form bonds. These bonds enabled them to bridge the gap between fear and NCDs, between minimal institutional health care and NCDs.

The bonds formed among the women as they face the challenges of NCDs and their risk factors are drawn from a common experience shared within the community – *Life is difficult. What can we do?* However, in this ‘seeming’ hopelessness, there is a positive action - communal care. The small networks formed among the women in the community emphasises the significance of the horizontal networks women established among their neighbours. The exchanges of health information, the willingness to do some household chores for neighbours that are sick, giving tomatoes or salt when a neighbour needs it, accompanying members of the community to hospitals, or doctors they know or to a pharmacy to get a discount; all of these are just instances of what they *do* for each other.

Women’s small, informal, caring networks offer an alternate choice to the aloof and often times uncaring healthcare providers in formal health settings. It benefits not only the women, but also men for care is not gendered. In this regard, the negotiated openings for care transforms traditional ethics of care. It offers viable alternatives that may be considered in the formulation of policies for NCDs in slums.

## **Discussion and Conclusion**

NCDs and their risk factors in Indian slums are an urgent issue. It presents the reality of the double burden of infectious diseases and noncommunicable diseases in slums. As mechanisms responding to IDs are often in place in many health systems of LMICs, their preparedness in managing the growing challenges of NCDs

and their risk factors are still wanting. This situation leaves behind many slum residents who are often left to cope with NCDs and their risk factors by themselves. The high cost of treatments, health structural limitations such as limited number of skilled healthcare workers, insensitive health care providers, under supplies and similar situations exacerbate their already vulnerable condition.

In this regard, our study showed that Indian slum condition is a fertile ground for the development of NCDs and their risk factors. The observed high prevalence of NCD risk factors in the slums of India affirms this observation. Affecting both slum men and women, the observed NCD risk factors prevalence is mediated by gender roles suggesting the gendered risk factors causal pathway of NCDs in the slums. Similarly, the issue of treatment non-adherence is also affected by gendered roles, although women's disadvantaged is made more pronounced by policies not sensitive to the gendered nuances of healthcare. In the midst of heightened concern regarding slum residents' predicament vis-à-vis NCDs in slums, the study found slum women's informal acts of care that they share amongst their neighbours provide a platform where slum residents establish a network of care. A grass root approach from the slums that can be used as a network of care; hence, offering an initial arena of care.

From the findings of the study; it is proposed that this observed informal care could be transformed into an approach for monitoring, surveillance, caring, and information sharing in slums. This would organise the informal care as an accessible resource, and could be adopted elsewhere as a means to initiating NCD practices in slums.

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