

Awareness Gaps and Structural Barriers to NCD Prevention and Care-seeking: A Life- Course Qualitative Study in Eastern India

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Abstract

Background:

The burden of non-communicable diseases (NCDs) has been steadily rising across all groups in India, posing a significant public health challenge. However, evidence on the knowledge, lifestyle and factors influencing care from marginalized populations in Eastern India remains limited. This study explored the knowledge, attitudes, lifestyle practices, and enablers and barriers to health-seeking behaviour among adults and adolescents in rural, tribal, deltaic, and hilly regions of West Bengal, Jharkhand, and Odisha.

Methods:

We conducted a cross-sectional, exploratory qualitative study across eight districts between October 27, 2025–November 25, 2025. Twenty-four focus group discussions (FGDs) were conducted with 160 adults (aged ≥ 30) and 101 adolescents (aged 11–19 years) in Bengali, Hindi, Nepali and Odiya languages. Data was analyzed using ATLAS.ti following an inductive thematic approach, framed within a Social-Ecological Model.

Results:

Across all regions, NCD awareness among adults was symptom-driven, with limited understanding of causes and risk factors. Adolescents developed an 'observational' awareness by witnessing parental illness. Routine preventive screenings were not considered important and health-seeking behaviour symptom-driven. Diets were carbohydrate-heavy shaped by food insecurity, with unhealthy foods consumed as survival strategies. Tobacco and alcohol use were widespread; with substance use culturally embedded in Jharkhand. Adolescents acknowledged their own unhealthy eating, inactivity, and peer substance use. Primary barriers to care included fear of medication dependency, reliance on informal providers, counselling gaps, financial constraints, geographic inaccessibility and service gaps. Facilitators included increasing awareness through individual counselling, social and behaviour change communication (SBCC) programs, outreach services and strengthening the volume and capacity of frontline workers.

Conclusions:

Addressing India's NCD epidemic requires a life-course, community-centred, preventive approach that addresses the risk factors from adolescence to adults. Policy must strengthen primary healthcare, frontline health systems, social protection, and SBCC to overcome barriers, improve early detection and long-term NCD outcomes.

Introduction

Non-communicable diseases (NCDs) are the leading cause of morbidity and mortality worldwide, often described as a silent and largely invisible epidemic.⁽¹⁾ In 2021, NCDs accounted for 7 of the 10 leading causes of deaths globally, contributing to 43 million deaths.^(1–3) Nearly 73% of these NCD deaths occur in low- and middle-income countries (LMIC), highlighting global inequities in prevention and health care systems.^(2,4)

In India, the burden of NCDs—particularly hypertension, diabetes mellitus and cancer—has been steadily increasing across all age groups. NCDs account for nearly 63–65% of all deaths, rising from 37.9% in 1990, reflecting a marked epidemiological transition from infectious to non-communicable diseases.^(3,5,6) The recent National Family Health Survey NFHS-6 (2023–2024) reported a marked increase in diabetes in India from 15.6% in NFHS-5 (2019–2021) to 20.9%, underscoring the escalating challenge of NCDs in the country.⁽⁷⁾ Ischaemic heart disease and diabetes are the leading contributors of NCD-related deaths.⁽³⁾

Notably, the onset of NCDs in India occurs a decade earlier (≥ 45 years) compared to many high-income countries.⁽⁸⁾ This is driven by a complex interplay of risk factors, including dietary transitions, sedentary lifestyles, tobacco and alcohol use, rapid urbanization alongside rising obesity, stress, ageing, and environmental air pollution.^(9–11) Not just adults, NCDs are increasingly affecting younger populations in India, who were traditionally considered at low risk.^(12–14) India is among the three countries with the highest incidence of diabetes in children and adolescents.⁽¹⁴⁾ This shift is driven by the early adoption of lifestyle-related risk behaviours during adolescence, including unhealthy diets, inadequate physical activity, tobacco and alcohol use, and rising overweight and obesity.⁽¹⁵⁾ This underscores the need for a life-course approach to NCD prevention and management.⁽¹⁶⁾

To address this crisis, Government of India launched the National Programme for Non-Communicable Diseases (NP-NCD), which includes the National NCD Portal for case registration and screening of “ >30 -year” population and real-time treatment monitoring. Additionally, the teleconsultation services link Health and Wellness Centres (HWCs) with higher-level facilities to strengthen primary care.⁽¹⁷⁾ However, despite these efforts, the NCD burden continues to rise across both privileged and resource-limited populations and gaps exist in preventive services.⁽¹⁸⁾ The current NCD programs focus on screening and tracking, and have a weaker emphasis on social and behaviour change. Socioeconomic inequalities further influence disease risk, health behaviours⁽¹⁹⁾ and the problem is further compounded by multimorbidity, limited awareness particularly in rural and marginalized areas, delayed diagnosis and inadequate disease control.^(20,21)

Eastern India—particularly West Bengal, Odisha, and Jharkhand, bears a substantial and growing burden of NCDs. West Bengal, in particular, exhibits a disproportionately high burden of cardiovascular disease, diabetes and stroke.^(22,23) Studies from rural areas suggest up to 75% of residents are

affected by at least one NCD, while urban hypertension rates have reached up to 42%.⁽²⁴⁾ Across West Bengal, Odisha, and Jharkhand, abdominal obesity is increasing among adults, alongside a rising burden of stroke.^(7,22,25–28) Furthermore, poor health seeking behaviour⁽²⁹⁾ and treatment adherence remains a major concern particularly in West Bengal, with substantial non-adherence to medications and lifestyle recommendations (67.1%), often linked to lower socioeconomic status.⁽³⁰⁾ Poor health knowledge, socioeconomic disparities, delayed diagnosis, and barriers to accessing healthcare services are other challenges, particularly in rural and tribal populations.⁽²¹⁾⁽³¹⁾

