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Health Inequities in India: A Focus on Some Under-Researched Dimensions

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Health Inequities in India

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Health Inequities in India
A Focus on Some Under-researched Dimensions

T.K. Sundari Ravindran[1], Mohan Rao[2]

The world has never been as rich as it is today. Yet substantial proportions of the global population live short and brutal lives, haunted by hunger, ill-health and disease. The average life expectancy in Sweden countries in 2015 was 82.4 years; that in Swaziland was 58.9 (WHO, 2017). Over the last 30-odd years, as the world entered a neo-liberal turn to economic growth, along with a growing wealth gap between rich countries and poor countries, and between the rich and poor within countries, there is also a growing health gap. For example, the maternal mortality rate in the black population in the United States is three times higher than that in the white and is increasing. In India itself, a person born in Kerala can expect to live 18 years longer than one born in Bihar or Jharkhand.

Indians are living through a period of unprecedented economic inequality in more than a century, and this is largely true for most countries of the world. In 2017, 73 per cent of the wealth generated in India went to the top 1 per cent of the population, while the poorest 50 per cent were able to corner only 1 per cent. We as a country boast of having 101 billionaires, while 224 million people live below the poverty line of US$ 1.90 per day (Oxfam International, 2018).

Fifty years ago, speaking about justice in access to health and healthcare, Dr. Martin Luther King Jr. said:

> *Of all the forms of inequality, injustice in health is the most shocking and the most inhuman because it often results in physical death (50th Anniversary of Dr. King's Healthcare Quote). https://www.forbes.com/sites/danmunro/2016/03/25/the-50th-anniversary-of-dr-kings-healthcare-quote/#54e85ec730b5. Accessed 9 May 2018).*

It is well known that health inequities in India are shaped by region, by socio-economic development, by class, religion, caste, gender and sexuality. In general, states of the south are doing better in terms of human development indicators than states in the North. But there are also sharp differences by regions within states. For example, the Malabar region of Kerala lags behind the rest of the state in health and socio-economic indicators. Similarly, northern Karnataka lags behind Old Mysore in all these indicators. But it is not as if everyone in the backward regions suffers the same unfairness. In all these regions the rich have better access to the social determinants of health and are more likely to live longer and healthier lives. In India, of course, caste and identity are also markers of health inequities. Thus the SCs, STs and Muslims, in general, tend to have poorer health and access to health systems. The public health system, weakened by decades of under investment, has failed to fulfil its expected role of protecting the poor and marginalised from inequities induced by the market mechanism.

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There are other populations too that are marginalized on the basis of disability, mental health, sexuality and homelessness. For example, research suggests that people living with chronic mental health problems tend to die earlier than the general population. What we attempted to do in this project was to bring these to the fore in public health conversations, so that researchers may start exploring these areas in however tentative a manner. The Supreme Court argued that the LGBTQI population was "minuscule". This is no reason for their rights to be snatched away, nor for their health inequities to not be studied. In the Indian context, even a minuscule population comprises a substantial number of people, not to be ignored by public health workers and researchers.

This Special Issue of *eSocial Sciences and Humanities* aims to bridge, in a small way, the evidence gap on health inequities in India. The Special Supplement is being produced as a part of the project *"Closing the Gap: Health Equity Research Initiative in India",* implemented by the Achutha Menon Centre for Health Science Studies (AMCHSS), the Public Health Wing of Sree Chitra Tirunal Institute for Medical Sciences and Technology. The Project is a response to the need for actionable evidence and for policy advocacy on attention to health inequities in the country. Set up in 2014 with financial support from the International Development Research Centre (IDRC) Canada, the "Closing the Gap: Health Equity Research Initiative in India" project aims to

> *contribute to the advancement of a sound, actionable and measurable evidence- base on inequities in health in India with a view to influencing government and civil society initiatives to prioritize the reduction of health inequities.*

During 2014-17 the initiative undertook numerous activities including an evidence-synthesis exercise. This exercise revealed that the evidence-base on health inequities in India is limited and narrow. While the number of studies was not too small, their contribution to our understanding of the processes and mechanisms underlying health inequities was very limited. Studies on health inequities by income/ wealth, caste or ethnicity and sex/ gender tended to describe the nature and extent of gaps and their correlates, but did not examine why these gaps continued to exist. More disconcerting was the discovery that there was almost no published research on health concerns of many population groups such as migrant workers, the homeless, persons living with physical and psychosocial disabilities and persons of diverse gender identities and sexual orientations. We therefore sought to bring out a collection of articles focusing on neglected health concerns and population groups.

About this issue

This special issue of eSocial Sciences and Humanities on health inequities in India started as a modest attempt to bridge the evidence gap on the subject. This issue includes 12 papers on various dimensions of health inequities in India.

Eight of the papers are on sex or gender-based inequities in health. The papers take diverse perspectives. Some focus on unequal burden in the ways illness is experienced or in care-giving roles, or unequal barriers to healthcare. The others use a gender-lens to examine health-systems issues such as health financing and universal healthcare. Together, they constitute a rich collection of studies on health inequities in India by sex and gender.

Of the remaining four papers, two are on health of the urban poor, a population rendered invisible by averages which show urban population to be better resourced than the rural. The 11th paper is on is on social exclusion and health of Muslims in Maharashtra. The 12th is a paper that calls to question the feasibility of achieving universal health care without recognising the role of and forging a partnership with practitioners of popular traditional medicine, who cater to the healthcare needs of some of the most marginalised sections of society.

Although our call for papers had specifically focused on themes that had the most evidence gap, the final line-up of papers does not include any paper on most of these population groups. This is despite specific efforts made by the editors to actively seek out researchers and activists working with some of these populations. There were many slips between the cup and the lip. The 73 abstracts we received and the 38 abstracts we selected had at least one or two papers on various under-studied population groups. However, their numbers dwindled when we received the full-length papers. Many dropped out also at the stage of revising and resubmitting papers.

