**Title: Individual and community experience of rising burden of Non-communicable diseases in two case districts of Nepal: a qualitative exploration**

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**Declarations**

***Competing interests***

We declare no conflict of interest.

***Authors' contributions***

SRS conceived and drafted the initial manuscript. AM, JF, DL, DWL, AV and RP all critically reviewed and revised the initial manuscript. SRS prepared the final manuscript. All authors read and approved the final manuscript.

**Abstract**

**Introduction:** Non-communicable diseases (NCDs) are a rapidly emerging global health challenge with multi-level determinants popularly known as social determinants. The objective of this paper is to describe the individual and community experiences of NCDs in the two case districts of Nepal from social determinants of health perspective.

**Method:** This study adopted qualitative study design to identify the experiences of NCDs. Sixty-three interviews were conducted with key informants from different sectors pertinent to NCDs prevention at two case districts and policy level in Nepal. Twelve focus group discussions were conducted in the selected communities within those case districts. Data collection and analysis were informed by the adapted *Social Determinants of Health Framework*. The research team utilised the framework approach to carry out the thematic analysis. The study also involved three sense-making workshops with policy level and local stakeholders.

**Results:** Three key themes emerged during the analysis. The first theme highlighted that individuals and communities were experiencing the rising burden of NCDs and metabolic risks in both urban and rural areas. The other two themes elaborated on the participant’s experiences based on their socio-economic background and gender. Disadvantaged populations were more vulnerable to the risk of NCDs. Further, being female put one into an even more disadvantaged position in experiencing NCDs risks and accessing health services.

**Conclusion:** The findings indicated that key social determinants such as age, geographical location, socio-economic status and gender were driving the NCDs epidemic. There is an urgent need to take action on social determinants of health through multi-sectoral action, thus also translating the spirit of the recommendations made a decade ago by the *Commission on Social Determinants of Health* in addressing a complex challenge like NCDs in Nepal.

**Background**

Nepal has observed a rapid growth in the burden of NCDs in the last two decades, with more than half of the disease burden due to NCDs (1-3). The majority of NCDs in Nepal belong to the four groups of NCDs (cardiovascular diseases, diabetes, chronic respiratory diseases and cancer) with cardiovascular diseases alone contributing to 22% of the total burden (1, 2, 4). National surveys indicate that metabolic (elevated blood pressure, total cholesterol and glucose levels) and behavioural risks (tobacco use, alcohol consumption, limited physical activity and poor dietary habits) factors of NCDs are driving the epidemic of NCDs in Nepal (5, 6).

Global evidence suggests that NCDs are a complex problem and driven by multi-level determinants, popularly known as social determinants (7, 8). It is thus clear that understanding and tackling NCDs must move beyond behavioural factors and take multi-level factors into account, including socio-economic and commercial determinants of health (7, 9). However, developing countries like Nepal have limited evidence regarding social determinants of health in addition to pre-existing health system issues which presents as barriers in preventing complex problems like NCDs (10). Prevention efforts relating to NCDs are often confined to limited behavioural campaigns in Nepal due to limited understanding of NCDs and their social determinants. Local evidence relating to the social determinants of NCDs could provide valuable insights to inform health system action. This study is an effort to present such local evidence. The objective of this study is to describe the individual and community experiences of NCDs from a social determinants of health perspective in Nepal.

**Methods**

This study is a part of the PhD study of the first author which adopted qualitative study design to identify the experiences of NCDs as discussed below.

***Study area***

The selected key informants were interviewed between July and October 2016 from two purposively selected case districts (Bhaktapur and Morang districts) and at policy level (Kathmandu, the capital city) in Nepal. Further, one municipality (urban geo-political administrative units) and two Village Development Committees (rural geo-political administrative units that are commonly abbreviated as VDC) from each districts totalling six clusters (Madhyapur Thimi Municipality, Dadhikot VDC and Sipadol VDC from Bhaktapur, and Biratnagar Municipality, Tankisinwari VDC and Bahuni VDC from Morang) were purposively selected for community level data collection (key informant interviews and focus group discussions).

***Study techniques and tools***

Key informant interview and focus group discussion (FGD) were the qualitative research techniques employed and accordingly interview schedule and focus group discussion (FGD) guideline containing semi-structured open-ended questions were developed. The *WHO Framework for Action on Social Determinants of Health* was utilised to shape the research tools and analysis (8). The interview schedule and FGD guideline were first developed in English and translated into Nepali.

