



How social norms and values shape household healthcare expenditures and resource allocation: Insights from India

Sumit Kane^{a,b,*}, Madhura Joshi^b, Ajay Mahal^a, Barbara McPake^a

^a Nossal Institute for Global Health, Melbourne School of Population and Global Health, The University of Melbourne, Victoria, Australia

^b Gokhale Institute of Politics and Economics, Pune, India

ARTICLE INFO

Handling Editor: Professor Alexandra Brewis

ABSTRACT

We present a novel perspective on thinking about and studying healthcare spending in contexts where few health-related financial risk protection mechanisms exist and where out-of-pocket spending by households is the norm. Drawing on interviews conducted across 20 villages in two states of India, we illustrate and problematize how a complex interplay of social norms and cultural factors underpin spending decisions within households in such contexts. While our analysis draws on the fieldwork at large, we present our findings through selected narratives - stories of patients suffering from chronic breathlessness. We engage with and reveal the various ways in which social norms dynamically drive this household economy, and shape resource allocation-related decisions. We conclude that in health system contexts where out-of-pocket spending by households is the norm, it is essential to recognise the pragmatic and calculative nature of intra-household allocation of resources, and how it involves bargaining and negotiations at the intersection of social norms, economic class, caste, gender, age, and productive status. And at the same time, how all of this occurs within the economy of the family, and how it plays out differently for different members of a family is also important to recognise. Such recognition can not only help one better appreciate how this household level economy may sometimes maintain and perpetuate entrenched hierarchies and gender inequities, crucially, it can help target health related social protection policies and strategies and make them more responsive to the needs of the most vulnerable in the society and within households.

1. Introduction

Questions about healthcare-related expenditures have been widely studied across disciplines, with scholars in health economics and public health, leading the way. The largest body of work focuses on macro-level determinants and consequences of healthcare expenditures (e.g., Jung and Streeter, 2015; Mahapatro et al., 2018), broad trends, political choices, and population health (Sriram and Albadrani, 2022; Lyszcza and Abdi, 2021). Then there is research that adopts a meso-level perspective to study the health expenditure patterns and financial burdens at a household level, including by exploring the expenditures at different stages of the life-cycle (e.g., Hong and Kim, 2000; Kim and Yang, 2011). Studies that take a micro-level perspective on healthcare expenditures, typically work with the household as the unit of analysis and examine resource allocation within households (Agarwal, 1997;

Jung et al., 2022; Borde et al., 2022). Within this micro-level perspective, while it is recognised that allocation of resources within household and families is as much a social and cultural process as an economic one (Marmot et al., 2013), there is a relative dearth of scholarship examining this.

The few studies that have explicitly examined how social and cultural factors shape healthcare-related spending within families and households point to the influence of social norms in these processes. This literature suggests that decisions around healthcare expenditure within households are shaped by, reflect, and reproduce social norms, and gender and age-related social hierarchies and power dynamics (Jose, 2003; Tur-Sinai et al., 2018). This insight also emerges indirectly from the large body of literature on healthcare-seeking decisions and behaviours, including from India (e.g., Bhandari and Kannan, 2010; Pati et al., 2013; Kapoor et al., 2012; Kane et al., 2022).

* Corresponding author. Nossal Institute for Global Health, Melbourne School of Population and Global Health, The University of Melbourne, 207 Bouverie Street, Carlton, VIC 3053, Melbourne, Victoria, Australia.

E-mail addresses: Sumit.Kane@unimelb.edu.au (S. Kane), madhura25.joshi@gmail.com (M. Joshi), Ajay.Mahal@unimelb.edu.au (A. Mahal), Barbara.McPake@unimelb.edu.au (B. McPake).

<https://doi.org/10.1016/j.socscimed.2023.116286>

Received 25 October 2022; Received in revised form 19 September 2023; Accepted 26 September 2023

Available online 27 September 2023

0277-9536/© 2023 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

Here, we build on some of these insights to dwell deeper into and examine how socio-cultural factors and dynamics shape healthcare-related spending choices and decisions within households in India. We examine how shared understandings embedded within cultural notions of justice, propriety, familial obligations, socially desirable behaviours, and traditions, shape choices and decision about and legitimate claims over the allocation of finite resources within households. [Uberoi \(2006\)](#) has highlighted the role of social norms and culture in driving the decisions about the allocation of resources within Indian families. In this paper we unpack how socio-cultural factors (moral feelings, emotions, values, norms, and obligations in the social space) shape decision making processes around the allocation of resources towards healthcare at the household level in India.

Culture here, is understood in its broadest sense - as a system of meaning, knowledge, and actions, which constitute and shape all aspects of social life. As a system of knowledge, culture sanctions normative behaviours and other socially acceptable ways of acting, so that the constructed 'meaningful' world is consolidated, reinforced, transmitted, and maintained in the present, and over generations. As a system of action, culture is what enables individuals and communities to "act upon their world so that new meanings can be negotiated" ([Nastasi et al., 2017](#)).

Foregrounded by this recognition, the inquiry and analysis in this paper are informed by and conducted at the intersection of two broad strands of theoretical understanding. First, the work of [Elster \(1989\)](#), [Tourey \(1995\)](#), and [Clandinin and Rosiek \(2007\)](#) which focuses on the nature of social norms and how they dynamically operate as motivations for decisions and actions that are irreducible to rationality. Second, [Rinchin \(2005\)](#) who understands the family as a social space, a site of caring, nurturing and sharing, and a place to imbibe and learn, but crucially for us in this paper, also as a place for bargaining, contestation, disciplining, and reproduction of social norms. Within this broader understanding of the family and the household as social structure, we reveal the dynamics that underpin the economy of healthcare expenditures and resource allocation within households and family units and highlight the significance of its recognition for policy and practice. In a health system context like India, which is characterised by a large, diverse, poorly regulated private health sector, and a poorly functioning public health sector, we argue that a nuanced understanding of the complex dynamics that drive household resource allocation towards healthcare can help inform more effective policy choices.