There are many reasons as to why this could have occurred. One is the neglect of social sciences in schools of public health. While it is heartening that public health is receiving belated recognition and many schools have come up in the last two decades, they continue to be dependent on mainstream epidemiological methods, with an emphasis on quantitative data and not enough attention being focused on social science theories and qualitative data and processes. It also appears that many advocates for social justice, gender equality and the rights of marginalized groups have not prioritized researching and writing in general, or do not focus on health inequities in particular. This calls, on the one hand, for strengthening social science interventions in public health schools and a greater sensitisation to the needs of marginal communities among health workers and researchers; and on the other, greater involvement by advocates and activists in research and writing to put health inequities and health rights of all on the public health agenda.

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Marginalisation and Access to Safe Abortion

A Case Study on the Struggles of a Narikuravar Woman in Kumbakonam, Tamil Nadu

Bhuvaneswari Sunil[*]

This paper explores the realities and complexities experienced by women in marginalised communities in accessing safe abortion services. It specifically explores the experiences that shape the perceptions and behaviour of Narikuruvar women towards accessing both public and private reproductive healthcare facilities. This is illustrated by the case of a married Narikuravar woman who had undergone self-induced abortion in Kumbakonam, a town in Tamil Nadu. In addition, the paper examines the circumstances that force women in the margins to adopt unsafe, self-induced abortion and discusses the strategies used by the Narikuravar woman for self-induced abortion. This is a qualitative research study and has used a phenomenological lens to capture the individual experiences of the woman across diverse life events associated with pregnancy, motherhood and abortion. The paper describes how contextual factors such as lack of access to resources and decision-making structures intersect with other cultural and gender identities of women. The principal argument here is that the needs, aspirations, interests, knowledge and agency of women from marginalised communities are not recognised in public and private decision-making spaces, and this impacts on women's sexual and reproductive rights.

Keywords : Induced abortion, unsafe abortion, reproductive health, Narikuravar women, marginalised, exclusion, access.

I

Introduction

Access to safe abortion services is crucial for women's realisation of their reproductive rights. However, access to safe abortion services become fraught with complexities in the socio-economic and cultural spaces of marginalised and vulnerable women. Within the right to health framework, vulnerability means deprivation of the rights to certain individuals and groups who have been denied the rights of in exercising agency (Chatterjee and Sheoran, 2005). Similarly, marginalisation is a process by which some groups of people are being pushed or kept out of the system, or are being maintained in a peripheral, disadvantaged position within that system (Khanday and Akram, 2012). Such vulnerable and marginalised groups of people become disadvantaged as compared to others mainly on account of their reduced access to livelihood opportunities, medical services and the underlying determinants of health such as safe and potable drinking water, nutrition, housing and sanitation. This paper aims to demonstrate how women of the Narikuravar community face

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the double discrimination of gendered and community-related vulnerabilities in accessing safe abortion services. Narikuravar in Tamil Nadu are a nomadic community, which was denotified from its criminal status in mid-20th century, and which is now classified as belonging to the Most Backward Class.[1]

By illustrating the case of a married Narikuravar woman who had undergone a self-induced abortion, this paper examines the complexities that emerge in her day-to-day experiences in accessing reproductive health services and facilities. It also examines the nature of vulnerability and marginalisation of women from the perspective of the Narikuravar woman. It further illustrates the strategies availed by the Narikuravar woman while practising self-induced abortion and their implication regarding their marginality and vulnerability.

The Medical Termination of Pregnancy (MTP) Act, 1971, terms abortion as legal in India. The MTP Act does not necessarily provide women the choice to terminate a pregnancy. However, it may be viewed as progressive because it allows for safe abortion services up to 20 weeks of pregnancy under certain conditions, through certified providers of MTP. Many women from poor, vulnerable and marginalised communities still find it extremely difficult to access safe abortion services. Studies have observed that women belonging to de-notified tribes and most backward classes have poor health outcomes (Tiphagne, 2015). Among denotified tribes and other socially excluded communities, women bear the brunt of the exclusion, because of the ways in which the state and society stigmatise them, resulting in the feminisation of stigma (Agrawal, 2004). The poor health outcomes among women from constitutionally defined Most Backward Classes may be attributed to poverty, under-nutrition, lack of sanitation facilities, hygiene, safe drinking water, and access to healthcare as well as feminisation of stigma and socio-cultural barriers which prevent them from utilising the available services (Tiphagne, 2015, Agrawal, 2004, Korra, 2017, Radhakrishna, 2007).

The right to sexual and reproductive health implies that "people can have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so (United Nations Fund for Population Activities [UNFPA], 2014: 45)". Implicit in this last condition are the right of men and women to have access to contraceptive information and services of their choice to regulate their fertility, and to have access to safe abortion services for indications that are permitted by law (ibid). Nevertheless, ground realities illustrate that health inequities exist; women are marginalised in their day-to-day life, and they become vulnerable as their basic rights to access safe sexual and reproductive rights are denied. For instance, Jejeebhoy et al., (2012) have observed that women in rural areas of India have inadequate access to safe abortion services. Recent data shows that 15.6 million abortions took place in India in 2015, of which 73 per cent were medication abortions that happened outside the health facilities (Singh et al., 2018). In Tamil Nadu, according to a 2012 study, only a fifth of the Primary Health Centres (PHC) was equipped with operation theatres, and less than 5 per cent of the 24/7 PHCs provided MTPs (Sunil and Ravindran, 2012).

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[1] According to some activists and academicians, there are no denotified tribes in Tamil Nadu, although denotified communities exist. The Narikuravars are nomadic tribes, whose primary occupation was hunting. However, these communities were notified as Criminal Tribes by the British under the Criminal Tribes Act, 1871. Apart from enforcing their identity as criminals, such enforcements also prevented them from practising their traditional livelihoods. Their access to forest resources was also constrained by law. Several people turned to other occupations such as selling beaded ornaments. The Criminal Tribes Act of 1952 repealed the notification, thereby de-notifying the tribal communities. In Tamil Nadu, though the Narikuravars are lobbying for the Scheduled Tribe status, they are currently classified constitutionally as the Most Backward Class.