***Study procedure***

The sampling strategy to select key informants entailed purposively identifying stakeholders knowledgeable and experienced in NCDs prevention and control at policy and district levels from across the sectors (11). The potential policy level key informants (n=24) were identified by referring to the list of the multi-sectoral committee members proposed by the *Multi-sectoral Action Plan for the Prevention and Control of NCDs 2015–2020* in Nepal and accordingly, finalised in consultation with supervisors and local experts in Nepal. The district and VDC/municipality level key informants (n=39) were identified through consultation with District Public Health Offices, who also helped us identify two communities within each VDC/Municipality for the focus group discussion.

Policy level key informants included participants from Ministry of Health, Department of Health Services, other sectoral ministries, national level non-government organisations and international non-government organisations. District and community level key informants included participants from District Health Office, Local Development Office, local non-government organisations, primary health centres, health posts, local schools and VDC/municipality offices. The purpose of the key informant interview was to illuminate the experience and perspectives of key stakeholders in relation to the current situation of NCDs in Nepal. The time of interviews ranged from 30 to 60 minutes and they were conducted in Nepali.

Twelve FGDs were conducted at the community level in the six selected VDCs/municipalities. Each FGD included five to 10 community people experiencing and/or caring for family members with NCDs and their metabolic risks. The purpose of FGD was to capture negotiated views on NCDs and metabolic risks as experienced by individuals, families and community members belonging to different socio-economic groups. Therefore, two FGDs were conducted in each VDC/municipality with one FGD conducted in a socio-economically disadvantaged community and the other in an advantaged/mixed community. The FGDs were facilitated by the first author with the help of local Female Community Health Volunteers and all FGDs were recorded after obtaining informed consent. FGDs were conducted in Nepali. The time of an FGD ranged from 45 minutes to one hour.

The interviews and FGDs audio recordings were first transcribed in Nepali and then translated into English for coding and thematic analysis. The research team utilised the *Framework Approach* to carry out the thematic analysis guided by the study framework (12). *Dedoose (Socio-cultural Research Consultants)* (13), a web-based data management platform, and *MS Excel 2016 (Microsoft)* (14) were used to manage the qualitative data and facilitate the analysis. Two sense-making workshops at each of the case districts and one at the national level were conducted in early 2018 to obtain feedback and suggestions on the preliminary findings from the stakeholders. Ethical approval for this study was obtained from the Massey University Human Ethics Committee (SOA 16/37) and Nepal Health Research Council Ethics Committee (Reg. no. 163/2016) respectively. The participants were clearly informed about the purpose and voluntary nature of the study using a simple information sheet. Written consents were obtained from all participants involved in the study.

**Results**

Three significant themes relating to individual and community experience of NCDs and metabolic risks emerged through the analysis.

***Everyone is experiencing the rising burden of NCDs and metabolic risk factors, both in urban and rural areas***

Almost all key informants and focus group discussion participants shared that their communities were experiencing a rapid increase in NCDs such as cardiovascular diseases, cancer and diabetes and their metabolic risks, particularly hypertension, hyperglycaemia and high cholesterol. A FGD participant from urban Bhaktapur stated:

*“Here, many people are suffering from sugar [Diabetes]. Amrita and many others have sugar. They had sugar earlier than I had.” (ID: 71)*

An FGD done in a rural indigenous community in Morang district revealed that just as many people were suffering from hypertension in their communities.

*“In the house of about 4 members, 3 people have high [blood] pressure.” (ID: 67)*

Another commonly discussed concern by both policy and local level key informants was how the burden of NCDs was affecting the younger population. Hypertension or hyperglycaemia were previously unheard of in younger adults (under 40s) in those communities as well as Nepal. A policy level key informant added:

*“Increase in blood pressure with increasing age and increasing blood pressure at young age is quite different things. We have been observing high blood pressure in people below 20 years of age.” (ID: 5)*

Almost all participants raised strong concerns about the how key behavioural risks of NCDs such as junk food habits, tobacco and alcohol consumption, and physical inactivity were increasing. An FGD participant from rural Bhaktapur observed the negative influence of junk food on the traditional dietary practice, even in rural settings.