Understanding the knowledge, beliefs, lifestyle practices, risk behaviours and structural barriers that shape health-seeking behaviour is important. However, existing studies are largely disease-specific, adult-focused, or geographically limited, with minimal evidence integrating life-course perspectives across diverse vulnerable geographies in Eastern India.⁽³²⁾ Understanding the awareness and lifestyle of both adults and adolescents is important as in adults risk behaviours and disease is already established, while adolescents represent a critical population for primary prevention through modification of early-life risk behaviours. The insights will inform contextually relevant and equitable NCD prevention and management strategies.

Materials and Methods

Study Design and Setting:

This cross-sectional qualitative study aimed to explore the knowledge, lifestyle practices, and enablers and barriers to health-seeking behaviour among adults and adolescents in rural West Bengal, Jharkhand and Odisha. The research was situated in districts where community-based health and nutrition program of Child in Need Institute (CINI) were already being implemented. Study sites were purposively selected to represent underserved, vulnerable, and hard-to-reach geographies with high NCD risk profiles in the Eastern Indian region. The geographies reflected diverse topographical and socioeconomic landscapes, tribal belts of Jharkhand and Odisha, hilly terrains in Kalimpong and Darjeeling, the *Rarh* region of Purulia and Bankura and riverine islands of 24 Parganas(S).

In West Bengal, Bankura and Purulia are remote, rural, socio-economically disadvantaged districts in the west, with dominance of tribal and scheduled castes, and characterized by infrastructural deficits, insufficient health awareness, undernutrition, low education, and dependence on agriculture and physical labour. Kalimpong and Darjeeling are mountainous districts in the north where difficult terrain, natural calamities, and harsh climate affect the livelihood opportunities, education and healthcare utilization. 24 Parganas(S) in the south is a deltaic region that faces climate shocks, fragile livelihoods, and limited connectivity, which limits access to health services.

In Jharkhand, *Dumka* in the north-east is recognized as one of the backward districts, while *Khunti* has been designated a NITI Aayog Aspirational District. Both are predominantly tribal districts, marked by low literacy, high poverty, and limited-service delivery, coupled with infrastructural deficits making them critical sites for understanding community vulnerabilities and barriers to healthcare.

In Odisha, Koraput district, specifically Boipariguda block, is characterized by fragile livelihoods, poor connectivity, and limited-service delivery, which exacerbate health inequities and restrict access to care. Its inclusion provided complementary insights, ensuring that the study encompassed diverse socio-geographic contexts where tribal communities face compounded disadvantages.

Data Collection Tool and Procedures:

Study tools for focus group discussions (FGD) were prepared and revised in discussion with experts in public health and program implementation. The study adhered to the COnsolidated criteria for REporting Qualitative research (COREQ) guidelines for qualitative research reporting. FGDs were preferred in this study over individual interviews to map community-wide norms and observe social interactions that influence their overall attitudes and behaviour. The questionnaires were developed for the study and are displayed in the Supplementary material.

The adult FGD questionnaires comprised five components: 1. background information; 2. perceptions and awareness of common NCDs such as diabetes, hypertension and cancers (awareness, causes, perceived risk, perceived seriousness of disease, family history, high risk groups); 3. lifestyle practices (dietary habits, physical activity patterns, and practice of substance abuse); 4. health-seeking behavior and service utilization (health seeking behavior, screening practices, barriers and enablers for health access, awareness about services at HWCs); 5. motivators for care seeking and communication channels (health information sources, motivators of care seeking).

The adolescent guide was tailored to explore NCD awareness, perceived causes, their lifestyle and daily habits, factors that would shape their behavior, awareness about health services, health utilization, and preferences for social and behavioral change communication strategies allowing participants to build on each other's experiences and highlight shared practices.

Questionnaires were translated from English into Bengali, Hindi, Nepali and Oriya languages by field staff from respective regions. Field teams from all study sites were trained on qualitative methodology and facilitation by public health researchers. Those who facilitated the discussions had a minimum of masters in social science or public health, were local residents of respective regions, and, were both males and females. They were either the supervisors at the level of Gram Panchayats or were district coordinators or state unit heads of CINI's community-based interventions. The questionnaires were pilot tested in a select group of invited local stakeholders prior to the commencement of the study.

Study participants:

The study inclusion criteria were adults more than 30 years of age of both the genders; and adolescents aged 11-19 years of both the genders. Participants were purposively invited face-to-face for FGDs by either home visits or through Accredited Social Health Activists (ASHA). Some adolescents were part of adolescent peer groups. All participants were explained about the reasons for doing the research. FGDs were conducted with a group of 8-10 participants, in regional languages, in a closed room or open community spaces or in Integrated Child Development Services (ICDS) centers, face-to-face by a team of facilitator, field notes taker and an assistant. Background information and informed consents were collected prior to starting the discussion. Discussions were audio recorded with participant consent and typically lasted 40-50 minutes. Field notes taker recorded field notes during the discussion.