Studies have noted that women who underwent an abortion by uncertified providers experienced multiple post-abortion morbidities (Banerjee and Anderson, 2012; Bhattacharya et al., 2010). Research has also shown that self-induced abortion could result in incomplete abortion and complications such as multiple organ failures and septic abortions (ibid). Self-induced abortion is reported to be usually practised through the self-administration of abortifacient-drugs (Ramachandar and Pelto, 2005). Some of the reasons for self-induction of abortion or seeking care from unqualified providers included cost, perception of pain and adverse effects, fear of surgical abortion, convenience, desire for fewer clinic visits, and to cope with the gendered household roles (Ganatra et al., 2010, Sri and Ravindran, 2012, Berer, 2005). However, there is no published data on abortion practices of women from marginalised communities.

II

Methodology

This paper is a part of the author's doctoral research work that examines the motherhood and abortion experiences of 16 married women across diverse caste segments and social locations in Kumbakonam,[2] Tamil Nadu. The group includes Hindu women drawn from diverse social classes, castes, age-groups, employment status, education, geographic location and ethnicity.[3] The fieldwork for this research was carried out during the year 2015-2016. The larger study from which this case study is drawn, used a phenomenological approach to capture the experiences across diverse events associated with pregnancy, motherhood, and abortion among the respondents of the study. Based on the phenomenological method described by Giorgi (1985), the respondent was asked to describe personal dimensions of a situation experienced in daily life. From the description, the researcher identified its essence, the most invariable parts of that experience, located within a context. Narratives shed light on the essential meaning of "being-in-the-world to the lived truth" (Lindseth and Norberg, 2004) and helped in analysing the meaning governing women's decision-making and the actions shaping their identities, agency, and the nature of relationships with other actors in their everyday lives. The study used observation and in-depth interviews to collect data. I used an observation checklist and an interview guide for data-collection. The transcripts of interviews were used to identify the main and sub-themes. I then correlated the themes to the literature on the subject, based on my intersubjective experience.

Of the 16 respondents interviewed for the larger study, the case of the Narikuravar woman Vanathi[4] remains unique. Her experiences, capabilities and strategies differ from those of other women respondents in the study. Factors such as ethnicity, culture, prevailing gender relations, nature of livelihoods and the historicity of exclusion may have contributed to the uniqueness of this case.

This paper, narrated in the form of a case study, is based on my interactions with the Narikuravar woman. I identified the respondent through convergent interviews that I had conducted initially with a few young Narikuravar women who were selling beaded jewellery near the temple premises

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[2] Kumbakonam is a temple town, located within Thanjavur district of Tamil Nadu. It is predominantly agricultural and rural. Kumbakonam is one of the health blocks in the district with five PHCs and one head Quarters hospital located in Kumbakonam Municipality. Most of the private clinics and hospitals are located in the Kumbakonam municipality area

[3] Narikuravars do not identify themselves as Hindus. My respondent said that they have a clan Goddess such as Kali (Goddess Parvathy) and Eswaran (Lord Shiva), to whom they offer animal sacrifice.

[4] Name changed to ensure confidentiality

of Kumbakonam. During the convergent interviews, I explained the purpose of my research and enquired about the prevalence of abortion among married women.

Subsequently, a young Narikuravar woman introduced me to her neighbour and aunt. I informed the Narikuravar community about the intended objectives of my research. The headman of their community gave me permission to enter their village and discuss my research with the women. Building trust with all the members of the community was a crucial step in this particular field site. Along with regular home visits, I had to engage in several sessions of informal group discussions with women and girls in the community. We discussed issues related to the lifestyle, occupation, notions on the education of the girl child, general health problems and health-seeking behaviour of the people in the community.

Over a couple of months, Vanathi felt comfortable enough to share her life experiences with me. I initiated the formal in-depth interviews after she expressed her trust in me. She also permitted me to record her conversations. The interviews were conducted in three sessions of two to three hours. The site for the interview was the living space of the respondent in her hut. The first two sessions were held in October 2015 and were followed by another interview in April 2016. The gap between consecutive interviews gave me sufficient time to review the transcripts, identify the gaps and seek clarification of the original responses. The interviews were recorded in Tamil and later translated into English.

This paper has its limitations. The insights drawn from the experience of one woman may not necessarily reflect the experience of marginalised women in her and other backward communities. Moreover, my position as an outsider in the life-space of Vanathi was undoubtedly a hindrance to understanding the suffering that women like her undergo. However skilled and equipped I am in the subject area of my research, my ability to capture the true essence of Vanathi's lived reality is limited. Across her conversations with me, there were clear-cut boundaries that alienated me from her immediate lifeworld. To her, I was an outsider on par with the experts and other formal health care providers, while her immediate life-space consisted of her husband, her children, her in-laws and her Narikuravar community. On many occasions, she referred to her beliefs, practices, and experiences as 'mine' or 'ours' referring to the women in her community, in contrast to 'yours' signifying my presence as the outside researcher. She shared many of her struggles, though she was hesitant in the beginning. However, towards the end of the final interview session, Vanathi had developed considerable trust and emotional involvement with me. Moreover, such sharing happened voluntarily without my insistence. The following sections narrate critical insights drawn from the interactions.

III

The Life and World of Narikuravar Women

The Narikuravars, residing on the outskirts of Kumbakonam, are a close-knit community. They live in small huts with thatched roofs, clustered together. The local people refer to the men and women of this community as 'Kuravan' and 'Kurathi', respectively. The men are usually involved in hunting small animals and birds which they sell in the local market. Both men and women (including young girls) are engaged in making and selling beaded jewellery in specific spots in the temple town. Some young girls from this community have begun to pursue an education in a nearby government school and are not involved in any entrepreneurial activities. However, in many instances, girls drop out of school and engage in selling beaded jewellery.

