



# Understanding low mobilization for non-communicable diseases among people living with NCDs: A qualitative study on hypertension in urban South India

Carolin Kroeger<sup>a,\*</sup>, Shuba Kumar<sup>b</sup>, Rani Mohanraj<sup>b</sup>, Sripriya Kundem<sup>b</sup>, Kate Bärnighausen<sup>c</sup>, Nikkil Sudharsanan<sup>c,d</sup>

<sup>a</sup> University of Oxford, Department of Social Policy and Intervention, Barnett House 32 Wellington Square, Oxford, OX1 2ER, United Kingdom

<sup>b</sup> Samarth, 100 Warren Road, Mylapore, Chennai, 600 004, Tamil Nadu, India

<sup>c</sup> University of Heidelberg, Heidelberg Institute of Global Health, Heidelberg, Im Neuenheimer Feld 130/3, 69120, Heidelberg, Germany

<sup>d</sup> TUM Department of Sport and Health Sciences, Technical University of Munich, Munich, Germany

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## ABSTRACT

There is low civil society mobilization for NCD policies in low- and middle-income countries (LMICs) despite a growing NCD burden. While existing research explains low mobilization largely through constraints such as inadequate funding and capacity at the organizational level, we explore the issue from the perspective of people living with NCDs and ask how lay understandings of hypertension may inform potential mobilization for multisectoral policy actions by people living with hypertension. To explore this question, we develop a theoretical framework that casts mobilization as a function of people's recognition of disease importance, attribution of NCD risk factors to government policies, beliefs about who bears responsibility for NCD prevention and management, and beliefs around efficacy of multisectoral policies. We present findings from 45 semi-structured interviews with people living with hypertension in a qualitative study in Chennai, India. Our thematic analysis reveals that respondents can dedicate limited time and resources to actions around hypertension. People living with hypertension also strongly internalize responsibility for developing and managing their condition and focus primarily on achieving lifestyle changes. Instead of demanding multisectoral policy action around hypertension, respondents recommend that government actions focus on measures that enable their lifestyle changes, such as increasing awareness and health care capacities, and express doubts about the efficacy of government policies. Our findings expand existing theories around mobilization by revealing how people's own understanding of their illness, its risk factors and their underlying drivers, as well as their perception of challenges in NCD policy making can present barriers to mobilization around multisectoral policies. Theory on health social movements would benefit from a deeper integration of individual perspectives and a closer consideration of the specific challenges of living with NCDs given the local context.

## 1. Introduction

India faces an increasing burden of non-communicable diseases (NCDs) (Arokiasamy, 2018). In 2017, NCDs accounted for 46.6% of all disability-adjusted life years and 47.6% of all deaths in the country (Menon et al., 2019). Urgent efforts are needed to prevent and control NCDs in India and other rapidly aging middle-income countries.

Although NCD prevention and control are often framed around individual decision making – such as improving lifestyles and adhering to medicines – governments have the potential to affect NCD risk factors at

the population level through multisectoral policies (Mohan et al., 2013). The World Health Organization (WHO) recommends several 'best buy' interventions to address four major NCD risk factors: physical inactivity, tobacco consumption, alcohol consumption, and diets high in salt, fat, and sugar. The interventions include restrictions or bans on advertisements for tobacco and alcohol, taxes and other pricing policies on tobacco, alcohol, and products high in salt, fat and sugar, as well as product reformulations to reduce trans-fats and salts (WHO, 2013).

In line with the global call to action and growing evidence that government-level policies can affect NCD risk factors (Cook et al., 2014),

\* Corresponding author. St Antony's College, 62 Woodstock Road, Oxford, OX2 6JF, United Kingdom.

E-mail address: [carolin.kroeger@spi.ox.ac.uk](mailto:carolin.kroeger@spi.ox.ac.uk) (C. Kroeger).

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the Indian government enacted the National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS) in 2010 and the National Multisectoral Action Plan for the Prevention and Control of Common Noncommunicable Diseases (NMAP) in 2017 (MoHFW, 2018; MoHFW, 2013). The NPCDCS aims to integrate activities by other NCD-related policies, such as the National Tobacco Control Programme and the National Programme for Health Care of the Elderly, and commits to health promotion and awareness generation, as well as increased screening, early detection, and affordable treatment (MoHFW, 2013). The NMAP sets out to establish mechanisms for a whole-of-government approach including public policies as well as legal and fiscal measures that reduce risk factor exposure (MoHFW, 2018).

Even though these programs are signs of progress on NCD control, they are criticized for their insufficient scope, implementation, and enforcement (Siegel and Stuckler, 2011; Thakur et al., 2020). For instance, the NPCDCS faces criticism for inadequate food labeling and many products that are produced in informal markets escape government regulation (Shang et al., 2018; Siegel and Stuckler, 2011).

Given the criticisms of many multisectoral policy programs, there is growing awareness that civil society can increase awareness, advocate and help devise policies, support implementation, monitor governments and businesses, and ensure accountability (Arora et al., 2011; Healthy India Alliance, 2017; Renshaw et al., 2020; UN, 2018). Within this framework of civil society action, some argue that political mobilization of those most affected by the NCD epidemic may be necessary to achieve effective policy change (Reich, 2019). We understand mobilization by people living with NCDs to comprise different measures that build pressure on governments and communities to act on NCDs. This includes individuals forming interests, building ties within their communities, and taking concrete actions to improve NCD prevention and management (Nedelmann, 1987; WHO, 2017). For example, individuals can discuss and increase awareness of how governments can affect NCDs with their social networks, join organizations and become spokespersons, publicly protest and exert pressure on their elected officials, participate in meetings with the government, and contribute to policy formations (WHO, 2017).