Reflexivity:

Facilitators were local CINI staff with prior relationships in the communities. While this facilitated trust, it may have introduced social desirability bias, particularly regarding health system critiques. Facilitators explicitly stated their independent research role prior to each FGD.

Data Analysis:

Audio recordings were transcribed verbatim and translated to English and reviewed for accuracy. Data analysis was conducted using ATLAS.ti (version 25.9) by following the inductive thematic approach i.e. codes were built independently by two co-investigators, by comparing patterns and theories that emerged from both the adults’ and adolescents’ data. The code book was shared among co-investigators and revised based on discussions and consensus, if there was a discrepancy. Additional codes that emerged inductively during the analysis were included. Emerging codes were organized into broader themes using the thematic framework reviewed by all authors. Themes were refined, finalized, and tabulated in Microsoft Excel.(33) Representative quotes were selected to illustrate key findings. Data collection continued until thematic saturation was reached, meaning no new insights emerged from additional interviews or discussions.

Results

Background details

Between October 27, 2025, and November 25, 2025, 24 FGDs were conducted with adults (aged 30 years and above) (n=16) and adolescents (n=8). Table 1 describes the background details of adult study participants (N=160) across three states. The number of discussions were five in Bengali (West Bengal), four in Nepali (Darjeeling and Kalimpong-West Bengal), five in Hindi (Jharkhand) and two in Odiya (Odisha) language. Participants had a median age of 56 years (IQR: 45-62) years. Majority (60.6%) were females and rest (39.4%) were males. Among the respondents, 30 (22%) had no formal schooling, 32 (23.5%) had completed primary education, 24 (17.6%) had studied till middle school, 28 (21%) had completed high school, and 12 (9%) had attained intermediate-level education; 10 were graduates or above. Educational information was not available for 24 adults.

Table 1: Background details of adult participants state wise

	West Bengal	Jharkhand	Odisha	Total
Number of discussions	9	5	2	16
Number of participants, N	103	41	16	160
Gender, n (n/N%)				
<i>Male</i>	43 (41.7)	11 (27)	9 (56.25)	63 (39.4)
<i>Female</i>	60 (58.2)	30 (73)	7 (43.7)	97 (60.6)
Age, years				
25-45	24 (23)	11 (50)*	2 (12.5)	37 (26)
46-60	42 (41)	5 (23)	10 (62.5)	57 (40.4)
>60	37 (36)	6 (27)	4 (25)	47 (33.3)
Education, n (n/N%)				
<i>Illiterate</i>	20 (19.6)	7 (40)*	3 (16.7)	30 (22)
<i>Primary</i>	24 (23.5)	3 (17)	5 (28)	32 (23.5)
<i>Secondary</i>	17 (16.7)	2 (11)	5 (28)	24 (17.6)
<i>High school</i>	26 (25.5)	1 (5.6)	1 (5.6)	28 (20.6)
<i>Intermediate</i>	7(6.9)	4 (22)	1 (5.6)	12 (8.8)
<i>Graduate and above</i>	8 (7.8)	1 (5.6)	1 (5.6)	10 (7.3)
Occupation, n (n/N%)				
<i>Technicians & Associate Professionals</i>	1 (0.1)	1 (5)*	0	2 (1.4)
<i>Clerk</i>	4 (4)	1 (5)	0	5 (3.6)
<i>Service Workers & Shop/ Market Sales Workers</i>	7 (6.8)	0	3 (18.7)	10 (7.2)
<i>Skilled Agricultural, Forestry & Fishery Workers</i>	12 (11.7)	9 (45)	0	21 (15.2)
<i>Craft & Related Trades Workers</i>	1 (0.1)	1 (5)	0	2 (1.4)
<i>Plant & Machine Operator and Assembler</i>	0	0	1 (6.25)	1 (0.7)
<i>Elementary Occupation</i>	17 (16.6)	1 (5)	6 (37.5)	24 (17.4)
<i>Home maker</i>	38 (37.8)	7 (35)	6 (37.5)	51 (37)
<i>Pensioner</i>	22 (21.6)	0	0	22 (16)
<i>Not available</i>	1	21	0	22

*Missing data on age (n=19), education (n=23) and occupation (n=21) was missing from Jharkhand

The study included 101 adolescents across three states, see Table 2. The median age was 15 years (IQR: 14-16), with 69% girls and 31% boys. All were school going, the majority (47.7%) in high school or middle school (30%). Two did not continue education after grade 9 and one was engaged in farming.

Table 2: Background details of adolescent participants

	West Bengal	Jharkhand	Odisha	Total
Number of discussions	6	1	1	8
Number of participants	76	17	8	101
Gender, n (n/N%)				
Male	21 (27.6)	9 (53)	1 (12.5)	31 (30.7)
Female	55 (72.4)	8 (47)	7 (87.5)	70 (69.3)
Age, years				
11-15	50 (66)	1 (50)*	2 (25)	53 (61.6)
16-20	26 (34)	1 (50)	6 (75)	33 (38.4)
Education, n (n/N%)				
Primary	1 (1.3)		0	1 (1.2)
Middle School	24 (31.5)	2 (11.7)*	0	26 (30)
High school	37 (48.7)		4 (50)	41 (47.7)
Intermediate	13 (17)		4 (50)	17 (19.7)
Graduate and above	1 (1.3)		0	1 (1.1)
Not available	0	15 (88.2)		15
Occupation, n (n/N%)				
Student	76 (100)	1 (6)	6 (75)	83 (96.5)
Farming	0	1 (6)	0	1 (1.2)
Staying at home	0	0	2 (25)	2 (2.3)
Not available	0	15	0	15