The Narikuravar lead a frugal existence, with most adults living on one meal a day, either bought from road-side vendors for a low price, or left-over food from the town's wealthier population. Some adults have 'prasad' from the temples as a meal. Most families buy breakfast for their children from a local shop, and the government's mid-day meal scheme ensures lunch for school-going children. . It is the responsibility of either the man or the woman, whoever reached home first, to cook their dinner. Another interesting feature is that, following childbirth in the family, it is the responsibility of the husband to prepare food for the family. This practice continues for a few months. During this time, the mother who has given birth to the child is supposed to take adequate rest. This normative behaviour is carried forward through the concept of *'theetu'*.[5]

School-going boys and girls are routinely teased by their classmates as *kuravan* or *kurathi* in a demeaning manner. People rarely identify them by their names, but refer to them as the 'daughter of kurathi' or *'pasimani oosimani vikravanga'* (those selling beads and needles). The indigenous dialect of the Narikuravars and their unique physical attires, ornaments and other associated cultural practices contribute to such stereotyping and exclusionary practices. Middle-aged and senior kurathi women still wear a skirt and a blouse, with the half-saree draped in their style (in contrast to the modern saree culture). However, I also came across a few young adolescent girls who regularly wear the churidar and kurta.

The historicity of their exclusion, which identifies them as thieves and criminals, continues even today. Conversations with elderly Narikuravar women revealed the frustration, helplessness, and vulnerability of their social identity and position. According to an older Narikuravar woman,

> "We are always viewed as thieves and robbers!...If anything goes missing anywhere, the police will first come looking for us! They come…search, and sometimes harass us."

The abortion experience of the Narikuravar woman presented below has to be understood within the larger context and historicity of exclusion that the community experiences. Through this case study, this paper attempts to demonstrate the lack of access to abortion which is shaped by failure to recognise the needs and aspirations of the woman alongside denial of meaningful opportunities for decent and dignified livelihoods, safe housing and reliable social networks.

IV

'Motherhood and Right to Abort – Their Way or My Way'

Vanathi, a Narikuravar woman, believes that she got married to her husband sometime between the ages of 18 to 22. She estimated her present age to be between 25 and 30 and reported that she had been married for the last six to eight years. It was her husband's second marriage. He married Vanathi when his relationship with his first wife failed. The household of Vanathi consists of her father, husband, and three children. Her father owns the house in which the family lives.

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[5] *Theetu* is a culturally represented term that denotes isolating the woman during different occasions associated with her body. For instance, following delivery, theetu is a period when the woman is not allowed to cook or come outside her house for a specified period. In some cultures, it also refers to the monthly menstrual period. During post-abortion, as the woman experiences bleeding, theetu is enforced for a stipulated period. In my opinion, the cultural construct of theetu is yet another recursive process that constrains the freedom of women.

Vanathi has three sons aged six, five and two-and-a-half, respectively. She had delivered a baby boy for the fourth time. But this child (immediately after birth) was given away for adoption, outside their caste and community. A distant relative had facilitated the adoption.[6] Multiple cultural factors shape such decisions of Narikuravars. The community has a keen preference for girls over boys. The preference for daughters is because, among the Narikuravars, the bridegroom's family has to pay a bride price of Rs.50,000 at the time of marriage. Besides, it is also widely perceived that the man, once married, is likely to listen to his wife because she is the one who meets his sexual needs, and is unlikely to support his parents in their old age. I observed that most of the Narikuravar households preferred to have two boys and two girls.

During my fieldwork, Vanathi's husband was the only earning member of the family. Vanathi was unable to pursue her business due to poor health. Vanathi's husband earns Rs. 200-300 per day by selling beads or animals. They keep aside approximately Rs. 150 to 200 for buying beads and accessories for their business. Apart from this, their daily expenses amounted to Rs. 100 to 150. The expenditure was related mainly to travel, tea, betel leaves for chewing and groceries. They allocated a portion of this income for the next day's tea and breakfast for children. They also spent money on buying alcohol. Most of the men and women (including Vanathi) in the community were habitual drinkers. According to Vanathi,

> "On many occasions, my husband fails to get me brandy, and this leads to a quarrel… In our community, after delivery, the mother is given brandy to drink to get rid of the *mangathvali* (post-delivery pain)… However, as days progressed, we became addicted to it."

The Narikuravar households are economically vulnerable and this leads to a hand-to-mouth existence. Their vulnerability deepens on days of heavy rains or if they don't have the money to pay for the beads and accessories. Vanathi explains:

> "Even if I go to the bus stand to sell the beads, I may end up getting around 50 to 60 rupees a day, out of which I have to spend for tea, five rupees for bus fare, 20 rupees for betel leaves and tobacco…then, what is left? These days, there are many sellers in the bus stand. There is a lot of competition, and at the same time, there is not much of a profit. Furthermore, the police also restrict us from doing our business in many places. What can we do then?"

Pregnancy, risk, and the decision to abort: Vanathi decided to seek an abortion at four months' gestation when she realised that she was pregnant for the fifth time. Two factors influenced her decision to have an abortion. One, Vanathi developed uterine prolapse during her fourth delivery. Health care providers had warned her against future pregnancies as hazardous to her health and life. Two, according to the community's belief systems, her pointed belly at four months suggested that she would once again give birth to a baby boy. Her husband did not want any more male children and therefore wanted her to have an abortion.

Accessing abortion in public health care settings: Vanathi did not obtain abortion from a health care provider or hospital in either the public or the private sector. According to her, these services and institutions were more of a threat to the Narikuravar women. Justifying her decision not to approach a health facility for abortion, Vanathi narrated the harrowing experiences of one of her neighbours:

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[6] There are claims at the field level that these are not adoptions but the sale of newborn babies. Should this be true, it points to child trafficking at the community level.

> "My neighbour, a young girl, had a spontaneous abortion immediately after her marriage. They first went to a private clinic….We can go to a hospital only at four to five months of pregnancy...In the private clinic, they began to scan her by placing a tube through her vagina. They said that there were still some (products of conception) left inside her stomach [uterus]! Her bleeding had not stopped. They demanded 5000 rupees to perform the abortion. She bargained with them saying that she had only 1000 rupees….They refused to carry out the abortion. She pleaded with them to evacuate her uterus completely and promised to pay 1500 rupees by borrowing from someone. She then had to go to the government hospital where she underwent a bitter experience. The hospital staff were not at all humane. They did not give even an injection or tablet to her (for pain-relief). The nurse in the government hospital took it (product of conception) out by directly putting a big *kambi* (iron rod or wire). It was very painful! Tell me, how will we go to such places?"