2. Methods

Findings presented here are from a multi-methods study that aims to understand the choice of providers, costs incurred, and care-seeking journeys of those experiencing severe chronic breathlessness for more than 6 months. The broader study involves three components - household survey, discrete choice experiments, and a qualitative inquiry. This paper reports findings from the qualitative inquiry conducted in 20 villages across Uttar Pradesh and Maharashtra states of India over a period of 8 months in 2019–2020; the inquiry focused on unpacking the illness and care experiences of those suffering from chronic breathlessness. We purposively selected and interviewed 41 respondents; study participants were recruited through a three-step process. In the first step, in the selected village all those households with a member with the condition were identified for inclusion in the sampling frame for the broader study (the line list); a preliminary consent for inclusion in the broader study was sought; basic demographic and household characteristics were recorded. Identification was done with help from local community health worker and village elders. Step 2 - at the end of each day, the study team discussed the line list to identify those most suitable for inclusion in the qualitative inquiry (criteria: likelihood of being insight rich, based on the initial interaction). Step 3 - those identified were approached for an initial interaction on the next day; and from amongst these, those judged most suitable for inclusion in the

qualitative inquiry (as assessed by the 1st and 2nd authors) were interviewed. Interviews followed two broad lines. How chronic breathlessness was understood generally, and by different members of society; how its occurrence was explained; how different members of the family relate to and respond to the problem; and what implications these understandings have for care-seeking decisions. The second line of inquiry delved into the specifics of the participant's/patient's/family's experience with the illness. The qualitative interviews were semi-structured, and the interview process was such that participants could also share what they considered important. Such an approach to the interviews helped us to better understand the patient's situation, how they reacted to their situation, how they related to how others in the household and society saw them and their illness, and what ways the illness/problem had shaped their identity. The important aspect of the qualitative interview is the self-reflexivity of the researcher and the research process. It is well recognised that the responses are the result of the multiple factors which are at play during the process of the interviewing, including but not limited to the physical space, the researcher's social identity and his/her responses to the interviewee. These insights when analyzed in relation to the social context help us provide nuanced explanations of the healthcare-related decisions that are/were made within the household.

Interviews were conducted in the local language i.e., dialects of Hindi and Marathi. They were conducted in the homes of the interviewees at a date and time of their convenience. Typically, each interview lasted between 60 and 90 min. The research team debriefed at the end of each day of fieldwork to discuss emerging findings; debriefing sessions were audio-recorded and transcribed and included as field notes which among other things included reflections on the context broadly, and verbal and non-verbal cues noted during the interviews.

All interviews were audio recorded and transcribed verbatim in the interview language; transcripts were then translated to English. All transcriptions/translations were checked for completeness and accuracy by authors and were imported to and analyzed in NVivo. SK and MJ performed the coding independently using a codebook that was developed based on apriori theoretical and empirical readings and understandings, and also informed by a preliminary analysis of the data. Coding and analysis were iterative and involved repeated readings of interview transcripts, listening to audio recordings of interviews and debriefing sessions, and cross-checking of coding between the two coders to ensure the reliability of the coding. Memos and annotations were recorded - after interviews, during coding, while listening to audio recordings, and expanded during discussions between authors. Of the 41 participants, 22 were women (UP-thirteen; MH-nine) and 19 were men (UP-eleven, MH-eight). Ages ranged between 35 and 80 for women and 45 to 82 for men; the duration of illness (severe breathlessness) for women ranged between 3 and 30 years and between 1.5 and 30 years for men. The vast majority identified themselves as socioeconomically disadvantaged.

3. Analytical approach

We adopted an abductive approach involving observations, interviews, discussions between researchers, revisitation of interviews in light of emerging findings and theory, to unpack how sociocultural factors shaped healthcare related spending decisions within households. The abductive approach involves consciously being open to inferences that may fall outside of an initial theoretical frame or premise ([Tavory and Timmermans, 2014](#) p44). While the analysis draws on the fieldwork at large, it is anchored around and presented through selected narratives - stories of patients suffering from chronic breathlessness. The 'narrative' serves a dual purpose. On one hand, it is an account of particular experiences and events, on the other hand it also provides a window into interpretative frameworks being mobilised by patients and sufferers as the narrators ([Atkinson, 2009](#) p 2). The function of these narratives then is to represent not just the lived experiences of particular study

participants, but also to provide meaningfulness to the experiences across study participants. The narratives also offer an approach to advance the understanding not just of the individual patient's experience, which it anyway rarely is, but also of the immediate and broader social circle. Analysis of the narratives is premised on [Clandinin and Roziek's \(2007 p 37\)](#) view that "humans, individually and socially, lead storied lives" and on [Atkinson's \(2009\)](#) view that what people say and tell should be treated as "speech acts" (p6) and expressions of "socially shared resources" (p 5). The understanding being that people use various rhetorical devices and flourishes (deployments of demeanour, stance, micro-actions, tone of voice, and body language) to socially present oneself, or one's position with respect to others or the social norms. These performative elements are enacted in the presence of others, often together with the use and invocation of "discursive resources and conventions" (p 6) to produce private, public or a combination of these accounts. Analysis of form and function was given particular importance to explicitly uncover nuances that would be overlooked or missed if verbal accounts were treated with a thematic analysis approach alone. Thus, in our analysis we treat people's accounts as both expressive and constitutive. The point being that people, in telling their stories actively "interpret their experience" so as to make it "personally meaningful" - and that any analysis needs to take this into account ([Connelly and Clandinin, 2006 p 375](#)). In what follows, the role of sociocultural factors, understood broadly, is unpacked at two levels. First, at the level of how they shape spending on healthcare within households and second by examining various ways in which they can help explain and understand healthcare related spending decisions and the discourses around these, within households. The analysis engages with and reveals the nature of social norms and the various ways in which they dynamically operate as motivations for decisions and actions within the family. The analysis reveals how the 'moral economy of the family' not only underpins spending decisions on healthcare within households, but it also sometimes helps maintain these social structures. In doing so, we present a novel perspective on thinking about and studying healthcare spending in contexts where few health-related financial risk protection mechanisms exist and where out-of-pocket spending by households is the norm i.e., forms a substantial or whole share of healthcare costs.