*Missing data on age, education and occupation (n=15) from Jharkhand

Awareness, lifestyle, practices

Limited awareness and symptom-driven understanding of NCDs:

A core finding of this study is that awareness of NCDs was limited and largely shaped by personal (by adults) or observed (by adolescents) experiences. In West Bengal, adult community members demonstrated a moderate but inconsistent understanding of NCDs. Some could identify common symptoms (hypertension as dizziness, hypotension as weakness and diabetes as delayed wound healing). However, knowledge about prevention, underlying risk factors or asymptomatic progression was limited. Many did not view regular screenings as important unless symptoms appeared, although they recognized NCDs as widespread in their community.

If there's a wound, it takes longer to heal with sugar, with pressure, head gets worse..(Community member_Bankura)

In Jharkhand, awareness was lower compared to West Bengal. Many lacked clarities on the asymptomatic nature of NCDs. Diabetes was often described through folk observations: *"We know a little. In villages, if ants gather on urine, we take it as a sign of diabetes."* (Community member_Dumka). There was minimal understanding of prevention, and routine screening was not common.

In Odisha, awareness was largely low, primarily restricted to individuals already living with a diagnosed condition. However, the concept of early detection and preventive screening remained elusive. Similar to the other states, the trend of symptom-driven healthcare utilization was seen.

"When we feel unwell, we go to the medical (clinic) and consult a doctor." (Community member_Koraput)

Adolescent understanding: awareness shaped by observation of family illness: In Odisha and West Bengal, adolescents defined health through the lens of their parents' struggles. A "healthy" body was simply one that didn't need a "field worker visit" or "daily pills."

Emerging Awareness but Conceptual Gaps Adolescents knowledge was fragmented in the sense they could name "BP" or "Sugar, but had limited conceptual clarity on underlying biology, mechanisms, risk factors, and long-term implications. Though awareness was skewed, motivation to learn and staying well, resonated across all regions showing realization and willingness to change.

"Seeing people fall sick motivates me to stay healthy; taking part in sports and supportive friends also help."(Adolescent member, WB)

The Normalization of Risk:

In all states, adults perceived that anyone can get NCDs but more presented in the elderly.

"Nowadays, more in the elderly—body slackens. (Community member_Bankura).

Notably, disease risk was perceived to be linked with physical exertion; for instance, one participant noted,

"It can happen, but in our family it doesn't easily; we all work hard—those who sweat [are] less likely to have sugar. (Community member_Bankura)

Lifestyle practices:

Both groups of participants across all regions identified a complex interplay of dietary and lifestyle factors as the primary drivers of the NCD epidemic.

Intergenerational Diet Patterns: Across the three states, both groups perceived the cause of rising NCDs to unhealthy eating habits, such as consumption of salt, fried items, sweets, low water intake, reused cooking oil, food adulteration, easy access of junk food, skipping meals and irregular dietary timings due to work. Adults from all regions reported carbohydrate or rice dependent diets with pulses and vegetables. Fish or meat consumption was reported to be occasional. Meals were often skipped or the timings were irregular due to work demands.

High salt and sugar consumption and unhealthy foods emerged as key lifestyle risk factors, with regional variation. Notably, adolescents from West Bengal had a strong recognition of NCDs appearing in younger ages and their own unhealthy habits viz., junk foods, high-fat foods, smoking and tobacco consumption. The curiosity and willingness to learn were however, strong.

"Diabetes can affect any age group; it's more common in older adults but is now appearing in youth as well." (Adolescent group member, West Bengal)

"We don't keep our body fit; we keep eating shop-fried items, oily fries, fast food—chips and these fried things." "I prefer home-cooked nutritious food, keep sugar/oil low, maintain hygiene, and do light exercise." (Adolescent group member, WB)

Food insecurity: Discussions revealed unhealthy dietary behaviours are not choices, but survival strategies. Adults in Jharkhand described eating "only salt and rice" due to financial instability and food insecurity, with irregular eating patterns and skipping meals. Adolescents mirrored this, acknowledging the harm of "maida" (refined flour) but noting that "poverty" makes these them only accessible foods. In Odisha too, economic hardships were reported, where participants reported "eating whatever is available" despite knowing the nutritional risks.

"We eat one time in the morning, around 9–10 we eat, and then we stay the whole day. In the evening, if we feel like it, then we eat; if we don't feel like it, we don't eat." (Community member_Khunti)

We eat with salt; if there is nothing, we eat with salt. (Community member_Khunti)

Substance Use as a Cultural Norm:

Across all three states adult participants reported high tobacco and alcohol use, and smoking. Substance use practice was also reported among adolescents. A critical finding in Jharkhand was the substance use practices were embedded in social and cultural contexts such as festivals and community gatherings. Community narratives influenced adolescent perceptions, especially regarding lifestyle and substance use. Adolescents did not view tobacco or alcohol as a "deviant" youth behavior but as a "ritualistic" adult behaviour (e.g., drinking during Pooja/festivals).