I also realised after interacting with Vanathi, that she and other women from her community had limited admittance to the Government General Hospital. She preferred the *'aspathri'* – the PHC – which was nearer and less intimidating.

Vanathi lamented,

> "We never go to the *periya aspathri* (Government General Hospital). None of us in our community like that place. The *aspathri* (PHC), which is nearby, is alright… they conduct our deliveries. If the delivery takes place in this *aspathri* (PHC), we return home immediately. However, if it becomes very complicated, we are always referred to the *periya aspathri*… But they do not want to take us in there… They ask us 'Why have you come here?'. We have to give them money! Unless we give them 1000 rupees, they do not even bother to see us. We have to request innumerable times to examine the patient...
>
> In our culture, if the bag of water bursts, we are asked to exert pressure and our stomach is massaged. The baby will come out, and it is cleaned. But quite strangely, in these hospitals, they will say, *mukku, mukku* (Push, Push)! Where do we have the stamina to push?... Moreover, in these hospitals, people ask us to have food immediately after delivery. On the other hand, in our culture, we maintain *pathiyam* (a strict and controlled diet) for the first three days. We do not eat during these days. We have coffee and maybe a bun, once or twice in a day. If we eat, the baby might get affected with *maantham* (an indigestion problem among newborns and infants). Gradually, after a month, we start eating plain rice that is cooked well with a bland *rasam* made of tomatoes, a green chilli, and some pepper powder."

Health coverage in the study area is generally good and provided through primary health centres located within a 1km radius of many settlements. However, only the district government hospital (8 km) provided D&C usually as a procedure for evacuating the uterus when women presented following a spontaneous abortion with or without morbidities. I learnt that government hospitals did not provide abortion unless a sterilisation procedure is accepted.

Narikuravar women see the PHC as a place promoting institutional deliveries. For any delivery-related complications, induced abortion, and other reproductive health problems, women are referred to the district general hospital. Thus, access to services is limited to facilities where Narikuravar women experience loss of dignity.

Vanathi's views on sterilisation hints at how the women in this community feel culturally alien to mainstream healthcare practices. According to Vanathi,

> "That sister who comes here (the government's Village Health Nurse) always insists on the operation (sterilisation). People in our community consider it a bad sign to have

> a protruding stomach after delivery. But, after the operation, the hospital people leave our stomach untied… and when we start our normal diet, it will bulge out. In our community we believe that with a bloated tummy after delivery, we cannot walk or even go around seven villages. Many women who underwent the operation have big paunches. After delivery we usually tie a long cloth around the stomach as we do during our menstrual period."

To my query, 'Is that why you did not go for the operation?' Vanathi laughed and replied,

> "It is not always like that…. I also wanted to have the operation…. However, I had to maintain *theetu* after the abortion of my fifth child. There was a lot of bleeding…. So, I was asked to visit the hospital after the *theetu.* However, when I asked my mother-in-law to accompany me to the hospital, she declined and said that she was unwell and also that she did not have enough money to travel. During the time of *theetu* itself, the sixth one stayed back.[7] (she conceived for a sixth time)…. God has given me one more child, and now I will give birth. I am just hoping for a girl! Everybody says that it will be a girl. Maybe, after that I will go for operation….(On a lighter note), there are women in my community who have gone through the operation after giving birth to three to six children as well!"

Accessing abortion through other channels: Following her decision to abort the fifth child, both Vanathi and her husband went to the pharmacy and explained to the chemist about their predicament. The chemist then provided her the abortion pills for a price of 500 rupees. He also took the signatures from both of them certifying that he was not responsible for any untoward incidents following the consumption of the pills. The chemist also gave her the directions for taking the pills. During one of our first interview sessions (after almost two months of her abortion experience), Vanathi said,

> "The chemist gave me abortion pills to be consumed only for three days. He instructed me to take the pill with water. There were five tablets in the strip…"

The second and third interview sessions were held with Vanathi after a period of five to six months respectively. During these interactions, Vanathi revealed that she took one pill for three days each, after breakfast. Vanathi recollects that she menstruated on the very first day of consuming the pill. However, she observed that the flow did not stop for almost a month. Commenting on prolonged bleeding, Vanathi said,

> "My people pointed out that if the bleeding prolonged, then it would be harmful to my body. Therefore, they asked me to eat rice with a special curry made from plantain flowers and onions. They said that it would flush away all the leftover stuff (products of conception) from the stomach (uterus) *(pisuru ethavuthu iruntha vandhidum).* I acted on their advice, and it all got cleared. Besides, I ate pineapple. It kept my body cool and light like a flower."

Vanathi continued to share her abortion experience, though without much emotional involvement:

> "I cleaned the extra stuff (products of conception) myself! .... Once you take the pill, it will come out…. I continued pressing my stomach… then, I took that (the products of conception) in a cover and threw it far away. I had mild cramps when it came out and was feeling very tired. I placed thick clothes on my vaginal

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[7] Indicating that she became pregnant again. Later, as I was writing this paper, I came to know from the grassroot health worker that the baby born to her of the 'sixth' pregnancy following the abortion did not survive. And she finally underwent the sterilisation procedure. As the grassroot health worker was transferred to another location, it was not possible for her to ascertain the details of the delivery or cause of death of the newborn.

> area and took rest for two days…. I also took some pills for body pain …. I rested for two days, eating rice, bun and having some tea. I became alright. That's all."

My body, My vulnerability! Neither his nor theirs!: Vanathi believes that she became pregnant again within a month of this abortion experience. By the time I was having the third interview session with her, she was five months pregnant. On my inquiry of whether her husband asked her to undergo abortion this time as well, she replied,

> "He asked me to take the abortion pills again. I refused and said, 'I will die if as much blood is going to come out of me again.' Already I am feeling weak and tired!"

I sensed from my brief conversations with her during this time that she was not happy with her husband (although she was not letting him down). As I probed further on why her husband was not accompanying her for sterilisation, she replied with a feeling of discontent,

> "There are already enough quarrels going on between us. I took those abortion pills, only after he asked me to do so, didn't I?"