*“We used to have fried corn, soya bean and stuffs like that. But we now have noodles [Pre-packed noodles].” (ID: 76)*

Participants also reflected on the contribution of tobacco and alcohol use in increasing the burden of NCDs. The use was facilitated by the easy availability of those products in both rural and urban areas. A community level key informant from rural Morang shared:

*“You are asking about shops where cigarette isn’t found. Cigarette is found in each and every shops but not all shops sell drinks.” (ID: 64)*

***Experience of NCDs and metabolic risk factors by disadvantaged groups is worse than that of advantaged groups***

NCDs were affecting everyone irrespective of socio-economic status. However, the degree of exposure and vulnerability was reported differently among the advantaged and disadvantaged groups. Key informants discussed frequently how disadvantaged groups were more exposed and vulnerable to the risk of NCDs and how these groups had limited ability to change their socio-economic circumstances influencing their choices and behaviours linked to NCDs. A policy level key informant described:

*“If a poor has a sedentary life style, and even if he is made aware, it is very difficult for him to take corrective action due to his social circumstances. Like you see in malnutrition chain, a poor is circled by different disadvantages keeping him in vicious cycle.” (ID: 15)*

Participants indicated that disadvantaged groups gave less priority to their health, possibly due to low awareness and socio-economic circumstances. A Female Community Health Volunteer from Bhaktapur shared how a disadvantaged rural community reeling under underemployment and low socio-economic progress was experiencing a rise in addictive behaviours and possibly NCDs:

*“Typical drinking start from the morning and will continue till evening as many people are unemployed and gather in such local shops and discuss about charm of foreign employment and politics. No wonder the problem [NCDs] is increasing in our communities.” (ID: 33)*

A rural health worker from Morang highlighted poor dietary practice among the disadvantaged groups and possible linkage to increased metabolic risks among them.

*“The maximum number of patients in OPD belongs to Magar community and Rishidev community [Disadvantaged Groups]. They don’t eat balanced diet, and Magar eat more fatty food like pork meats.” (ID: 61)*

Long duration of NCDs progression often resulted in recognising one’s risk of NCDs and accessing services for the prevention and treatment of one’s health conditions at the late stages among disadvantaged groups. In particular, socio-economic circumstances deterred the disadvantaged group in seeking timely treatment of their health conditions due to the fear of catastrophic health expenditures. A key municipality level key informant shared:

*“If they [Disadvantaged Group] get checked up then new disease will come up and then this will increase tension.” (ID: 44)*

Further compounding the vulnerability to the stresses of poverty and low awareness was key informants frequently describing the disadvantaged groups’ access to public health services as being very limited. A policy level key informant elaborated:

*“If we further look deeper into the system, our health system have not been able to reach the lower tier. We need to ensure and be capable that the basic minimal services reach to unreached and marginalised groups.” (ID: 3)*

In contrast, advantaged groups have increased access to services, which has decreased their vulnerability to NCDs and widened the health inequity gap in the Nepalese context. A policy level key informant described:

*“The reason for decreasing disease burden among rich is because of timely availability of treatment, physical activity, healthy diet, periodic health check-ups, health awareness. Rich people undergo treatment even when they see minor symptoms.” (ID: 4)*

***Gendered experience of NCDs problem***

Gendered experience of the NCDs problem was often observed during both interviews and focus group discussions. Females were much less likely to know their NCD risk status compared to males. A female FGD participant from rural Morang stated a common expression as follows:

*“I don’t know mine since I have never taken measurement.” (ID: 67)*

A key informant from urban Morang shared that women often accessed health services at the very late stages of disease symptoms.

*“Males generally go for checking their pressure level while females go after they encounter problem.” (ID: 59)*

This delay in accessing preventive services could be related to the widely prevalent gender discrimination in Nepalese society, which was reflected upon by a key informant from rural Morang.

*“This [Gender] discrimination is prevalent everywhere. This is not only the problem of poor and lower caste people but also prevalent among the rich and higher caste people.” (ID: 53)*

Some key informants noted that the effect of gender discrimination was readily reflected in access to and use of health services. A vivid example of the impact of cultural norms was in the way that men could easily access health services while women needed to seek approval from male members or elders. A key informant from urban Bhaktapur elaborated:

*“Due to this discriminatory and dominating cultural norms, female do not go to treatment often unless serious. They also have limited outside knowledge including food and calorie related information.” (ID: 44)*

The table below presents a summary of the individual and community experiences of NCDs from the two case districts.