There are strong precedents for civil society mobilization around health issues in India. Civil society repeatedly challenged the strong ties between the tobacco industry and the Indian government, which contributed to the adoption of the Tobacco Control Act in 2003 and the National Tobacco Control Programme in 2007 (Bhojani et al., 2013b; Kashiwabara et al., 2011; Kaur and Jain, 2011). Similarly, Jan Swasthya Abhiyan, the Indian chapter of the global People's Health Movement, has co-ordinated over a million people in health assemblies and protests to increase health care access and mitigate health inequalities, which successfully shaped major policies such as the National Health Mission launched in 2005 (Campbell et al., 2010; Campbell and Scott, 2012). Since 2015, the Healthy India Alliance coordinates civil society efforts around NCDs and organizes protests and conducts awareness and advocacy work to mobilize people living with NCDs (Healthy India Alliance, 2017).

Despite these successful efforts, civil society efforts for NCDs are still nascent and the engagement of people living with NCDs has sometimes fallen behind expectations. Existing efforts have also focused primarily on tobacco control and less on other important NCD risk factors (Bhojani et al., 2013b; WHO, 2017). Existing research on challenges for civil society action around NCDs in LMICs focuses on structural issues, such as inadequate funding, capacity constraints or a lack of coordination among civil society organizations, governments, and global health actors (WHO, 2017; Herrick, 2017; Stuckler and Basu, 2011; Smith et al., 2016; Magnusson and Patterson, 2019). There is a dearth of literature that seeks to understand the issue from the perspective of people living with NCDs who may not feel compelled to mobilize for a range of reasons. They may not understand NCD risk factors and the link to government actions or may not believe that the government is responsible

or capable of taking action (Herrick, 2017; Unwin et al., 2016). Their perspective is a central piece of the puzzle because they form the backbone of civil society and can influence the content and nature of civil society actions (Brown et al., 2010).

Our paper addresses this important gap in the literature and asks how lay understandings of hypertension may inform mobilization for multi-sectoral policy actions by people living with hypertension. We first synthesize a theoretical framework from the literature on medical sociology and global health that is generally applicable to mobilization and illness experience for NCDs. The framework explores the recognition of disease importance, attribution of NCD risk factors and beliefs about responsibility for prevention and treatment, and beliefs about efficacy of actions. We apply the framework using semi-structured interviews with hypertensive adults in Chennai, India, and explore possible barriers to potential mobilization based on patients' understandings of hypertension, how to address it, and their illness experience.

We focus on hypertension, which is a persistent elevation of blood that is largely asymptomatic but if left untreated, poses a significant risk for heart attack, stroke, kidney disease, and a multitude of other chronic diseases (Gupta, Yusuf, 2014). Most hypertension cases have an unknown cause, known as essential hypertension, but improving physical activity and diet and reducing alcohol consumption and smoking are important parts of hypertension prevention and control (NHS, 2017). Individuals, civil society organizations, and governments can help control hypertension by regulating salt, tobacco, and alcohol and encouraging physical activity through better urban design and activity spaces. Hypertension provides a compelling study for NCDs as a whole since it is linked to all four major NCD risk factors, it is the leading risk factor for NCD mortality in India, and the hypertensive population in India is expected to more than double in size due to rapid aging and population growth (Gupta and Xavier, 2018; Sudharsanan and Geldsetzer, 2019).

## 2. Research framework: theoretical reasons for low mobilization

Brown et al. (2010) theorize that individuals may mobilize around health-related issues if they are discontent with the dominant beliefs about disease causation and treatment, form a connection with other people that creates a collective illness identity, politicize their illness by focusing their efforts on challenging power and policies in government, science or the private sector, and feel empowered to act. This process emerges out of the individual illness experience. In turn, this experience is shaped by the dominant beliefs and scientific knowledge about causation and treatment, as well as government policies and activities by civil society, the media, and private actors (Brown et al., 2010). Thus, upstream factors influence individual illness experience and frame mobilization by people living with diseases.

We therefore adapt the process developed by Brown et al. (2010) in our theoretical framework and bring it together with NCD-relevant political economic and individual behavioral theories (Brown et al., 2010; Campbell et al., 2010; Campbell and Scott, 2012; Reubi et al., 2016). Our framework is structured around recognition of disease importance, attribution of risk factors and policies, responsibility for prevention and treatment, and efficacy of potential demands. Based on these themes, our framework offers a way to explore how lay understandings of NCDs and illness experience may present challenges or inform potential mobilization by people living with NCDs.

An important factor for individual mobilization is the recognition of a disease as a serious and wide-reaching issue that needs to be collectively addressed (Brown et al., 2010). Individuals are likely to form their opinion on which diseases are important to act on based on public information they receive and by estimating the burden of diseases through observations and conversations in their social network. However, the extent of the NCD epidemic often remains invisible in many LMICs due to under-resourced data and surveillance systems and the portrayal of

NCDs as “diseases of affluence”, linked to indulgent lifestyles and urbanization, that predominantly plague high-income countries or upper income groups (Reubi et al., 2016; Stuckler and Basu, 2011, p. 22). For example, although NCDs are the leading causes of death, NCD-related civil society organizations in India are still in a “relatively early stage” that is “limited primarily to pockets of concerted action” (MHA, 2020; WHO, 2017, p. 3). This can influence the subjective perception of disease importance and stop people living with NCDs in India and other LMICs from recognizing NCDs as a real and intensifying problem that requires collective action (Brown et al., 2010).