4. Findings: unpacking the moral economy of intra-household resource allocation for health

The narratives presented below are what [Ely et al. \(2005\)](#) have called "lived stories ... individual and collective, retold, and reconstructed" of study participants suffering from chronic breathlessness. Through these stories and our analysis of these stories, we try to "bring readers into the settings, characters, actions, dialogue and events" ([Ely et al., 2005](#)) in the lives of our study participants, and in doing so we attempt to shed light on the phenomenon of interest – the dynamics underpinning the economy of intra-household resource allocation towards healthcare. The narratives are representative stories which together highlight the range of experiences across the spectrum of our respondents. We present and discuss these narratives under themes that have emerged from our data.

5. The gendered nature of intra-household resource allocation: Ganesh and Laxmi's stories

5.1. Ganesh's story

Ganesh was about 58 years old, and he lived with his family in a small village in Uttar Pradesh state of India. He (by his own account) was the head of the household; he had three sons and one daughter; the daughter (in her early twenties) and one of his sons (in his mid-twenties) were by his side during the interview. Ganesh looked tired and much older than his 58 years and was sitting on a bed next to which stood a table that was full of strips and empty and half-empty bottles of

medicines of various kinds.

Ganesh began by telling us that he had been suffering from breathing problems for four years now, and how he had been hospitalised several times and had been treated by many. As the interview proceeded, he told us that he had, till 3 yrs ago, owned a fairly successful vegetables business in Delhi. But since he was increasingly unable to work, to manage the expenses of living in the city, the family had to move back to their ancestral village. He explained, with a mix of pain and pride how to treat his problems the family had had to sell off their land and borrow money. With tears in his eyes, and despair in his voice, he added how his children had to discontinue their education. As Ganesh hung his head and looked away, his son, who now runs the household, interjected to say, *"If we wouldn't have spent on our father's treatment, then people would have said that we're not caring for our father"*. He said this simply, as if it were a matter of fact. *"We just wish our father gets healthy. Because of his illness our lives have been stuck like a train gets stuck when its Engine does not work"*, Ganesh's daughter added.

Ganesh's and his family's decisions regarding spending on his healthcare are best understood considering his position in the household. The metaphor of an engine used by his children shows the place of a man in the Indian patriarchal family. Ganesh's children had to stop their education as they had no money to continue it. A simplistic reading would argue that Ganesh's position as the patriarch allowed him to demand care and claim resources towards his healthcare; that because he was the decision maker in the family, he could prioritise his own treatment over everything else. However, a more nuanced understanding is possible if one views these articulations as "accounts of a disclosing of a supposed internal attitude" and "situated claims and justifications." ([Radley and Billig, 1996](#)), or as what Atkinson (2009 p 5) calls "speech acts, as performative, and as cultural phenomena that express socially shared resources". Ganesh's son and his family were socially expected to do and be seen as doing all they could for their father. Ganesh was not happy about what his family, particularly his children, had foregone to pay for his treatment, but he was proud of what had been done for him (while he took these decisions, he did so with full support of his family and children). The children on the other hand expressed pride (they looked at each other knowingly, and the son, as he spoke, looked us in the eye and raised his head and chin as if to say that they had done the right thing and done it well) and presented a dignified and stoic front to each other, to their father, and to the research team. These "speech acts" ([Atkinson, 2009 p 6](#)) were a means for both Ganesh and his children to socially represent themselves, and their position with respect to established social norms; in as much as the acts were performative, they were also what Atkinson (2009 p 6) calls "discursive resources" which were mobilised by all family members towards producing private, public or a combination of these accounts. While these speech acts and discursive resources allowed all, particularly the children to construct the image and narrative of a dutiful, all agreeing, happily sacrificing, ideal India family, as the interview progressed, we could see that these resource allocation decisions hadn't clearly been as simple and uncontested as we were being told. Family members' body language and the prompt, sharp interruptions whenever someone drifted from the idealised narrative, clearly suggested that what we were being told was what the family wanted us to believe.

Ganesh's story also suggests that gender acts as a key mediator in the decision-making process. Often in the case of women, the primary decision maker was a husband, son, or a brother – though not totally nor always so. For almost all women participants in our study (some elderly women being the exception), the decision to be part of the study was also taken by the head of the household who was nearly always a man. In large parts of Indian society, which is largely patriarchal, the man is the head of the household and the primary decision maker; the man, at least nominally has the highest power within the household. Ganesh's case and our findings at large affirm this patriarchal structure and privilege. However, our findings suggest, and we argue that it is equally important to recognise that healthcare expenses are gendered not because men

control all resources and wield disproportionate decision-making power on household finances, but also because they normatively hold the responsibility for all expenses and the household's finances broadly. Hence, the patriarchal structure operates in two ways; on one hand it provides privileges to men while on the other hand it also makes the man solely responsible for providing and caring for all family members, as Ganesh's son's case shows, sometimes even at the expense of his own well-being.