"Some drink when angry." "Some drink during festivals, when there is Pooja (festival). By smoking too much bidi/cigarette, gutkha/>" (Adolescent member, Jharkhand)

"Packet tobacco-type products." "Many of my friends smoke bidi/cigarettes—tobacco. Later they may develop lung or stomach problems." (Adolescent group member, WB)

Gaps between knowledge and practice: Knowing the harms of unhealthy eating habits, some participants acknowledged the gap between knowledge and practice, particularly during cultural festivals:

"Diabetes rises with sweets, yet during festivals like Durga Puja or Kali Puja we end up eating sweets. Even after knowing, we eat. We also know salt raises blood pressure, yet we eat salty foods and raise it. (Community member_Gosaba).

Lifestyle and behavioural changes: Increased sedentary behaviour and reduced physical activity was noted in both adults and adolescents often attributed to mobile phone usage, age, financial stress and poor sleep patterns, in West Bengal, Jharkhand and Odisha. Those engaged in farming or hunting and homemakers reported doing hard work all day, suggesting they don't need physical activity.

Psychosocial Stress: Financial instability and associated stress were also identified as significant contributors to the rising burden of NCDs, across all states.

Reliable sources of health information

When asked the adults and adolescents about where they seek health information, adolescents expressed their family as the primary source, followed by social media, audio-visual media and frontline workers. They stressed social media is a fast medium to spread messages, while also acknowledging the

importance of street plays in raising awareness. *"Street plays/role-plays and videos, visual formats—work fastest; social media spreads messages easily too."*(Adolescent Peer Leader, WB).

Adults expressed ASHA workers as the main source of first-hand information about NCDs through home visits, meetings or screening services. When they are unwell, they visit health centres and consult a community health officer (CHO) or doctor or an informal provider.

Barriers and facilitators to regular screening and health seeking

Barriers:

1. **Low community awareness:** The health seeking behaviour across all the three states was delayed. Adults had limited knowledge and practice of early detection and preventive screening. Many participants believed medical consultation was necessary only after symptoms developed. This practice of delaying care until the symptoms develop was found to be a big barrier rooted in low community awareness about the importance of health seeking.

"Regular checkup is not necessary—maybe sometimes is enough". (Community member_Bankura)

"We've never gone for screening. (Community member_Dumka)

2. **Fear of lifelong dependency:** In Jharkhand, a unique "rule" was identified among adults: the belief that starting NCD medicine means taking it forever. This leads to their preference for dietary control and herbal remedies as a way to "stay out of the system."

If we take medicines then daily have to take. That's why we don't take, rule. (Community member_Khunti)

3. **Informal care seeking:** Adolescents in Jharkhand explicitly noted that *traditional and faith-based healers* are the "custodians of well-being" because they are embedded in the village. Some adults in Jharkhand reported going for exorcism (jhaad-phoonk) or private doctor, while some said they get themselves checked at Anganwadi centres and some do visit hospital for testing.

"If someone suddenly falls ill, we go to a nearby private doctor. (Community member_Dumka)

4. **The "Counselling Gap":** Adults in West Bengal reported that although screening services and medicine distribution are available, they observed insufficient counselling and infrequent health camps as frontline workers such as ASHA are often overwhelmed or low staffed for them to cover whole population. On the other hand, adolescents in West Bengal noted that while "government media" is good, they need "peer leaders" and "camps" because "holding one person at a time" (individual counselling) is difficult from the current overwhelmed health system.

"Camps are infrequent. When ASHAs/ANMs visit, it helps; otherwise we have to go to the clinic." (Community member_Koraput)

"Sometimes camps are held, so we go there."(Adolescent member_Jharkhand)

5. **Access barriers:** Both the groups mentioned "access barriers". While government medicines are free, indirect costs to reach health facilities due to long distance, poor road conditions, hard-to-reach areas and transportation difficulties (crossing the river in Gosaba, losing a day's wage in Koraput) make "free" care unaffordable.

"Bad roads and costs are problems. (Community member Koraput)"

"There's no transport; going for health checks is difficult, so we visit private doctors (Rampur/larger settlements). Reaching public facilities is hard." (Community member_Dumka)

6. **Financial and time constraints:** Wage loss from attending health facilities, lack of time and family responsibilities were also identified as barriers. Adolescents from Jharkhand stated that their family members risk losing wages if they take time off to visit clinics. Reliance on cheaper, informal providers or traditional healers, therefore, becomes the default.

"If no problem, we don't go—work stays. If body feels bad—we go; otherwise pressure of work."(Community member_Bankura)

"Medicines, check-up costs money. Money is the main problem. (Adolescent member_Koraput)

7. **Absence of providers at night:** In Jharkhand, adult participants highlighted the absence of doctors at night in health centres, leading to reliance on private practitioners:

"Doctors aren't present at the public health centre at night; sometimes we go during the day and get checked. We also get some checks done at the Anganwadi. These days we mostly use private doctors rather than the health centre." (Community member_Dumka)

8. **Health service limitations:** Several health service level barriers were reported viz., medicine stockouts, overcrowding and closures sometimes.

"Top of FormEven if we reach the hospital, medicines aren't always available for our specific illness; doctors say treatment isn't possible here, give vitamins, and send us back." (Community member_Dumka)

Facilitators:

Several facilitators were identified by the study participants that could improve NCD prevention and care.