Another challenge to mobilization around multisectoral policies is attribution of NCDs to risk factors and their underlying drivers. While the interplay between NCDs, risk factors, and the alcohol, tobacco, and food industry is well understood on a population level, individuals may not be aware of NCD risk factors and their relationship to policy-making and industry due to the complex aetiology of NCDs that often develop after several years of interactions between multiple risk factors (Herrick, 2017; Unwin et al., 2016). This complexity may undermine individuals’ understanding of risk factors and policies and present a barrier to potential mobilization around upstream factors.

In addition, the locus of responsibility for NCDs matters for potential mobilization. Individuals are often blamed for developing NCDs due to poor lifestyle choices or non-compliance with treatment (Reubi et al., 2016). This framing of NCDs as the result of irresponsible behavior may shift focus from politically amenable factors – such as regulation on unhealthy foods, alcohol, and tobacco – to behavioral change at the individual level that the state can support through health education and access to medication (Brown and Baker, 2012; Glasgow and Schrecker, 2016). If people living with NCDs largely hold themselves responsible and see only a small responsibility or role for the government in NCD prevention and management, then they may be less inclined to advocate for the government to control NCDs and place more emphasis on changing their individual behavior or choose forms of advocacy that do not challenge structural issues (Schermuly et al., 2021; Unwin et al., 2016).

Finally, individuals may not mobilize if they believe that their efforts have low efficacy or that their voices will not be heard or acted upon by governments. While the link between mobilization and perceived

success has not been studied in-depth in relation to NCDs or other health issues, quantitative research from India showed that people with lower trust and confidence in public officials and institutions are less likely to protest or participate in the democratic process (Bros and Borooah, 2013; Dutt and Spehr, 2004). One study hypothesized that people with low trust in the political system may find protesting unproductive because they do not expect authorities to meet their demands (Dutt and Spehr, 2004). This issue may be particularly salient in the context of NCDs in India and other LMICs where governments often cannot afford the regulatory and legal capacity to ensure formulation, implementation and enforcement of multisectoral policies that oppose the interests of private companies, the so-called “corporate disease vectors” (Moodie et al., 2013, p. 671; Siegel and Stuckler, 2011). Assumptions about the potential to achieve change and existing marginalization can foster “fatalism and passivity” among people living with diseases and limit their mobilization efforts (Campbell and Scott, 2012, p. 181; Chidambaram, 2020). Therefore, people living with NCDs may not be willing to mobilize if their assumptions about the influence of industry and government capabilities results in little faith that their government may respond to their demands and formulate, implement, and enforce multisectoral policies.

In short, to effectively mobilize around multisectoral policies, it is necessary that people living with NCDs recognize the scope and seriousness of NCDs as a collective issue, understand and attribute risk factors to governmental action, locate responsibility for preventive action around NCDs not only with themselves but also with policymakers, and have faith that their demands can successfully be formulated, implemented, and enforced. We adopt this theoretical framework (see Fig. 1) around recognition, attribution, responsibility, and efficacy to guide the analysis for our research question that asks how lay understandings of hypertension may inform mobilization around multisectoral policies by people living with hypertension.

### 3. Research methods

#### 3.1. Study setting

Our study was conducted in Chennai, a city of approximately 7

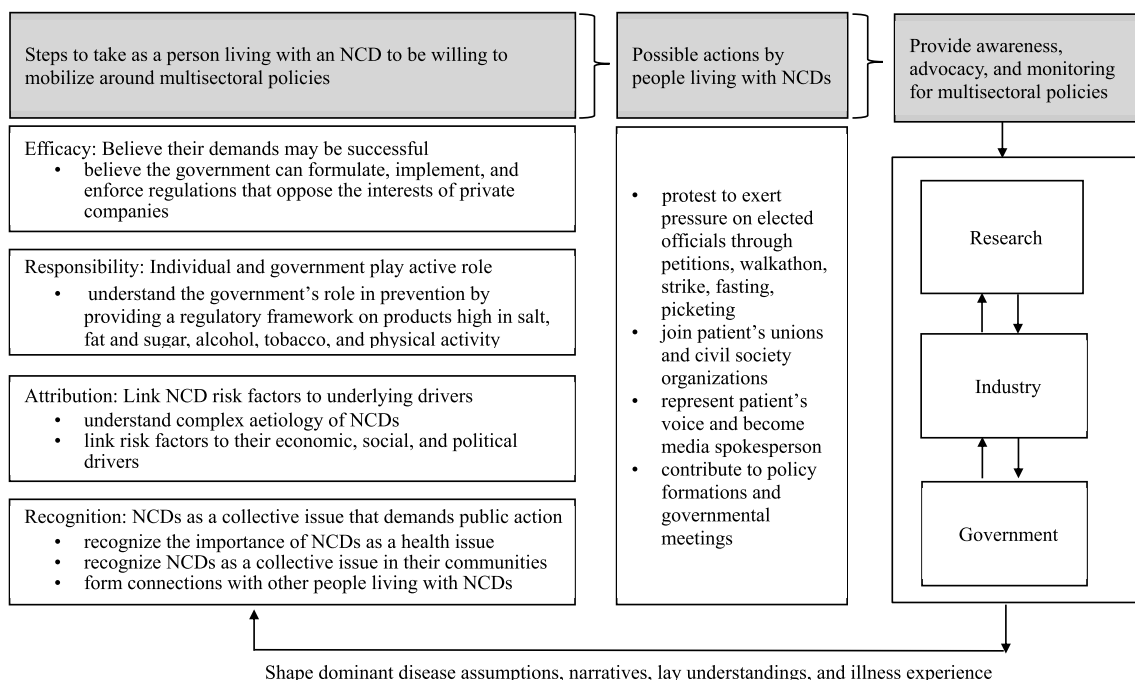


Fig. 1. Theoretical framework linking lay understandings of hypertension, civil society action, and multisectoral policies.