Vanathi's abortion experience also indicates how bodily issues and health concerns have affected her very survival. During one of our last interview sessions, Vanathi spoke in an emotional and pained tone:

> "When I was undergoing such a crisis, he (her husband) did not go to work!... He sat idly at home mending the *koodu* (cages). There was no income. He did not even bother about me. He got me neither a soda nor a coffee. He quarreled with me and went to his mother's house. He took my children as well... He left me to fend for myself. He was angry with me because I was not going out to sell the beads. You know that I am not allowed to get out of the house following an abortion? Post-abortion, we have a one-month *theetu*…. If a lactating mother sees me in my theetu, it is believed that her infant will have some *dosham* (curse) and it could affect the health of that child…. If they get affected by the dosham then we have to spend around 5000 to 6000 rupees…. To address that dosham, we need to offer a mudikayar (sanctified thread). To fetch those threads, we to go to Tiruchi or Vaikundam Malai, … otherwise that child will die…. How can I go out then? .... My health has also deteriorated! I feel so tired and have severe body pain. He was not even ready to take me to a doctor…. Being my husband, he has the responsibility of supporting me during my crisis. Instead, sitting idle without doing any job and hurting his wife is not decent. I hope you agree with me! .... I cannot eat those idlis sold by the street vendors for breakfast. I feel nauseated. It is much better when my husband makes some hot rasam and rice for me. But he is not at all interested in my health."

Other aspects related to reproductive health also add up to her vulnerability.

"Sometimes, we get infected by *pulla karuppu* (some kind of vaginal infection). When we approach the health centre or the medical shop, they give some ointment. The skin around the vagina becomes dark, irritating and itchy. In spite of using a lot of soap, the itching continues. If I scratch to relieve the itching, it will begin to burn…. Yesterday, I bought an ointment from the medical shop that cost Rs.35. During our periods, we (including other women) try to use cotton (pads) by attaching it to the cloth. However, I have no respite from the itching."

During my fieldwork, I realised that Vanathi and many other women among the *Narikuravars* have several gynaecological morbidities such as white discharge, abdominal pain, and rashes in the vaginal area. I also realised that, except for sterilisation, Narikuravar women knew almost nothing about any other contraceptive method such as oral contraceptive pills or IUD, or natural methods such as the 'Rhythm' method. They visited hospitals to take injections on occasions such as high fever, severe vomiting or diarrhoea. Moreover, institutions like the primary health centre did not provide any ointment or creams meant for treating women's vaginal infections. The pharmacist played a major role in facilitating many of their health related decisions.[8] Reproductive morbidities such as vaginal infections need to be understood in the context of the unsafe abortion experiences that Vanathi underwent. Medical conditions such as uterine prolapse have increased the complexities of her day-to-day life-struggles. Further, the concept of *theetu*, a practice of ritual pollution, and other social belief systems restrict her mobility and income-earning opportunities, limiting her access to healthcare.

V

Discussion

The findings of this study have the limitation of representing just a single case study. However, the insights gained speak of the larger constraints faced by several women of this community. The historicity of exclusion and marginalisation has certainly affected both men and women in the Narikuravar community. When compared with mainstream society, both men and women in this community are deprived of decent work opportunities and are often ostracised and discriminated against by the very agents that are meant to support their well-being. The above narratives explain how diverse factors such as insecure and marginal livelihoods, poor economic conditions, distrust of the formal health services and providers, and lack of availability of abortion at the primary care level restrict women's access to safe abortion services.

However, my field observations also show that the Narikuravar women are not only marginalised and oppressed by the external context, but also by factors that are an inherent part of their day-to-day lives. Although Narikuravar women have better physical mobility as compared to women of mainstream society in Kumbakonam, they are expected to use their mobility to earn money and contribute to the household. In fact, their spaces of freedom and decision-making are quite limited. This calls to question the emphasis on economic upliftment as a key strategy to empower women. Another point to reflect on is the vulnerabilities experienced by women because of their reproductive role, despite relatively egalitarian gender roles in everyday life. Narikuravar men and women maintain some kind of egalitarianism in their roles. Unlike the mainstream society in Kumbakonam, they prefer girl children over boys; they cook for one another, and share their income. However, when the woman becomes pregnant, or a mother, or undergoes abortion, the norms governing her day-to-day life change. The very actors who enabled her freedom during the pre-delivery or pre-abortion phase constrain her mobility, decision-making capabilities, and even her survival.

The present case study also highlights the need for ensuring access to safe abortion services to many marginalised women. The reproductive health burdens of vulnerable and marginalised women increase because of the dire absence of public provisions in medical abortion services. Health disadvantages among these women are higher also due to the discriminatory and corrupt practices followed by both public and private health care providers (Ramachander and Pelto, 2004). In this regard, both public and private health care institutions need to re-constitute as gender-sensitive agents of support, care and change. These actors also have to recognise the intersectional dimensions of women's marginalisation and oppression as well by other axes of domination besides patriarchy.

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[8] Similar observations have been made by Sri and Ravindran (2012).

Be it a Narikuravar woman or a dalit woman, my field observations show that all have similar stories of exclusion and humiliating experiences while accessing health care at public or private institutions. What differentiates a Narikuravar woman from others may be that she has the courage to clean herself by massaging her abdomen following a failed abortion attempt, while the others would have probably not dared to do so. However, this expression of courage should not be misconstrued as signs of her empowerment. Instead, it showcases the poor plight of women who are denied safe abortion services and are forced to undergo self-induced unsafe abortion. The findings of this paper thus emphasise the need to provide safe abortion services to women from marginalised communities without discrimination; recognise their needs, identities and aspirations, and ensure that they are adequately represented.

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Role of Sex and Gender in Post-Stroke Care
A Study in Gandhinagar District, Gujarat

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Globally, stroke leads to 21.7 per cent of deaths among women in the geriatric age-group. For those who have survived it, it demands prolonged care-giving. A relatively longer life expectancy adds to the higher stroke burden among women compared to men. In a country like India with an aging population, a non-functional healthcare system, and a large number of people living in poverty, the burden of post-stroke care, in entirety, gets shifted to households. Within Indian households, women are seen as the primary caregivers, putting them at risk of physical and psychological stress. Patriarchal social norms also place women stroke survivors in severe disadvantage in many ways.