Table 1: Key experiences of NCDs and their social determinants from the two case districts in Nepal

**Discussion**

This study indicated that communities have been experiencing increasing burden of NCDs in Nepal with geographic location, socio-economic status and gender influencing the vulnerability and exposure of different population group to those NCDs. National surveys and research have indicated the increasing prevalence of NCDs and metabolic risks among adults in both urban and rural areas (3-6, 15). The STEP survey of 2014 showed that NCDs metabolic risks were only slightly higher in urban areas compared to rural areas in Nepal, particularly, diabetes and obesity (6). However, these quantitative surveys do not highlight the lived experiences and vulnerability of the poor, rural communities and women or critically discuss the linkages of those experiences with social and commercial determinants of NCDs. This study complements the national surveys by illuminating how the local context influences community experiences of NCDs and their risk factors.

***Urbanisation and rural-urban interaction facilitating rise in NCDs***

Our study demonstrated that the rural population as much as urban population experienced NCDs. A possible explanation could be that rapid urbanisation is occurring in Nepal (16), which is facilitating rural-urban interaction and transference of urban influences into rural areas of Nepal. In particular, junk food and inadequate physical activity-based urban lifestyles are gradually being introduced to the rural environment due to urban-rural movement, hence nurturing similar businesses and lifestyle as noted in rural areas of the case districts. Research in India has documented findings that diets in rural India may be transitioning towards urban dietary practices due to increased urbanisation and urban-rural interaction (17). In addition, the availability and accessibility of junk food in many low- and middle-income countries have been well noted (18). In this study, participants did report that junk food companies have overwhelmed the market of both urban and rural areas in the case districts and communities are falling victim to their marketing strategies and developing junk food habits, especially among children.

The study also reported that tobacco and alcohol products were widely available and consumed in the case districts, resulting in an increased prevalence of NCDs. Tobacco and alcohol products have a cultural significance in the context of Nepal (19, 20). With the commercialisation of tobacco and alcohol products, the consumption of these products has further increased in both urban and rural areas (19). A Lancet review has critically analysed how these commercial motives of tobacco, alcohol and junk food companies are driving behavioural risks associated with increasing burden of NCDs (18). This commercial motive could explain the increased consumption of tobacco and alcohol, especially among young people, who have developed drinking and smoking habits due to easy availability. This has been further bolstered by limited monitoring activities from the respective authorities (21, 22). Authorities have not been able to strictly monitor the production and sales of tobacco and alcohol products as per the regulations. Evidence from India also suggests that alcohol companies are driving the drinking patterns among the young population in both urban and rural areas through marketing and influences at policy level (23). Overall, increasing rural-urban interaction is facilitating the increasing influence of commercial determinants in blurring the boundary of the concentration of NCDs in rural and urban areas of Nepal.

***The multiple challenges impacting disadvantaged communities and their risks of NCDs***

A disadvantaged community, in terms of socio-economic conditions and ethnicity, usually lies in the fringes and/or deprived areas of the villages/cities. The disadvantaged communities in particular have difficulty in accessing the public health services due to distance and socio-economic barriers (24). In this study, disadvantaged groups were often unaware of their metabolic risk status, resulting in delayed treatment of the conditions. Evidence from Nepal has shown that disadvantaged groups often have limited health literacy and service utilisation rates (25, 26). Further evidence from developing countries has indicated that young people and adults from these disadvantaged backgrounds are more likely to fall into the habit of smoking tobacco and consuming alcohol at an early stage due to stressful circumstances and get caught into the vicious circle of addiction and poor health (27, 28).

Furthermore, this study found that NCDs posed a significant financial burden to the families of the patient and deter individuals from disadvantaged groups from seeking care. A qualitative study in Uganda showed that due to pressure of meeting the basic needs and fear of catastrophic expenses, the disadvantaged group at risk perceive themselves at low risk of NCDs and delay the check-up and treatment (29). Health is considered as a need that can be delayed until any obvious disease occurs, which is complicated by the socio-economic circumstances and access to health services. Importantly, a lack of social safety protection within Nepal and similar developing countries may be preventing the vulnerable group from knowing their status of NCDs and getting themselves treated (30). In addition, government facilities in Nepal provide limited NCDs-related services and private sectors are often expensive and out of reach for the poor (3).