million inhabitants in the South Indian state of Tamil Nadu. We selected Chennai because our interest was in NCDs in urban environments where issues around health care access are less pronounced than in rural areas and where cities themselves have affected NCD risk factors and behaviors. In addition, we had local context expertise in Chennai. The city also has a high burden of hypertension. Approximately 25% of adult women and 29% of adult men in Chennai have hypertension, although only 38% of women and 24% of men are aware of their status (Prabhakaran et al., 2017). The majority of those who are aware of their hypertension also receive treatment. Treatment and medication are available free of charge in the public health sector in Tamil Nadu, which is lauded as a model for quality health services at low cost among Indian states (Parthasarathi and Sinha, 2016). Despite Tamil Nadu's comparatively strong performance, there remain gaps in efficiency as well as human resources and capacity, especially with respect to NCD care (PHFI and IHME, 2018). In Chennai, a number of facilities are in close proximity to the city's poorest residents, but a perception of the public sector as underfunded and understaffed has led to a relatively high consumption of private health care services (Ergler et al., 2011).

### 3.2. Data collection

In collaboration with Samarth, a Chennai-based research organization, we formed a team of five qualitative data collectors consisting of the first four authors and one additional Chennai-based data collector from Samarth. All data collectors were female, held undergraduate or post-graduate university degrees, had received training in research methods, were fluent in English and – those from Chennai – fluent in Tamil, the local language, with several years of experience in qualitative health research in the region.

Prior to data collection, we conducted a workshop together with the research team to build a shared understanding of our research aims around people's lay understandings of hypertension. This workshop also included training regarding the collection of qualitative data using pre-designed instruments. These instruments included the semi-structured interview guide with a section for reflexive and observational notes, participant information sheets, and consent forms. Instruments were pretested and revised throughout data collection. We conducted daily debriefing sessions during data collection to amend interview guides,

discuss and triangulate evidence, refine lines of inquiry and to consider the saturation of themes (McMahon and Winch, 2018).

Our qualitative inquiry centred on generating an understanding of hypertensive care, attribution of hypertension to risk factors, responsibility for prevention and treatment, and perspectives on governmental action. We additionally captured socio-demographic data including sex, age, children, and marriage/partner status.

Data collection took place from July to September 2019. The qualitative data collectors went into the field along with enumerators from an independent door-to-door quantitative survey on barriers to hypertension control (Sudharsanan et al., 2021). These enumerators identified adults who reported having received a hypertension diagnosis from a physician. Enumerators asked these adults if they would like to participate in either a survey or interview. Of those willing to be interviewed, we purposively selected respondents to achieve equal gender representation, socioeconomic variation, and represent different geographic zones in Chennai. Purposive sampling allowed us to reach those individuals that have a lived experience of hypertension, rather than those who have not. For example, older people are more likely than younger people to have hypertension, which is why there is a higher proportion of older people in our data.

In addition to this approach, Samarth leveraged their own networks in a complementary snowball sampling strategy to reach respondents from upper socioeconomic backgrounds that proved difficult to reach in a door-to-door approach. Table 1 displays the participants' demographic characteristics. We collected a total of 45 semi-structured interviews that were led by the Samarth-based data collectors and the first author. The interviews lasted 40–70 min and were predominantly conducted in Tamil to reduce potential language barriers. Interviews were conducted until no new themes emerged and the data reached saturation (Saunders et al., 2018).

### 3.3. Data analysis

We conducted thematic analysis using analysis software NVivo 12.6 and broadly followed the approach by Braun and Clarke (2006). First, the authors (CK, SK, RM, SK, NS) familiarized themselves with the data throughout the debriefing sessions. Second, the authors (CK, KB, NS) followed a hybrid inductive-deductive approach and created an initial

**Table 1**  
Demographic data on 45 interviewees.

Women					Men				
Age	Marital Status	Children	Occupation	Years since diagnosis	Age	Marital Status	Children	Occupation	Years since diagnosis
50	Widowed	≥1	NA <sup>a</sup>	2	67	Married	≥1	Unemployed	39
48	Married	≥1	Runs tiffin shop	10	54	Married	4	Retired hotel cook	4
37	Married	2	Homemaker	1	64	Married	2	Shop worker	0.9
59	Widowed	≥1	Homemaker	14	55	Married	0	Retired technician	12
29	Married	2	Unemployed	NA	76	NA <sup>a</sup>	NA <sup>a</sup>	Retired	16
47	Married	2	NA <sup>a</sup>	5	38	Married	NA <sup>a</sup>	Ticket officer	NA <sup>a</sup>
48	Married	≥1	Homemaker	14	66	Married	2	Runs logistics business	11
70	Married	≥1	Homemaker	6	44	Married	2	Software engineer	16
42	Married	2	Homemaker	3	55	Married	3	Tailor	15
55	Married	2	Homemaker	5	43	Married	1	Engineer	3
61	Unmarried	1	Retired Hindi tutor	28	64	Married	≥1	Factory worker	10
48	Married	1	Homemaker	6	72	Married	≥1	Retired	1
54	Widowed	2	Domestic help	4	67	Married	0	University officer	25
58	Widowed	≥2	Domestic help	10	42	Married	2	Watchmaker	3
59	Married	2	Retired Accountant	19	49	Married	2	Travel advertisement	2
71	Widowed	4	Runs eatery	5	60	Divorced	0	Retired accountant	15
50	NA <sup>a</sup>	2	Domestic help	5	68	Married	≥1	Retired mechanic	1
55	Widowed	1	Domestic help	1.5	70	Married	3	Mechanical engineer	36
58	Widowed	≥1	NA <sup>a</sup>	18	65	Married	0	Unemployed fisher	25
67	Married	2	Paediatrician	15	73	NA <sup>a</sup>	≥1	Retired help	4.5
59	Married	NA <sup>a</sup>	Retired principal	14	67	Married	2	Company manager	15
53	Married	2	NA <sup>a</sup>	1	45	Married	2	Unemployed	6
–	–	–	–	–	61	Married	3	Auto-driver & watchman	9