This paper aims to highlight how gender mediates treatment seeking, care receiving and caregiving in household settings in the aftermath of a stroke. A mixed-method study was conducted in two phases in Gandhinagar district, Gujarat. The quantitative component included a cross-sectional survey of 113 individuals in the age group 60 years and above, who had suffered stroke at least two years prior to the survey. The survey included a set of pre-tested tools to elicit information regarding participants' physical, social and mental problems, extent of disability and coping strategies. The qualitative component included in-depth interviews with a sub-sample of 30 individuals who were selected using 'maximum variation' and 'extreme cases' criteria.

Study findings point to the vulnerability of women as patients and as care givers. Among the patients, more women were widowed/separated/divorced (55.6 per cent) when compared to men (5.7 per cent); and more women (57.8 per cent) than men (45.6 per cent) were above the age of 70 years. A majority of caregivers were women, either the spouses or daughters-in-law; and most of them expressed prolonged sleep deprivation, depression, fatigue, body ache and raised blood pressure. Women reported having to undertake tasks such as physically lifting and supporting the male patients even though they were not fit to manage such tasks. Women caregivers often either gave up remunerative employment or were pushed to take up some remunerative work in order to make ends meet. Women stroke-survivors whose husbands were caregivers expressed a sense of helplessness, grief and guilt. An instance of a woman not being taken to hospital after stroke, too, was reported. Unlike some stroke-affected men who continued to be economically resourceful with pension, petty self-employment or owning property in their name, women stroke-survivors were often completely dependent on either their spouse or children.

Women, both as patients as well as care givers, are more adversely affected by stroke- related concerns than men. Apart from the problems rooted in the patriarchal arrangement the study also calls for a resilient and sustainable health care system which provides long-term rehabilitative care, to reduce the burden on women of post-stroke care-giving.

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I

Introduction

Stroke continues to feature as a public health concern for women across the world especially in old age (World Health Organization [WHO], 2009:63), both as individuals who are directly affected by the disease as well as caregivers for other stroke patients. Seshadri et al. (2006) observed that the lifetime risk of stroke is higher in the geriatric age-group, about 1 in 6 for men (14 per cent - 17 per cent) and 1 in 5 for women (20 per cent - 21 per cent) (p. 345). The burden of this disease was much higher among women than among men as women have a longer life expectancy. Although men had a higher risk of stroke, (Sealy-Jefferson et al., 2012:121), many studies have reported that the mortality rate is higher in women stroke patients as compared to men and that male stroke patients had better treatment outcomes than female patients (Wyller, 1999: 41). Stroke deaths account for approximately 22 per cent of deaths among women of the geriatric age group in middle-income countries like India (WHO, 2009:63). Studies have indicated that the effect of stroke is far higher in women, with fewer chances of recovery, affecting their quality of life and predisposing them to co-morbidities (Reeves et al., 2008: 915).

Stroke causes a wide range of physical and psychological problems and has a significant socioeconomic impact on the lives of survivors and their families. Post-stroke recovery is a slow and incomplete process causing irreversible impairments, compelling survivors to live the rest of their lives adapting to post-stroke disabilities. Many researchers have noted that only some stroke survivors recover entirely and regain their routine physical functions; however, approximately half of them have long-term mobility deficits and around a quarter to half of the survivors need some amount of assistance for their daily activities (Bonita, Solomon and Broad, 1997). In low and middle-income countries, poverty, poor healthcare infrastructure and limited access to care forces families of stroke-survivors to take care of survivors (Pandian, Srikanth, Read and Thrift, 2007: 3063).

Post-stroke-care entails a composite set of responsibilities shaped by factors such as the financial situation, cultural beliefs and gender norms of the household; interpersonal relationships within the family; and the presence of a competent healthcare system (Singla and Singla, 2016: 76). Disabled stroke survivors who need prolonged caregiving but are unable to afford the high cost of care and rehabilitation are often cared for by their families (Pandian and Sudhan, 2013: 128).

Many studies have reported that, within the household, women bear a higher burden of caregiving as compared to men as a part of their gender-role expectations, resulting in considerable physical and psychological hardship (Gosman-Hedstrom and Claesson, 2005; Pinquart and Sorensen, 2006; Banerjee and Das, 2016). A comparative study carried out to determine the improvements in quality of life (QOL) of stroke survivors and their informal caregivers, found that while the patients “appeared to adapt to new life situation and their QOL in socio-emotional and mental domains improved during the year between the follow-ups … the caregivers were on a lower level in emotional and mental domains, and their most important determinants of QOL were the age of the caregiver and the patients’ functional status” (Ann-Cathrin Jonsson et al., 2005: 803). Apart from the physical and mental stress, the burden of financial expenses was also a significant stressor seen in 81 per cent of the informal female caregivers (Das et al., 2010).

This paper is the outcome of an exploratory study in Gandhinagar district of Gujarat. The study aimed to document the physical, mental and social problems faced by individuals with post-stroke disabilities and innovations made by patients and caregivers to cope with demands of everyday life. We found that technical innovations made in the built-environment, furniture or assistive devices were minimum. Innovations were mainly in the form of strategies of family reorganisation. These were to ensure the presence of one or more immediate family members to provide care over the prolonged period of recovery and rehabilitation after stroke. Gender was a factor that configured these strategies. This paper aims to capture how the sex and gender of the affected individual and caregivers becomes a critical dimension along which these strategies get shaped.

II

Materials and Methods

We conducted a cross-sectional, descriptive study with a mixed method approach. Community approach was adopted to identify stroke patients with the help of Anganwadi workers, Accredited Social Health Activists (ASHA) and residents of villages. The study was conducted between January 2014 and October 2015.