5.2. Laxmi's story

Laxmi's story illustrates this point. Laxmi, a 45-year-old woman, hailed from a middle-income, higher caste, rural, agrarian family. She had been suffering from Asthma since as long as she could remember. She lived with her husband, his second wife, her stepson, and his wife, in a nice house. Laxmi told us that her husband was initially of the view that Asthma was a heritable disease and had thus decided to not have children with Laxmi and had married another woman (though polygamy is illegal and uncommon, it is socially acceptable in some parts of India). Laxmi clearly resented her husband's decision to get a second wife but was quick to emphasise that he had always been supportive of her treatment, and that over the years his misunderstandings about her illness had been cleared. She talked at length about the incident where she was admitted to the hospital and how her husband sold his then only Buffalo to pay for treatment. A Buffalo/Cow is an important asset for a modest farmer in India – Laxmi looked overwhelmed with gratitude when she said, *"My husband has really helped me get good treatment; he went wherever he was advised to go"*. Laxmi felt obliged to her husband and the family for, what she felt was a large amount of money spent on her healthcare – she also seemed to be offering the argument that it was because she had been so well taken care of that she had agreed to and accepted the second wife within their/her household. However, beyond major health crises, Laxmi's wishes for better healthcare were not a priority in the household allocation of resources. When family members were out of earshot, Laxmi told us in a hushed voice that if given the choice she would like better treatment, but that she couldn't, as she did not have enough power to contest, negotiate and claim the necessary resources.

Laxmi's story illustrates the complex gendered dynamics whereby when a family spends on the health of a woman, she, perhaps more than others in the family, experiences it as having received something more than she deserves. A man, as Ganesh's story illustrates, on the other hand may not have these concerns; a man instead has to reconcile with being responsible for adjudicating during such resource allocation related contestations and negotiations and balancing all decisions and linked household finances. However, this cannot be generalised. Other factors like economic status and age also intersect and play a significant role in the process that always involved some form of bargaining and contestation, explicit or tacit. And that these contestations and negotiations are themselves shaped by social norms which, as Agarwal explains (1997 p 37), play a varied and crucial role *"in setting limits to bargaining, in determining bargaining power for that which can be bargained over, and in influencing how bargaining gets conducted"*. This is further illustrated in Sunita's story below.

6. Intra-household resource allocation as negotiations at the intersections of class, caste, age, and gender: Sunita and Pushpa's stories

6.1. Sunita's story

Sunita, a 55-year-old woman, lives with her husband in a big bungalow in Kolhapur, a prosperous agrarian district. When we entered her house, she was chatting with her sister-in-law in her living room; her husband was sitting next to them and was silently listening to their conversation. Sunita belonged to an upper middle-class household, and

the family owned 8 acres of land which is a significant asset in that part of the country. Sunita told us that she had been suffering from Asthma for almost 3 years now – and that her husband suffered from Diabetes. Their monthly medical expenses were around INR 5000, of which approximately INR 1000 were towards Sunita's treatment. Sunita and her husband could manage these expenses comfortably. *'When I get an Asthma attack, I call a maid for household chores and take complete rest. Apart from the cooking, my husband and son do not let me do any other work during that period'*, she said with pride in her eyes. She continued and told us about her family's strict practices around food – adding with a knowing look that her family did not like the food cooked by the maid, and that culturally, outsiders were not allowed to enter their kitchen. *'I think a woman can shed away all other responsibilities, but food has to be prepared by the lady of the house. Even if I am not feeling well, I cook slowly at my own pace'*, said Sunita, with a sense of pride and resolve. The conversation veered back towards her care experience, and she began by stating that although she had consulted 2–3 doctors for her illness, she was glad that she had never been hospitalised. Sunita said that initially she used to visit a lady doctor from the village. She found her medicines to be effective. *'See, I am not educated. I judge doctors simply by the effectiveness of their treatment'*, said Sunita candidly. She was not aware of the doctor's qualifications, but she had her own observations and judgments about them based on her experience. *'For me, whether I get relief or not is what matters the most'*, she added. When asked about the severity of her illness, she reluctantly, in an almost apologetic manner, recalled the winter times when her distress tends to be the highest – this apologetic manner was in some ways common across all female participants from well-off families. Sunita went on to explain how she had also learnt that dusting aggravated her breathlessness; and therefore, how now, she had started avoiding these household chores. Sunita was well-adjusted to and responded well to her regular medicines.

Sunita's adult son (who was not present during our visit) was a farmer. His wife (Sunita's daughter in law) had at the time of interview gone to visit her maternal home. Sunita's sister-in-law lived next door; she helped Sunita routinely and particularly so during the exacerbations of her illness. Sunita had realised the fact that her illness would never be completely cured and that she would have to live with it; she, and her family seemed to relate to her illness as a matter of fact. It probably helped that their lives were not truly disrupted by her illness since they had enough monetary and relational resources to manage the disruptions caused by it. While Sunita, over time, seemed to have developed a kind of acceptance towards her illness, a key discursive feature of her account was the 'tension' she seemed to experience – between her needing and deserving treatment, the amount of money spent on her treatment, her not being able to fulfil her gender role fully, and her constant apologetic refrain that she was doing all she could. While Sunita's husband spoke little, he rolled his eyes when Sunita was lamenting about her 'tension'; he smiled a knowing smile and gave us a look which said, *'there she goes again – I just cannot understand why she thinks this way'*.

The literature which engages with gender equality in health in patriarchal societies like our study settings, focuses on how women's health is given less importance, and how, often, women struggle to mobilise resources within their homes to finance their healthcare. However, Sunita's story illustrates that the reality is much more nuanced. Her story offers an example of how expenditures on women's healthcare are not always experienced as a burden by the family, and of how, how they are experienced by the woman herself is complicated at the intersections of a range of factors, not least the financial status of the household, and critically, the relational resources they have at hand – illustrating the complex social and cultural dynamics underpinning the economy of the family. This feature of Sunita's story however was not unique, some version of it was true for all women (and men) across the study and study contexts – but not totally so.