1. **Increasing community awareness:** Awareness activities such as door-to-door engagement, community meetings and public announcements can enhance knowledge and motivate preventive and health seeking behaviours.
2. **Socio behavioural change communication:** Community members suggested raising awareness through information, education and communication (IEC) materials such as pamphlets, posters, radios and audiovisual media (television, advertisements, videos with short messages) in villages for sustained education. Adolescents spoke about stories or street plays and leveraging social media, especially to talk about physical activity.

"If the government, through newspapers and social media, tells everyone to do half an hour of exercise daily, I think it'll improve things everywhere, including our village." (Adolescent member_WB)

"Sometimes news or stories are useful". (Adolescent member_Odisha)

"We should put up posters". (Adolescent member_Jharkhand)

3. **Strengthening health services:** Community members across the three states suggested arranging *frequent health camps* and expanding *outreach* services with prior public announcements especially in remote areas—can help address geographic barriers. In addition, they suggested increasing nearby health centres with quality services, ensuring reliable medicine and diagnostic supplies through stock monitoring, providing evening services, transport arrangements, and expanding NCD-related programmes can substantially strengthen prevention, early detection, and management of NCDs in the community.

"If services were closer, more would get care. (Community member_Gosaba)

A good hospital here would help; there isn't one. We have to cross the river to Gosaba hospital—they aren't here...(Community member_Gosaba)

4. **Collective awareness:** Adolescents emphasized building collective awareness in the community through camps, engagement of schools, and local government bodies.

"We cannot tell one person at a time, so we'll do a camp; we'll arrange a camp... visit 10 houses, then another 10—thus awareness." (Adolescent Peer Leader_WB)

5. **Strengthening the capacity and volume of frontline workers:** Community members emphasized regular counselling and improving their capacity through refresher trainings.

*The number of centres needs to be increased—the sisters can't manage—the number of people here.(Community member_Gosaba)*Bottom of Form

Bottom of Form

Factors influencing the development and management of Non-Communicable Diseases using the Social Economic Model (SEM)

Based on the findings we have developed a Social Ecological Model (SEM) framework that shapes the development and healthcare management of NCDs,(34) as described in Figure 1. At the individual level, awareness, perceived severity of disease, socioeconomic conditions, stress, affordability, food diversity, and lifestyle behaviours—such as tobacco and alcohol use, consumption of high-salt and oily foods, irregular dietary patterns, physical inactivity, and adherence to medication—play a critical role in shaping risk and management of NCDs. At the interpersonal level, family support for accessing healthcare, peer educators, and adolescents within families can influence health behaviours. At the community level, frontline workers are most important in improving awareness, health behaviours and health seeking. At the organizational level, factors such as demanding workplaces, outreach services and health camps, accessible health facilities with referral systems, and reliable medicine supply chains affect service delivery and healthcare utilization. Finally, at the policy level, supportive measures including, strengthening of frontline worker capacity and workforce, quality NCD programmes, and social and behavioural change communication strategies are essential to address NCD prevention and management comprehensively.

Discussion

Our findings from adults and adolescents across three states in Eastern India demonstrate that NCD awareness is fragmented, health-seeking is reactive rather than preventive and risk is driven not by lifestyle 'choices' but by structural constraints—food insecurity, cultural normalisation of substance use—that are poorly addressed by current systems. These insights, framed within a Social-Ecological Model (SEM), underscore the urgent need for a life-course approach that moves beyond the current adult-centric screening paradigm to address risk behaviours from adolescence.

A core finding across all three states was that NCD awareness was predominantly symptom-driven, with limited understanding of asymptomatic progression, causation, or prevention. This aligns with a national NCD Monitoring Survey on 12000 households that showed nearly half of diabetics were unaware of their elevated blood sugar levels, rooted in low health literacy.(41). In Kerala, NCDs were commonly detected during hospitalization or when accessed for other illnesses or when the symptoms became severe.(42) This "symptom-centric" awareness has profound implications. When communities do not understand the chronic, asymptomatic nature of NCDs, they delay care until complications arise, leading to poorer outcomes and higher healthcare costs. These findings underscore that current awareness programs are insufficient and the need of sustained education on *asymptomatic chronic* nature, risk factors and the importance of routine preventive screenings.

Adolescents in this study recognized unhealthy habits—junk food, physical inactivity, and substance use. Yet, their knowledge did not translate into behaviour change. This gap between knowledge and practice is well-documented among Indian adolescents.(15,39) Other studies from southern India reported busy schedules and lack of time among adolescents for physical inactivity (40) underscoring the need to address these barriers and strengthen health education, promoting physical activity and healthy lifestyle behaviours in schools and colleges across India.

Participants in Jharkhand and Odisha described eating "only salt and rice" or "whatever is available" due to economic constraints. This challenges the notion of NCDs as "affluence diseases" and instead position them as consequences of structural inequality.(35) Food insecurity has been shown to increase the risk of cardiometabolic disorders such as excess weight, hypertension, and dyslipidaemia through reduced dietary diversity, erratic eating patterns, and chronic stress.(37) NCDs create a vicious cycle as disability and out-of-pocket expenditures deepen food insecurity and household poverty, (38), underscoring the need for social protection —such as food subsidies and cash transfers, alongside clinical interventions.