<sup>a</sup> NAs are values that were not reported in the interview process.



coding structure based on our debriefing sessions and our theoretical framework of recognition, attribution, responsibility and efficacy. For example, codes included perceptions of risk factors for hypertension, who respondents believe is responsible for prevention and management, and the respondents' recommendations to the government for actions on hypertension (Fereday and Muir-Cochrane, 2006). Third, the first author (CK) refined the coding structure during the coding of transcripts in NVivo and collated codes into themes, such as self-responsibility and inaccurate recognition of risk factors, through repeated reading of transcripts. Fourth, all authors reviewed and evaluated the coherence of the identified themes with respect to the research question during the final stages of the analysis and early stages of writing. We report the major relevant themes as the findings in this paper organized by each section of our theoretical framework.

During all stages of the research process, we carefully navigated issues around subjectivity and positionality to ensure the validity of data and analysis in a constructivist approach. During the development of the instruments, all researchers independently reviewed the interview guide and framed open-ended questions to avoid leading interviewees. During data collection, the interviewers and researchers regularly discussed emerging themes, surprising findings, and potential biases in the debriefing sessions, which ensured deep understanding and enabled triangulation of the data (McMahon and Winch, 2018). In addition, we triangulated data with existing empirical evidence on hypertension in India and cite ample verbatim evidence to allow readers to trace our interpretation of the data (Holliday, 2007).

### 3.4. Ethics

In line with ethical approval from University of Oxford (CUREC 1A/ODID C1A 19-047), the University of Heidelberg (S-355/2019), the Chennai Medical Association, and Samarth's ethics committee, the interviews took place in mutually agreed upon spaces, ensured auditory privacy, and established written informed consent by explaining the research process, data protection and rights to participants. Interviews were recorded with a voice recorder, transcribed, and translated verbatim into English and transferred into NVivo on password protected files and devices.

## 4. Results

We report the major themes along the four dimensions of our theoretical framework to explain how lay understandings of hypertension may inform and present barriers to mobilization around multisectoral policies among people living with hypertension. We find that although individuals largely grasp the importance of hypertension, they can dedicate a limited amount of time, material, and emotional resources to actions around hypertension. Moreover, respondents had an incomplete or inaccurate understanding of risk factors for hypertension and place responsibility for prevention and treatment of hypertension solely on themselves. Respondents rarely recommended action on governmental policy actions and some expressed doubts about the efficacy of governmental regulations. Instead of mobilizing around multisectoral policies, people living with hypertension focused on individual lifestyle changes, medication, and demanded expansions of health care capacity.

### 4.1. Recognition: hypertension competes for attention among limited time and resources

In our sample, people living with hypertension largely recognize hypertension as a health issue that requires intervention. Most respondents are able to name at least one of its health consequences, such as kidney disease, stroke, and heart attack. However, many describe having only fully grasped its severity and adjusted their health behaviour when they witnessed cases of hypertension and its consequences in their social network or were diagnosed with hypertension themselves. A

44-year-old man tells us that hypertension is

Such a common thing for South Asian lifestyle disease" but that he "didn't think of it as such a big deal, I did not realize until it came to me that it is actually a killer not merely a simple thing like headache or giddiness. [...] if I am not careful, I know what can happen. The shit can hit the fan and I can get a stroke. (Man, 44, married).

Respondents appear to recognize hypertension as a "silent killer", as one respondent put it, that is largely asymptomatic with consequences materializing only years later. They describe hypertension as "really dangerous" and some respondents express fear its long-term health consequences would make them incapable of living their life and render them a burden to their family. The health consequences and their social ramifications appear to incentivize respondents to seek control via medication and lifestyle adjustments.

Despite this recognition, actions around hypertension compete for time, material, and emotional resources in the daily lives of people living with hypertension. Worries about employment and family feature prominently across all socio-economic strata and regularly inhibit care-seeking behavior and informal exchange about hypertension. For example, a few respondents explained that they cannot afford the loss of time and income that attending a public hospital with long waiting times would entail. Other respondents do not find the "patience and time to sit and talk" to their neighbours and friends about their health and hypertension, which could be central to establishing awareness around the scope of the issue in the community. In addition to the worries of daily life, other pressing issues, such as the water crisis that plagued Chennai during the summer of 2019, demanded the attention of respondents. One woman, who worked as a domestic help, explained that she does not want the extra burden associated with raising concerns about issues such as pesticides and government action: "If I go and complain about all this, there will be unnecessary problems in my life. Why should I be bothered about it? I take care of my job and my house, and I keep to myself." (Woman, 55 years, Widowed). With time and money being finite and often scarce resources, people choose carefully how to spend them and allot a limited amount to actions that go beyond controlling their hypertension to prevent its health consequences.