6.2. Pushpa's story

Pushpa, a study participant from a lower caste and class, presents an insightful contrast – her story represents the lived experience of some, particularly the poorer and lower caste women in our study. Pushpa was the major wage earner in her household and held much direct sway within the family, but still, for reasons very different from Sunita's, she did not allocate resources (from the income she herself generated) to her own treatment. Pushpa was a daily wage earner (manual labourer) whose house was located outside the main village (because the family belonged to the lower, scheduled caste community). Her entire family was around her when we visited them, her husband, daughter, and son. Pushpa had a commanding voice and clearly occupied a powerful position in the house for she was giving instructions to other family members. Her response to her disease was one that of resilience. She said, *"I don't skip any work; I work in the farm and also in the house. Even if I am in pain"*. Pushpa paused, and with a steely look in her eyes, she surveyed those around her, and with an easy casual pride, added *"I work"*. Unlike Sunita, Pushpa's economic situation does not allow her to spend as she would like on her treatment; equally importantly, her claim to being independent and the de-facto head of the household meant that she had to take responsibility for balancing all decisions and linked household finances – and that meant sacrificing her preferences for the greater good of the household. Pushpa's husband was a university graduate but had not been able to translate his education into gainful employment. While the family had respect for his education, his failure in being the breadwinner for the family meant that Pushpa now held the key position in her family – she was very aware that her work had given her this power, and that with this authority came responsibility and expectations of sacrifice. She made it a point to convey to all present that despite her illness she continued to work. Pushpa used the interview as a staging ground to perform a powerful solo act for us interviewers and her family – her performance was about her fortitude and grit, but also about her resistance and subversion of patriarchy.

Ganesh, Laxmi, Sunita, and Pushpa's stories help show that how "moral feelings, emotions and values, norms and obligations in the social space" (Palomera and Vetta, 2016 p 414) impinge upon intra-household allocation of resources towards healthcare is much more nuanced than the current literature from India tends to suggest – they also provide a glimpse of how things are changing. Our study participants, without exception were at pains to reject the suggestion that intra-household allocation of resources towards healthcare were in any significant way gendered. They rejected these questions as being simplistic – the universal refrain was that these allocations are in the end pragmatic and are ultimately contested and negotiated within the financial status of the household, and critically, as the following story (Madan's story) shows, the relational and normative resources at hand, and as Pushpa's story showed, the economic value of individuals within households.

7. Absence of systemic health related risk protections and the tenuous reliance on social and network capital – Madan's story, relative to Sunita and Ganesh's stories

Madan is a 75-year-old man living in a village in Kolhapur district of Maharashtra state of India; he has been suffering from breathlessness for many years. Madan is a farmer who owns a small piece of land, and agriculture is the only source of income for his family. It was in his small house, in a remote village that we conducted his interview. Madan had one son and one daughter. His daughter had moved to her husband's home in a nearby city after her marriage. Madan was very welcoming and very keen on talking to us. Madan and his wife both suffered from heart related problems. Madan told us that he had six holes in his heart. Guided and supported by his nephew (his nephew was a doctor), Madan had received treatment at a big hospital in the city. Madan needed a heart bypass surgery to treat the holes in his heart and he told us how

difficult it had been for his family to manage the expenses for this major surgery; he visibly tensed-up while elaborating his hospitalization experience. He explained how in those trying times, the local member of parliament had helped him and paid his hospital bills. Tears welled up in Madan's eyes as he expressed his gratitude; he said *"In my care seeking journey I have received help from many people-friends, relatives, and politicians. Today, I am seventy-five and alive because of them"*, he said as he wiped his tears. His friends and relatives had proven to be a major support system for him during his illness. He however made it a point to emphasise that he was aware that he had had to repay the money that he had borrowed. He added with confidence *"Ultimately, who you know ... is very important"*, highlighting how his social network had served as his safety net in his difficult times. Madan's daughter (who lives in a city) had suggested to him that he look for government schemes for senior citizens, and while initially reluctant, Madan, with his daughter's help had been able to apply to one such scheme successfully. He added, *"for people like me, government help is crucial; it has saved me from penury"*; he went on to explain how the help had saved him from selling off his land and farm animals. Madan told us about how it was he who had taken all the major decisions regarding his illness (and all health-related matters in his household), adding repeatedly that all decisions related to health seeking boiled down to money and to affordability.

Madan's story reveals what we consistently found across study participants and study contexts – that in the absence of a well-functioning public health system and other social security measures, one's social network was all many had as social security. That Madan's nephew was a doctor ensured that he received the right guidance, and critically, that his daughter knew about and could help him apply for government subsidies that he was eligible for, meant that even if he had had to borrow money for his treatment, he did not have to sell his income generating assets, and was not reduced to abject penury. Madan's relational and social capital, something that can also be understood as being a part of the moral economy, was clearly substantial, and it saved him. Crucially, this reading of Madan's story helps put in perspective the stories of the many (amongst our study participants) who did not have access to the kind of social and network capital that Madan had. Madan was in fact an exception amongst our poorer study participants (the vast majority) – while all had mobilised some social and network capital, what they had was not even close to the relatively deep relational pockets that Madan could access. For the poorer participants in our study, the chronic nature of their illness in fact had eroded the little social capital they had; many had to sell land and animals, many became indebted, and many more felt broken, as much by their illness as by the lack of social support.

8. Discussion and conclusions

The last two decades have seen a series of studies on healthcare related expenditures from India e.g., Kastor and Mohanty (2018), Thakur and Sangar (2020), Chowdhury et al. (2018), Dash and Mohanty (2019). These studies, drawing primarily on large scale survey data, highlights how in the Indian health system context, in the absence of reliable health related risk protection arrangements, it is the family that ends up bearing the healthcare related financial burden. While this literature successfully shines light on the family and the household as the centre and site of all action in this space, what transpires within household as they grapple with minor and major illnesses, and with decisions around expenditures to cope with these illnesses, is not yet well understood. In this paper, using illustrative narratives, we have tried to provide this insight through a deep dive into and through a nuanced examination of family level relational and social dynamics shaping healthcare related spending choices and decisions in India.