Substance use was highly prevalent across all states, particularly from Jharkhand. The Global Adult Tobacco Survey 2016–2017 reveal that 38.9% of adults in Jharkhand consume tobacco,(45) reflecting the cultural acceptance that extends even to healthcare personnel.(46) Similarly, alcohol consumption in adults and adolescents in tribal belts of India are rooted in their social and cultural structures.(47,48). Strategies must engage community leaders, reframe cultural narratives, and address the social contexts in which substance use occurs. Policy measures such as legislatures, taxes, restricted availability and culturally sensitive community-led awareness campaigns are essential.

The fear of lifelong dependency on NCD medications, particularly in Jharkhand, led many to prefer home remedies or explore traditional medicines, as seen in Kerala.(43) Such beliefs also reflect legitimate concerns about the financial and social costs of lifelong treatment in resource-poor settings. This "*medical pluralism*" is well documented in tribal belts, where spiritual and physical health are deeply intertwined in their culture along with ignorance resulting in limited engagement with health services.(44) Rather than condemning informal care, NCD strategies must acknowledge and work within this pluralistic landscape, potentially integrating traditional healers into referral pathways to improve early detection.

A consistent finding across all states is that ostensibly free NCD care is not affordable for the marginalized. The indirect costs—wage loss from attending facilities during working hours, transportation across difficult terrain, and reliance on private providers—force many into delayed care. This shows that those living in remote, hard-to-reach, and impoverished backgrounds have differential access to healthcare and risk for adverse outcomes.(35) In concurrence, a systematic review on health seeking behaviour among NCDs patients in India revealed financial constraints, geographical barriers, low awareness, medicine stockouts, health system inefficiencies, cultural beliefs, and transportation issues influence healthcare utilization and delay care. (36) Addressing these structural barriers requires outreach-based screening models that operate outside standard labour hours and transport arrangements for daily wage labourers.

While India's NP-NCD 75/25 initiative have expanded screening infrastructure, our findings reveal a critical "counselling gap" in remote areas. This gap is significant because awareness alone is insufficient; sustained counselling is essential for behaviour change and treatment adherence. Strengthening the capacity and volume of frontline workers through refresher training, task-sharing, and dedicated NCD-focused workers is essential. Other studies from India have also highlighted the gaps in knowledge and skills of frontline workers regarding NCDs.(49,50) Additionally, leveraging peer educators and community platforms can complement formal health system efforts.

A pivotal insight from this study is the urgent need for a **life course approach** to NCD prevention.(16) We found NCD risk behaviours being established well before age 18- unhealthy diets, reduced physical activity and substance abuse- —yet current programs focus almost exclusively on the over-30 population. The current program, Rashtriya Kishor Swasthya Karyakram (RKSK) focuses heavily on reproductive and sexual health, with no systematic NCD screening or prevention for this group. By the time individuals enter the NP-NCD screening bracket at age 30, metabolic damage may already be significant. Therefore, integrating NCD monitoring into adolescent health programs and schools is essential to shift the paradigm from reactive management to true prevention.

A major strength of this study is its multi-state, life-course perspective combining both adults and adolescents across diverse and difficult geographies (deltaic, mountainous, tribal and rural) in India and using local languages to capture nuanced insights. The inclusion of adolescents provides a unique "life-course" perspective, identifying early windows for intervention before risk behaviours become entrenched. The methodology included different districts of West Bengal so the perspectives are likely to be similar to other rural areas of West Bengal. By utilizing the SEM, the study moves beyond individual-level behaviour to examine the systemic, community, and policy-level drivers.

The study has several limitations. Being a cross-sectional study and smaller number of discussions from Odisha and Jharkhand, the findings provide a snapshot and cannot establish causality or be generalized to entire Eastern India. The purposive sampling method may have introduced selection bias, and the majority female participation limits gender-based comparisons. Data from Jharkhand had substantial missing demographic information, which constrains socioeconomic conclusions for that state. Additionally, the social desirability bias may have influenced responses, particularly regarding substance use or traditional healers. The reliance on self-reported data also suggests that actual dietary intake and physical activity were not objectively measured. Lastly, facilitators were local staff, which may have influenced critiques of the health system despite explicit statements of independent research roles.

Our findings highlight a mismatch between current awareness programs and community needs. NCD policies must decentralize awareness strategies, empowering local community groups to deliver messages that resonate with cultural beliefs. The CINI Method offers a human rights-based framework grounded in the principles of the Social Ecological Model, emphasizing facilitation, capacity building, fosters community and leadership engagement, supporting stakeholders achieve sustainable change and advocacy for strengthening health systems.(51) Scaling up such community-centred models

requires policies that integrate culturally sensitive interventions, SBCC strategies, and social protection mechanisms while actively engaging community groups.

Our findings are directly relevant to researchers, practitioners, and policymakers working to strengthen equitable NCD prevention and primary healthcare, and contribute to the growing evidence base supporting community-centred and life-course approaches to chronic disease prevention. Future strategies are needed to improve health and nutritional literacy of public, early disease detection and continued follow-up by integrating community-based care interventions and reducing inequities in NCD care. This includes community mobilization activities, individual and community-based group village meetings, alongside the development of context-specific SBCC campaigns, as well as leveraging the social media. At the community level, counselling gap" must be addressed by strengthening frontline worker capacity as well as engaging families, peer educators, community leaders and local government institutions. Health camps should be more frequent and conducted at convenient times to minimize wage loss. At the organizational level, there is a need for universal, financially and physically accessible, high-quality primary care for delivery of preventive interventions and for early detection and treatment of NCDs. Integrating traditional healers into the formal referral pathway may also improve early detection in tribal areas. At the policy level, policies for social protection, tobacco and alcohol control, and quality NCD programmes are required that focus on a life-course approach through cross-sectoral collaboration between health, education, and social welfare departments. Future research should also employ longitudinal designs to track the impact of these community-led interventions on NCD incidence and treatment adherence among marginalized populations.