### 4.2. Attribution: unclear risk factors and underlying drivers

While respondents appear to understand the implications of uncontrolled hypertension for their personal health, most respondents struggle to present a comprehensive and accurate understanding of risk factors and underlying drivers that the government could plausibly change. In accordance with biomedical evidence, key risk factors that respondents report are unhealthy diets high in meat, salt, and oil. In contrast to biomedical evidence, respondents very rarely related hypertension to alcohol or tobacco consumption. Instead, respondents placed high importance on the role of excessive emotional tension in causing their hypertension, although central guidelines for hypertension do not include chronic stress as a risk factor (Chobanian et al., 2003). According to respondents, these tensions stem from "office tensions" that include high work demands, job insecurity and irregular working hours, and from "family tensions" that refer to intra-household conflicts and disputes about family values. Respondents also diverged from current biomedical evidence when several respondents linked their hypertension to the increased use of fertilizers and pesticides in industrial agriculture. A small number of respondents also reported that they do not know what caused their hypertension or cited hereditary factors and co-morbidities as causes. The complex aetiology of hypertension appears to be overwhelming or discouraging to respondents at times. One respondent illustrates this when she describes how she experiences consultations with her doctor:

Drs confuse us by telling this and that. BP [blood pressure] is correlated to thyroid and everything is correlated with one another. So [...] we become more confused, we will think it is better we take medicines and go on with our daily issues. (Woman, 48, married)

Overall, respondents rarely make the link between multisectoral policies and regulation to hypertension or other non-communicable diseases.

Instead of multisectoral policies, people focus their recommendations for actions on hypertension on generating awareness, expanding hospital capacity to reduce waiting times, and increasing the number of neighbourhood-based camps that conduct screening for hypertension, dispense medication, and educate on NCDs. Even respondents who had a good grasp of underlying risk factors and their political economy focused their recommendations on enabling individual change through awareness, education, and medication, rather than multisectoral policy actions. The following response from a 44-year-old married man who developed hypertension when he was only 28 years old, illustrates that identifying the political economy of NCDs does not necessarily translate into arguing for political action on these factors:

I am sure there is a rise in lot of lifestyle diseases [...] the irony is that it is actually nowadays expensive to be healthy. [...] It has to do with mass production and instant gratification, like you must know that sugar is the real heroine. [...] most of what we do is dictated by our surroundings. [...] Surrounding says buy buy buy or eat this or eat that [...] slowly we are going to believe [...] that to lead a great life you have to necessarily go and eat your burger and come back. [...] I don't know [how we can fix it]. It is a policy issue.

He laid out in simple words some of the key factors driving the NCD epidemic, namely trade, advertisement, pricing. He identifies the spread of NCDs as a "policy issue". Yet, when we probe what he thinks should be done, he argues for health care provisions that enable individual action:

everyone should assume that they will get hypertension. [...] you tell me it will reduce my lifetime by 10 or 20 years. And then you see what choices you can make. [...] I think some fear mongering is not wrong. [...] So what can the government do is maybe provide some dietary services, provide some counselling, make it accessible, make it once a month in x y z. hospital, it is free for walk in. The diabetologist will tell you what you can do.

To conclude, even the few respondents who identified political-economic factors rarely suggested action on them and rather targeted the health system to improve awareness and treatment that enable individual behavioral change.

#### 4.3. Efficacy: question the efficacy of government actions

Some of the few respondents who do make a link between hypertension and multisectoral policies – whether accurate links to tobacco control or biomedically inaccurate ones to fertilizers – express a distrust in the government's ability and capacity to devise, implement, and enforce policies that oppose private companies. One respondent argued that private companies easily evade regulations:

In foreign countries they correct everything following rules and regulations. In India we have rules, along with easy ways to get away with the rules (Man, 64, married)

The reasons that a few of the respondents identify for the lax enforcement of regulation are weak state capacity and corruption. One respondent vehemently explains:

Why the government is not taking any action on this? Why the government is not conducting any camps? [...] Why the government is not questioning about fertilizers? For all those things, money is the

primary reason. [...] The government wants only the money. [...] (Man, 55, married).

While some respondents also voiced support for policy action, there appear to be more general concerns about the ability to devise, implement, and enforce multisectoral policies and regulation which respondents linked to weak capacity and corruption.

#### 4.4. Responsibility: place responsibility for developing and treating hypertension with themselves

In addition to a weak understanding of underlying risk factors, associated multisectoral policies and doubts about governmental action, respondents largely place responsibility for developing, treating, and controlling hypertension on themselves. The account of a fifty-five year old woman neatly summarizes the overarching theme of accepting self-responsibility because of irresponsible lifestyle choices in the past:

I believe that I did not take care of my health properly and did not keep my body under proper control. I did not have any diet restriction and I ate whatever I felt like eating. That is the reason why my BP has shot up very high. Hence, I am responsible for it. (Woman, 55, widowed).

Another woman laughs when we ask her why she does not place any responsibility elsewhere and tells us that.

It is not possible. [...] What can others do to us. [...] The problem is with us only. I cannot blame others. (Woman, 59, married).

Respondents strongly affirmed their own responsibility and often directly associated responsibility with blame: "Nobody else to be blamed" and "I cannot blame others" were frequent answers to probes around responsibility.

Respondents' sense of responsibility appears heightened by their impression that they have access to information on hypertension prevention and medical care. One respondent corroborates that no one else is responsible for him having developed hypertension because "they are giving a lot of information in television". Another man explains that he is able to be more responsible for his health than his parents because

Now we are educated, we read newspapers, magazines [...] what they [parents] would do if anything happens is to go and see the doctor but we being more aware are able to take some precautions-precaution is better than cure (Man, 60, divorced).

This account expresses that increasing availability of health information over the past few decades may have enabled individuals to take charge of their health and focus on prevention of diseases. Consultations with medical staff who provide awareness, information and medication additionally enable respondents to take on responsibility:

doctors can tell everything, but we have to follow it, [...] whatever the doctor says the final person is you. You choose what you want to buy and eat. (Male, 66, married)

Thus, self-responsibility for development and treatment of hypertension is pervasive among people living with hypertension who feel they had all the information available to have made better lifestyle choices in the past.