Our stories illustrate how various notions such as being healthy or unwell, if unwell, for whom, how much, when one should intervene, the choice of healthcare, and the expenditure on healthcare are driven by social and cultural explanatory antecedents. While the stories highlight

the importance of social and cultural factors in understanding household resource allocation (Katz, 1997), they also reveal that factors like social and gender norms do not themselves exert causal effects. The stories show that causal effects emerge and manifest at the intersection of other structural forces viz economic class, caste, gender, age, and productive status, to both constrain and enable human agency and decisions. They ultimately also expose how these causal processes are underpinned by an entrenched patriarchy.

Elster has argued that ‘social norms provide an important motivation for action that is irreducible to rationality or indeed to any other form of optimizing mechanism’ (Elster, 1989 p33). Norms are sustained on one hand by feelings of embarrassment, guilt, and shame that a person faces by violating them, and on the other hand by feelings of pride, self-efficacy, moral fortitude, and fulfilment amongst those who conform to and are recognised by society as upholding important social norms. Social norms thus have a strong grip on the human mind as human beings fear the consequences of violating these norms. That Ganesh’s daughter invoked the metaphor of the Train Engine to refer to Ganesh despite him not being the breadwinner of the family for a long time, is particularly revealing. It signposts the complexity of what drives healthcare related resource allocation within households in India. For one, it sheds some light on the normative moral and social imperatives that drive Ganesh’s son’s decisions (the de facto patriarchy) to spend far beyond his means towards his father’s treatment. While his status within the household means that Ganesh continues to receive the care he wants, his feelings of helplessness about the sufferings of his family, and his worries about the future of his children are a greater source of anguish to him than perhaps his illness itself. Ganesh’s inability to extract himself from his normative status as head of the household, and the reluctance of his family to relieve him of that role has its origins partly in the performative aspects of patriarchal social norms – the rigidity of which, as Ganesh’s story shows, was the reason for his family experiencing impoverishing health expenses. However, it is critical to note here that Ganesh’s family expressed great satisfaction in the care they were providing, and they took immense pride in the sacrifices they were making for their father – it was a key process by which the family, but the son in particular, was accumulating what could be considered normative, patriarchal, moral capital. Beyond illustrating how social norms shape intra-household dynamics, Ganesh’s story also poignantly reaffirms the mainstream definition of the family “as a space of caring, nurturing and sharing [...] family as burdened with the duty of replicating the structure and if that does not happen, there is guilt for defiance or failure” (Rinchin, 2005 p719). A contrast also becomes evident - Pushpa has agency because she continues to be the main breadwinner, and Ganesh because he has been the breadwinner patriarch in the past and is able to call on that history to lay a claim on household resources.

While Ganesh’s story highlights the power of social norms in shaping intra-household contestation, negotiation, and resource allocation; echoing Agarwal’s view (1997), Sunita’s story illustrates how allocation within households is shaped at the intersection of extra-household structures like class, gender, broader social norms, and to some extent, age. Sunita’s family had the financial means to hire a maid to help Sunita, and they were open to hire help too. And while this helped, the dynamics around the allocation of resources towards Sunita’s treatment and towards paying for domestic help were rather complex. Sunita invoked social and gender norms for continuing with her work in the kitchen; given her family’s wealth and willingness, she could have easily had help in the kitchen – yet she chose otherwise. Her sister-in-law literally lived in the same dwelling, and helped Sunita on all fronts, but Sunita chose to remain responsible for the cooking in the house. Sunita’s actions can be understood on two interlinked levels. First, through understanding the symbolic importance of the kitchen as a social site within Indian homes. For women the kitchen is a key site for the enactment of their gender role within the family and society – the one who lords over this site, has the rightful claim to being the woman of the house. Exiting from the kitchen would thus be tantamount to Sunita

ceding a key status signifier - status within the household but also within society - which clearly, she did not want to, even if it was greatly inconvenient for her. Sunita in fact made it a point to tell us, and perhaps more importantly to all within earshot, that this was her choice – she seemed to be somehow reiterating her contestations and claims. Second, through understanding Sunita’s vocal attempts to provide to us and to all within earshot, a justification for the monies being spent on her treatment. For instance, Sunita, not so subtly compared the expenses on her treatment with what was spent on her husband’s medicines; she alluded to how she had done her fair share of heavy lifting (as a homemaker) for the household and how it was only now that she wasn’t able to fully fulfil her role; and how, despite being unwell, she continued to fulfil her key gendered responsibilities in the household. This justificatory discourse was a common feature across many female participants in our study, including among those who were well-off – its articulation by the women, as Sunita’s story shows, revealed their struggles with the many layers of contestations within the economies of their families. While in well-off families this discourse was outwardly dismissed as being pointless (given that the family could afford help), amongst the poor this discourse was much more material- and it was one of the most awkward and often emotional part of many of our interviews. The exceptions to this discourse were the few matriarch-like elderly ladies in well-off families, and lower caste financially independent women like Pushpa; while the former almost nonchalantly and playfully invoked the privileges of age and talked about how they demanded and commandeered resources towards their care, the latter proudly claimed the resources they needed. The contrast between Ganesh’s and Pushpa’s approach to managing their illness is telling. While both were heads of their respective households, Ganesh benefitted from patriarchal privilege (in fact he claimed it and his family accorded it to him as a given) at the expense of his family members’ futures who had little room to contest and challenge his expectations. In contrast we see that Pushpa interprets her role as head of household as requiring her to sacrifice her health costs in the interest of the family. An interpretation rooted in the gender norm of the woman being the giver, and in the cultural, moral imaginary (and economy, as discussed further, below) of the ‘ideal’ Indian woman as someone selfless, altruistic, dutiful, and willing to sacrifice her interests for the greater good of the family (Uberoi, 2006 p33).