Conclusions

In conclusion, addressing the NCD epidemic in Eastern India requires moving beyond clinical interventions toward a life-course, preventive and community-driven approach that tackles awareness and structural barriers—physical accessibility, food insecurity, cultural normalisation of risk behaviours and financial stress. Simultaneously, strengthening primary health care services with SBCC strategies, addressing systemic inequities, and integrating NCD prevention into adolescent health promotion programs are essential.

Declarations

Ethics approval and consent to participate:

Ethics approval (IEC No: 05/25–26) was obtained from Institutional Ethics Committee of Child in Need Institute (CINI). Written informed consents were obtained from all study participants prior to starting the discussion. For those with limited literacy, thumb impressions were obtained in the presence of a witness who read and explained the consent form. The study adhered to the Declaration of Helsinki.

Consent for publication:

Not Applicable

Competing interests:

The authors declare that they have no competing interests

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Author Contribution

S.G.M., M.B., and V.G. conceived and designed the study. V.G. developed the study questionnaires with input from all authors. T.K. led the study and data collection, conducted the data analysis, and drafted the initial manuscript. I.B. provided support in data analysis and initial draft. S.G.M. provided overall guidance and oversight throughout the study and manuscript preparation. All authors reviewed, revised, and approved the final manuscript.

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Data Availability

All data supporting the findings of this study are available within the paper.

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Figures

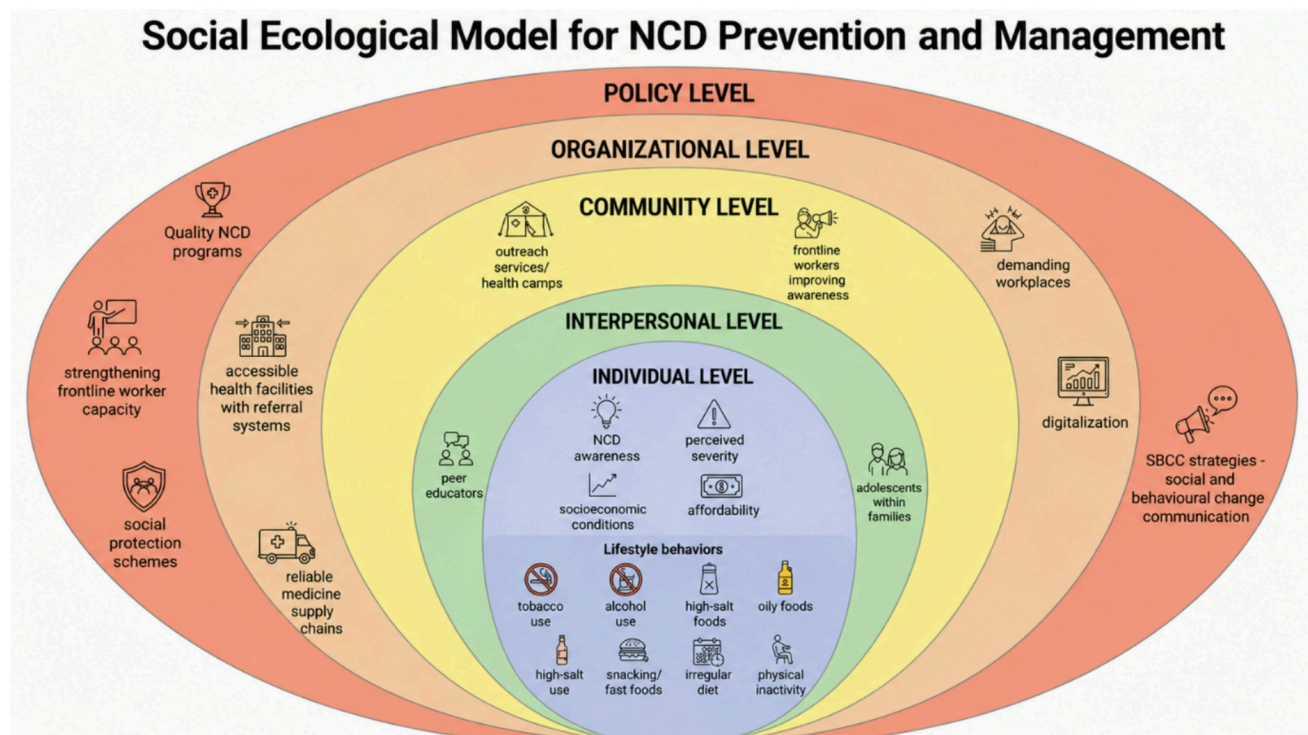


Figure 1

Factors influencing the development and management of Non-Communicable Diseases using the Social Economic Model (SEM) This framework illustrates the complex multi-level determinants that interact and influence NCD risk and care-seeking behaviours. Individual level focuses on personal attributes and behavioral factors; Interpersonal level represents the influence of social networks in shaping health-seeking behaviors and lifestyle; Community level highlights the importance of community health workers in improving awareness and engagement; Organizational level addresses the institutional settings; and Policy level delineates the systemic requirements.

Supplementary Files

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