## 5. Discussion

We developed a theoretical framework rooted in [Brown et al. \(2010\)](#) to examine how lay understandings of hypertension may inform potential mobilization by people living with NCDs. The framework included recognition of the scope and seriousness of NCDs as a collective issue, understanding and attribution of risk factors to government

policies, responsibility for preventive action, and beliefs around the efficacy of potential demands and policies.

We find that respondents recognized that hypertension affected their community and had increased over the past few decades. However, most respondents could only afford limited time, material, and emotional resources to discussions, care, and action around hypertension. These results are consistent with the literature which finds that struggles of daily life often prevent people living with NCDs in India from prioritizing their health and healthcare (Bhojani et al., 2013a). This issue has restricted mobilization in India in other instances. For example, a community project on AIDS in Kolkata had to engage the community by providing small payments and micro-loans to sex workers that freed up time and empowered them to be involved in the project in a higher capacity (Campbell and Cornish, 2010). It is reasonable that people with limited time and resources focus their efforts not on multisectoral policies but on what they think they have control over and what brings most immediate relief: Controlling their hypertension through medication and lifestyle changes and asking for governmental support in this process through the provision of health care capacity. Therefore, even if people living with NCDs recognize the importance of NCDs, understand their risk factors, and assume that the government has responsibility to act, they may not find enough time and resources to advocate for multisectoral health policies and choose to focus on more immediate remedies instead. This insight generated from exploring the illness experience of hypertension in urban India reiterates the importance of local research to adapt theories based on high-income countries to reflect the lived reality of many people living with NCDs in low-and-middle income countries.

Despite the increasing awareness around hypertension, our analysis also revealed gaps in understanding of risk factors for hypertension and their underlying drivers. The exclusion of alcohol and tobacco consumption as risk factors leaves out central industries from any potential demands for regulation, whereas the inclusion of fertilizers may misdirect potential actions because current biomedical research is yet to make a connection between fertilizers and hypertension and explore whether the respondents' accounts signal a true but still unacknowledged risk factor for hypertension. If people living with hypertension struggle to recognize risk factors correctly and completely and do not focus on connecting physical inactivity, tobacco and alcohol consumption, and diets high in fat, salt, and sugar to weak government regulations, it is unlikely that they mobilize around controlling these risk factors through governmental action.

This issue has surfaced in the past: Community engagement in anti-tobacco activism in parts of India has fallen behind expectations because the general public struggled to understand the connections between government sponsorship and the tobacco industry (Bhojani et al., 2013b). Other health movements have addressed these issues through awareness and education workshops. For example, a diabetes awareness and empowerment program in Chennai effectively mobilized the local community to raise funds, appeal to local governments, and construct a public park which helped triple physical activity levels in the neighbourhood from 1996 to 2004 (Mohan et al., 2006). The issue of a weak understanding of risk factors and drivers also invites reflection on our underlying framework. Brown et al. (2010) theorize that individuals may mobilize if they are discontent with the dominant beliefs about disease causation and treatment. In our study, it is not acceptance of the dominant beliefs per se that stands in the way of effective mobilization around multisectoral policies, but rather a weak understanding of risk factors and the implicated social, economic, and political factors. This insight reinforces the need to educate communities on both NCD risk factors and their underlying drivers to support community mobilization. While education is important, education alone may not be sufficient, and more efforts are needed to address other barriers to enable communities to mobilize. We find that some of the few individuals who made connections to upstream factors also recognize some of the very challenges in the political economy of health – such as conflicts of interest between

governments and businesses – that they could help solve by becoming involved in civil society organizations. At the level of the organization, existing NCD organizations in India report having faced defensive government and industry reactions (WHO, 2017). As previous evidence on the relationship between confidence in public institutions and protest in India suggests, people may not mobilize if they have the impression that their actions may not be successfully met (Bros and Borooah, 2013; Chidambaram, 2020; Dutt and Spehr, 2004). Therefore, it is important to consider how people living with NCDs perceive challenges in the political economy of health and connect them to their individual efforts since this can act as a deterrent to mobilization.

Finally, the strong conviction for self-responsibility among people living with hypertension aligns with the dominant narrative that NCDs are the result of individual lifestyle choices (Reubi et al., 2016). Several national NCD policies in India reflect this narrative. For example, the NPCDCS explicitly emphasizes “health promotion through behaviour change” and the government’s Fit India Movement advertises one of its events as a ‘Freedom Run’ to “help us all to get freedom from obesity, laziness, stress, anxiety, diseases, etc.” (GoI, 2020; MoE, 2019; MoHFW, 2013). In other parts of the world, health movements – notably those focusing on cancer – have actively tried to overcome victim-blaming and steer attention towards structural issues through guided workshops and advocacy work (Brown et al., 2010; Reich, 2019).

In the absence of such programs and consistent with the hypothesis that self-responsibility shifts focus from upstream determinants to individual behavioural change (Brown and Baker, 2012; Glasgow and Schrecker, 2016; Unwin et al., 2016), respondents’ recommendations to the government largely exclude multisectoral policies and instead focus on health care expansion in the form of diagnosis, treatment, and monitoring that can enable behavioral changes.