These findings are in line with the results of studies that have examined the household as a unit of production, distribution, and consumption in India – particularly that of Uberoi (2006) who has framed intra-household decisions and actions within the rubric of what she calls ‘the moral economy of the family’. Uberoi’s (2006) ‘moral economy of the family’ is different from the classical framings of the concept of ‘moral economy’ (Thompson, 1991; Scott, 1976; Palomera and Vetta, 2016; Fassin, 2009), and is relevant to our study context and to what we have encountered. Uberoi considers the moral economy of the family as a set of moral dilemmas and contradictions with antecedents in patriarchy and mediated through social and gender norms. In this system, not only women, but men (junior and senior) may be required to sacrifice their individual self-interest for the collective good. Uberoi argues that this moral economy of the family requires not only the disciplining of others but also self-discipline on the part of the patriarch or the de-facto head of the family (i.e., Ganesh’s son, Shankar’s son, or Pushpa). Uberoi adds that selflessness, altruism, duty, and sacrifice are considered as foundational principles of the family, and that men and women both are expected to sacrifice individual autonomy and freedom for the welfare of the family. The three stories spotlight how different aspects of social norms, values, and ethical dispositions shape the allocation of healthcare expenditures of healthcare related spending choices and decisions within households in India. They spotlight how the decision-making processes within this economy of the family are negotiated and “dialogic (rather than monologic) in construction”: dialogic in the sense that it is framed in terms of a set of moral dilemmas and contradictions”, and how the intra-household contestation and grappling with these

dilemmas and contradictions is underpinned by an imagined patriarchal ideal type of an Indian family and “a ‘traditional’ and culturally authentic form of Indian family life” (Uberoi, 2006 p 30, Kane et al., 2022).

In poorly functioning health systems, like in India, it is the family that ends up directly bearing the burden of arranging for and paying for healthcare. In the absence of reliable, accessible, and good quality healthcare, it is the family that thus holds the power to take decisions about individuals’ healthcare, and therefore the individuals’ position within the household becomes a critical aspect of intra-household decision making processes and related negotiations. Inevitably, as our findings illustrate, social norms play a huge role in the healthcare related resource allocation decisions within families. Our stories reveal that not only do social norms play crucial roles in setting the limits to intra-household contestation, negotiation, and bargaining, they also circumscribe individual power and how bargaining and contestation happens within the economy of the family – the moral economy of the family. Our findings reveal that these resource allocations decisions and decision-making processes are not only shaped by and negotiated at the intersection of competing social norms and moral imperatives, but these decisions also reproduce, reiterate, and maintain the very social norms that produce them, often problematically. Our analysis shows the inter-related nature of bargaining and negotiations “within and outside the household” and the “embeddedness of households within a wider institutional environment” (Agarwal, 1997).

Similar to our study context, in many low and middle-income countries, health systems are poorly organized, health-related social protections are weak, out-of-pocket expenses is the norm, and the family tends to bear the burden of healthcare-related decisions and expenses. We show and conclude that in such contexts, health-related financial risk protection policies and strategies need to better recognise the complex interplay of various social and cultural factors and structures which shape the intra-household allocation of resources related to healthcare. We further conclude that it is important for researchers and policymakers to recognise that while intra-household allocation of resources towards healthcare is a pragmatic and calculative exercise, it also involves multi-layered tacit and explicit contestation, bargaining and negotiations that occur at the intersection of social norms, economic class, caste, gender, age, and productive status within the family. And that all of this plays out differently for different members of a family. Such an understanding can help policymakers to better target health and social policies and strategies and to make policies and programs more responsive to lived realities of various segments of the population and different members of a family.

9. Funding

This work was supported by a grant from the Bill & Melinda Gates Foundation, India (Grant Number: INV-026980).

Data availability

The authors do not have permission to share data.