***Gender inequality and its impact on NCDs risks***

This study has indicated that women cannot access NCDs-related services they need when they want them. Men can access any health services easily and without having to seek anybody’s consent whilst females must seek approval from a male member or mother-in-law. Evidence from Nepal has shown that women have limited access to health services due to their low social status (31, 32). Due to their subordinate role and their family responsibilities, women often hesitate to seek care for their problems in the early stages of development of NCDs. These observations are common throughout the South Asia region and are linked with gender discrimination that a woman faces throughout her lifecycle (33). The participants in the study shared that gender discrimination was widely prevalent with sons getting better care and opportunities compared to daughters. Males are considered as breadwinners and future investment for the families, leading to preferential treatment of male children and neglect of female children (34, 35). In particular, the limited quality education opportunities for a girl child in her early years has a flow-on effect on empowerment and financial independence, often resulting in early marriage and early pregnancy (36). As a result, males have more autonomy and control of financial resources compared to females (37, 38). Comparatively, urban women, who tend to be more educated and economically active, are more autonomous in terms of decision-making and health service utilisation yet they also endure some form of dominance by men. Studies in Nepal have shown that women’s autonomy was influenced by education status, income level and age of the female, with patriarchal construct driving these root causes of female disadvantages (39, 40).

A key limitation of this study is that the results and analysis were based on the limited data available from the first author’s PhD study, which had broader scope (assessing situation, exploring behavioural risks, and their interaction with social determinants and modelling). The other notable limitation was limited participation of non-health stakeholders during the sense-making workshops, which may have affected the quality of feedback obtained during the workshops.

**Conclusion**

This study was able to highlight some of the key social determinants such as age, geographical location, socio-economic status and gender that are influencing the NCDs epidemic in Nepal. NCDs were widespread in both urban and rural areas and needed an urgent multi-sectoral response. Particularly, disadvantaged groups were the most vulnerable and the worst affected from NCDs. There is a need to monitor the exposure and vulnerability of rural residents, women and the poor to NCDs and their metabolic risks. This is further impeded by a disconnected and under-resourced health system. The findings of this study strongly indicated that lack of policy action for preventing NCDs and their social and commercial determinants is contributing to the escalation of NCDs problem in Nepal. The study reiterated the importance of understanding the complex issue of NCDs from the social determinants of health perspective. The findings of this study can help contextualise any generic social determinants of health framework to develop local tools to understand complex problems like NCDs and initiate local actions to prevent NCDs and their social determinants.

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**Table 1: Key experiences of NCDs and their social determinants from the two case districts in Nepal**

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| --- | --- | --- |
| **S.N.** | **Themes** | **Key experiences shared by participants** |
| 1 | Everyone is experiencing the rising burden of NCDs and metabolic risk factors, both in urban and rural areas | Community member suffering from hypertension, sugar and similar metabolic risks rapidly increasingAs many adults in a single house suffering from high blood pressureYounger adults being increasingly affected by metabolic risksKey behavioural risks of NCDs increasing. For example, traditional food which are often nutritious and locally sourced being rapidly displaced by junk food; tobacco products sold in almost all shops in the village, etc. |
| 2 | Experience of NCDs and metabolic risk factors by disadvantaged groups is worse than that of advantaged groups | Addiction to alcohol and tobacco products high among unemployed youths and disadvantaged groups resulting in possible high burden of NCDs in such groupPoor dietary practice among disadvantaged groupsDisadvantaged group having fatalistic attitude towards their health due to socio-economic stressors and low awarenessLocal health system severely limited in its capacity to deliver equitable and quality health services contributing to delay in presentation and service utilisation by disadvantaged groups |
| 3 | Gendered experience of NCDs problem  | Late presentation of female for the treatment of NCDs and/or metabolic risksLimited ability of female members within a family to make their own decisions to access health services Gender discrimination and disempowerment of female root cause of inequitable access by female |

**Figure 1: Study framework adapted from the WHO social determinants of health framework**

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