On the surface, it seems surprising to find calls for health care expansion in the context of Chennai, where the government of Tamil Nadu provides free medication and health care in public hospitals (Parthasarathi and Sinha, 2016; PHFI and IHME, 2018). However, the issues around capacity, human resources and infrastructure and the poor perception of public hospitals in Chennai may help explain why respondents still call for more action on health care (Ergler et al., 2011; PHFI and IHME, 2018). In addition, the exclusion of upstream multisectoral policies is a common issue in the wider politics of health which tend to focus on more immediate health care policies (Bambra et al., 2005). For example, established Indian civil society organizations for NCDs concentrate more on building awareness, resources, and health care and only take up policy work after several years in practice (WHO, 2017).

Whitmarsh (2017) offers another link between self-responsibility and a focus on health care: He argues that a wide availability of health information can create the expectation that patients actively seek out health information, know their individual risk factors, and accordingly choose strategies for effective prevention and treatment. Our data supports this argument, as respondents emphasized the role of increasing health information and medical care in empowering them to be responsible for prevention and treatment of hypertension. While the individual focus on self-responsibility and a focus on awareness and health care delivery may empower individuals and improve the quality and quantity of care provided, our analysis shows that it may also shift attention away from multisectoral policies at the governmental level.

This study holds critical insights for existing theory on health mobilization and policies on NCDs. We expand the traditional literature on health social movements by emphasizing the links between lay understandings of NCDs, illness experience, and mobilization in the absence of a mobilization program. By adapting Brown et al.’s (2010) framework to the perspective of people living with NCDs, we showed that illness experience, lay understandings of hypertension, and perceptions of the wider politics of NCDs – namely the struggle of NCDs to be prioritized among competing issues, the difficulty of linking complex risk factors to their underlying drivers, narratives around self-

responsibility, and conflicting government and industry interests – inform potential for mobilization around multisectoral policies. Therefore, people living with NCDs are not an exogenous force that independently advocates, raises awareness, and monitors governments and businesses. Instead, people living with NCDs are influenced by their own understanding of their illness and its underlying drivers, as well as their exposure to discourses and perceived challenges in NCD policy making. Therefore, theory on health social movements would benefit from a deeper integration of individual perspectives and illness experience, as well as a closer consideration of the specific challenges of living with NCDs in a given local context.

For policy, our results show specific barriers that civil society organizations may need to overcome to integrate people living with NCDs into their activities. Concerted mobilization programs can empower people living with NCDs to participate in projects and organizations by freeing up their time and resources and educating them on risk factors and their link to governmental actions. Our study provides the insight that in the absence of such programs, the sense of self-responsibility, lack of clear understanding, and limited resources may inhibit people living with NCDs from becoming involved in ways that effectively advocate for multisectoral policies. These findings do not question the potential of people living with NCDs to advocate for multisectoral policies, but rather provide insights into the barriers they face and why mobilization by people living with NCDs may not occur.

## 6. Limitations

The data is biased towards middle-aged to elderly people with the average age being 57 years, which precludes us from speaking on the experience of younger people living with hypertension. However, this bias is largely due to increasing prevalence of hypertension with age and thus resembles the general group of people living with hypertension (Gupta et al., 2019). An important limitation of this research and avenue for further research is the exploration of the role that socio-economic factors, such as gender, caste, and income, play in shaping illness experience and political subjectivities. In addition, further research can elicit more detailed views on mobilization around NCDs and explore concrete examples of successful or failed mobilization around NCDs.

A natural limitation to this qualitative study is in its transferability beyond urban South India. Urban South India is more educated, wealthier, and has better health services and life expectancy than many other urban parts of India (Census of India, 2011; Corporation of Chennai and State Planning Commission Tamil Nadu, 2017; Office of the Registrar General and Census Commissioner, 2020). Our approach and findings may transfer beyond urban South India, particularly to other LMICs, under careful consideration of context-specific factors. While LMICs are a heterogeneous group of countries, some LMICs may share India's experience of a recent rise in NCDs, as well as a lack of financial resources and institutional capacity to address NCDs at the policy, health care, and individual level. There may also be limited transferability beyond hypertension. Unlike some other NCDs, hypertension is largely asymptomatic, often not directly linkable to clear causes, and can be controlled with a comparably low-cost medication regime. Mobilization may thus be higher for more salient or less ambiguous NCDs. Further research should carefully examine how our approach and findings transfer to other case studies by considering the context- and disease-specific factors that may shape illness experience and barriers to mobilization.

## 7. Conclusion

We find that people living with hypertension in Chennai face barriers to mobilization around multisectoral policies. They may not be willing to mobilize because they can only dedicate limited time, material, and emotional resources to hypertension, believe they are responsible for developing and treating hypertension, have a weak understanding of

risk factors and their underlying political-economic drivers, and express doubts about the efficacy of potential multisectoral policies. Instead of advocating for multisectoral policy actions, people living with hypertension focus on making individual lifestyle changes, adhering to medication, and demanding expansion of health care capacities. This study highlights that illness experience, lay understandings of hypertension, and perceptions of the wider politics of NCDs may inform and limit potential mobilization around multisectoral policies among people living with hypertension. Ultimately, we suggest complementing existing programs that address structural barriers to civil society mobilization with programs that target barriers at the individual level and take into consideration the illness experience and lay understandings of people living with NCDs given their local context.

## Author contributions statement

Carolyn Kroeger. Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Software; Supervision; Visualization; Writing - original draft; Writing - review & editing. Nikkil Sudharsanan Conceptualization, Data curation, Funding Acquisition, Project Administration, Supervision, Writing - review & editing. Shuba Kumar Data curation, Methodology, Project administration, Writing - review & editing. Rani Mojanraj Data curation, Methodology, Project administration, Writing - review & editing. Sripriya Kundem Data curation, Methodology, Project administration, Writing - review & editing. Kate Bärnighausen Methodology, Writing - review & editing.

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## Declarations of competing interest

None.

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## Appendix A. Supplementary data

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