References

- Agarwal, B., 1997. “Bargaining” and gender relations: within and beyond the household. *Fem. Econ.* 3 (1), 1–51. <https://doi.org/10.1080/135457097338799>.
- Atkinson, P., 2009. Illness narratives revisited: the failure of narrative reductionism. *Socio. Res. Online* 14 (5), 16.
- Bhandari, M.N., Kannan, S., 2010. Untreated reproductive morbidities among ever married women of slums of Rajkot City, Gujarat: the role of class, distance, provider attitudes, and perceived quality of care. *J. Urban Health* 87 (2), 254–263.
- Borde, M.T., Kabthyer, R.H., Shaka, M.F., 2022. The burden of household out-of-pocket healthcare expenditures in Ethiopia: a systematic review and meta-analysis. *Int. J. Equity Health* 21 (14). <https://doi.org/10.1186/s12939-021-01610-3>.
- Chowdhury, S., Gupta, I., Trivedi, M., Prinja, S., 2018. Inequity & burden of out-of-pocket health spending: district level evidence from India. *Indian J. Med. Res.* 148 (2), 180–189. https://doi.org/10.4103/ijmr.IJMR_90_17.
- Clandinin, D., Rosiek, J., 2007. Mapping a landscape of narrative inquiry: borderland spaces and tensions. In: Clandinin, D.J. (Ed.), *Handbook of Narrative Inquiry: Mapping a Methodology*. SAGE Publications, pp. 35–76. <https://doi.org/10.4135/978145226552.n2>.
- Connelly, F.M., Clandinin, D.J., 2006. Narrative inquiry. In: Green, J., Camilli, G., Elmore, P. (Eds.), *Handbook of Complementary Methods in Education Research*. Lawrence Erlbaum, Mahwah, NJ, pp. 375–385. <https://doi.org/10.12688/f1000research.75808.1>.
- Dash, A., Mohanty, S.K., 2019. Do poor people in the poorer states pay more for healthcare in India? *BMC Publ. Health* 19 (1), 1020. <https://doi.org/10.1186/s12889-019-7342-8>.
- Elster, J., 1989. Social norms and economic theory. *J. Econ. Perspect.* 3 (4), 99–117.
- Ely, M., Vinz, R., Anzul, M., Downing, M., 2005. *On Writing Qualitative Research: Living by Words*. Taylor And Francis, ISBN 0-203-45817-6.
- Fassin, D., 2009. Les économies morales revisite’ es. *Ann. Hist. Sci. Soc.* 6, 1237–1266.
- Hong, G.S., Kim, S.Y., 2000. Out-of-Pocket health care expenditure patterns and financial burden across the life cycle stages. *J. Consum. Aff.* 34 (2), 291–313. <https://doi.org/10.1111/j.1745-6606.2000.tb00095.x>.
- Jose, S., 2003. Indian J. Gend. Stud. 10 (3), 405–429.
- Jung, J., Streeter, J., 2015. Does health insurance decrease health expenditure risk in developing countries? The case of China. *South. Econ. J.* 82, 361–384. <https://doi.org/10.2139/ssrn.2008987>.
- Jung, H., Kwon, Y.D., Noh, J.W., 2022. Financial burden of catastrophic health expenditure on households with chronic diseases: financial ratio analysis. *BMC Health Serv. Res.* <https://doi.org/10.1186/s12913-022-07922-6>.
- Kane, S., Joshi, M., Mahal, A., McPake, B., 2022. People’s care seeking journey for a chronic illness in rural India: implications for policy and practice. *Soc. Sci. Med.* 312 (2022), 115390 <https://doi.org/10.1016/j.socscimed.2022.115390>. ISSN 0277-9536.
- Kapoor, S.K., Raman, A.V., Sachdeva, K.S., Satyanarayana, S., 2012. How did the TB patients reach DOTS services in Delhi? A study of patient treatment seeking behaviour. *J. PLoS One* 7 (8). <https://doi.org/10.1371/journal.pone.0042458>.
- Kastor, A., Mohanty, S.K., 2018. Disease-specific out-of-pocket and catastrophic health expenditure on hospitalization in India: Do Indian households face distress health financing? *PloS one* 13 (5), e0196106. <https://doi.org/10.1371/journal.pone.0196106>.
- Katz, E., 1997. The intra-household economics of voice and exit. *Fem. Econ.* 3 (3), 25–46. <https://doi.org/10.1080/135457097338645>.
- Kim, Y., Yang, B., 2011. Relationship between catastrophic health expenditures and household incomes and expenditure patterns in South Korea. *Health Pol.* 100 (2–3), 239–246. <https://doi.org/10.1016/j.healthpol.2010.08.008>.
- Lyszczarz, B., Abdi, Z., 2021. Factors associated with out-of-pocket health expenditure in polish regions. *Healthcare (Basel)*. <https://doi.org/10.3390/healthcare9121750>.
- Mahapatro, S., Singh, P., Singh, Y., 2018. How effective health insurance schemes are in tackling economic burden of healthcare in India. *Clin. Epidemiol. Global Health* 6 (2), 75–82. <https://doi.org/10.1016/j.cegh.2017.04.002>.
- Marmot, M., Bloomer, E., Goldblatt, P., 2013. The role of social determinants in tackling health objectives in a context of economic crisis. *Publ. Health Rev.* 35 (9) <https://doi.org/10.1007/BF03391694>.
- Nastasi, B., Arora, P., Varjas, K., 2017. The meaning and importance of cultural construction for global development. *Int. J. School & Educ. Psychol.* 5 (3), 137–140. <https://doi.org/10.1080/21683603.2016.1276810>.
- Palomera, J., Vetta, T., 2016. Moral economy: rethinking a radical concept. *Anthropol. Theor.* 16 (4), 413–432.
- Pati, S., Hussain, M.A., Chauhan, A.S., Mallick, D., Nayak, S., 2013. Patient navigation pathway and barriers to treatment seeking in cancer in India: a qualitative inquiry. *Canc. Epidemiol.* 37 (6), 973–978.
- Radley, A., Billig, M.S., 1996. Accounts of health and illness: dilemmas and representations. *Sociol. Health Illness* 18, 220–240. <https://doi.org/10.1111/1467-9566.ep10934984>.
- Rinchin, 2005. Queering marriage and family. *Econ. Polit. Weekly* 40 (8), 719–720.
- Scott, J.C., 1976. *The Moral Economy of the Peasant: Rebellion and Subsistence in South-East Asia*.
- Sriram, S., Albadrani, M., 2022. A Study of Castastrophic Health Expenditures in India- Evidence from Nationally Representative Survey Data:2014-2018.
- Tavory, I., Timmermans, S., 2014. *Abductive Analysis: Theorizing Qualitative Research*. The University of Chicago Press, Chicago. ISBN-13: 978-0-226-18045-8.
- Thakur, R., Sangar, S., 2020. Socioeconomic differentials in the burden of paying for healthcare in India: a disaggregated analysis. *Health Syst. (Basingstoke, England)* 11 (1), 48–58. <https://doi.org/10.1080/20476965.2020.1848356>.
- Thompson, E.P., 1991. *The Moral Economy Reviewed*. In: *Customs in Common*. Merlin, London, pp. 259–351.
- Toury, G., 1995. The nature and role of norms in translation. In: *Descriptive Translation Studies and Beyond*. John Benjamins, Amsterdam-Philadelphia, pp. 53–69.
- Tur-Sinai, A., Magnezi, R., Grinvald-Fogel, H., 2018. Assessing the determinants of healthcare expenditures in single-person households. *J. Health Pol. Res.* 7 (48) <https://doi.org/10.1186/s13584-018-0246-8>.
- Uberoi, P., 2006. *Freedom and Destiny: Gender, Family, and Popular Culture in India*. Oxford University Press.