Research team

Besides the principal investigator and two co-investigators, the trained research team included two research associates with a medical background and five field investigators with a social work background. The research team underwent a two day-intensive training by a physiotherapist and a medical doctor, which introduced them to various terminologies used in the study tools, and to making an independent assessment of the mental health status, coping-behaviour and physical disability of stroke-patients. Field investigators were trained to administer questionnaires and assess responses under the supervision of research associates. Debriefing meetings with the principal investigator followed each field visit.

Research setting and Study population

The study was conducted in Gandhinagar district of the Gujarat state, India. The district has four blocks namely Mansa, Kalol, Gandhinagar, and Dehgam. The study population comprised stroke survivors in the geriatric age-group (60 years and above) who had suffered a stroke at least two years before the date of the survey in all four blocks of Gandhinagar district.

According to Census 2011, the total population of Gandhinagar district was 1,387,478 with 787,949 in rural and 599,529 in urban areas. The estimated number of stroke cases in the geriatric group for Gandhinagar district in Gujarat was calculated by using the age-specific prevalence rate of 8.47/1000 (Indrayan, 2005: 205). The population in geriatric age-group was 110,998 and hence, the estimated number of stroke cases was 940.

Study design

The study had two components – quantitative and qualitative. The quantitative component included a survey of stroke-survivors and/ or their caregivers to whom a set of pre-tested tools were administered. The qualitative component comprised of in-depth interviews with a sub-sample of participants drawn on the basis of theoretical sampling from those sampled for the survey. In addition to the in-depth interviews, details of the living space of stroke-survivors and the innovations they or their families had made to cope with disabilities were captured.

Sample size and sample selection

The sample for the survey was selected through population proportionate sampling method. We selected 14 villages through systematic random sampling, aiming to draw two participants from each village. We repeated the process for all the four blocks in the district. Fifty-six villages/urban wards were selected in Gandhinagar district, 14 villages from each block. From these locations, we included 113 individuals in the survey and carried out qualitative in-depth interviews with a sub-sample of 30 individuals from this group.

Selection criteria for participants

For the quantitative survey, all the individuals in the geriatric age-group, who had suffered a stroke at least two years before the date of survey, were selected. For qualitative in-depth interviews, we drew a sub-sample of 30 participants from the quantitative survey, using the 'maximum variation' and 'extreme cases' criteria. The dimensions considered for selection of participants for the qualitative component of study were gender; whether professional support was received or not; type of disability; availability of a toilet within the house; family support (presence of spouse, other immediate family members or compete neglect); effect on livelihood and/or adjustments made by family members to deal with care-giving for stroke-survivors.

Those who had developed disabilities due to reasons other than stroke; those who had suffered stroke less than two years before the date of survey; and those who were not in geriatric age-group were excluded from the study.

Study tools

For the quantitative component we used a set of structured tools including a customised tool to elicit socio-demographic and illness related information, the Brief Cope Scale to capture mental health status and coping behaviour of participants (Carver, 1997), the Scandinavian Stroke Scale (SSS) to assess the extent of post-stroke impairment (Scandinavian Stroke Study Group, 1985) and the Barthel Index (BI) to measure dependence in activities of daily living (Mahoney and Barthel, 1965). The tools were already validated for the Indian population (Mohanraj et al., 2014), and translated into the Gujarati language.

For the qualitative component, an interview guide with probes was prepared to interview stroke survivors and immediate family members. As the purpose was to capture the lived experiences of the patients and immediate family members, the interviews were relatively unstructured. Efforts were taken to have individual interviews, but often this was not possible, and the interview had to be conducted in the presence of other members of the family, with responses coming from them as well. As the study was also about caregiving, in situations where the stroke-affected member was not able to answer or was deceased, caregiver(s) or family members were interviewed. In other words, the unit of data collection and analysis in the qualitative component was the household as the dynamic unit that has been experiencing stroke and caregiving as an ongoing process. Interviews were audio recorded, and field observations were written. Photographs were taken to capture the living space and innovations related to post-stroke caregiving.

Data analysis

Data from the quantitative component was analysed using descriptive statistics and Pearson correlation. Gender differences on BI were assessed by Chi-square test. For the qualitative component, audio recordings of IDIs were transcribed and translated into the English language with all personal identifiers removed, and these were checked for accuracy. Transcripts were uploaded as primary documents in qualitative data analysis software and were coded for a pre-decided set of codes derived from the tool plus additional codes generated concurrently as the data collection proceeded, during debriefing meetings post each field visits, and during the process of familiarisation with data. Iteratively, five themes were identified, and the data was organised into these themes. Inter-relationships across themes were also explored.

Ethical consideration

Ethical approval for the study was obtained from the institutional ethics committee of the host institution. During the fieldwork, members of the research team were made aware of the practical issues of research ethics. Stroke-survivors and their family members were informed about the study using a participant information sheet, were assured of anonymity and confidentiality and were informed about their right to withdraw at any point in time. Before seeking consent, consent forms were given to respondents who could read, and for those who could not read, the ASHA or Anganwadi workers or neighbours were asked to help explain the content of the form. For the qualitative component, consent was sought and obtained especially for audio recording and taking photographs. Photographs were taken in such a manner that respondents' identities were not divulged.

III

Results

Quantitative component

The following tables capture the result from analysis of data from the survey along the dimension of the sex of the stroke-affected participant. The first table captures the socio-demographic characteristics of participants. In terms of age profile, the mean age of male participants was 68.68±7.41, and for female participants it was 70.51±7.82. Distribution across age groups shows a greater proportion of men in 60-69-year age-group and a greater proportion of women in 80+ year age-group.

Table 1: Socio-Demographic Characteristics of Participants

Variables	Categories	N (per cent) Male	N (per cent) Female
Gender	Number of Male and Female patients	68 (60.2)	45 (39.8)
Age group	60 – 69	37 (54.4)	19 (42.2)
	70 – 79	24 (35.3)	17 (37.8)
	80 +	7 (10.3)	9 (20.0)
Age (Years)	Mean	68.68	70.51
	Std. Deviation	7.41	7.82

Marital status	Currently Married	63 (92.6)	20 (44.4)
	Divorced/Separated/ Widowed	5 (7.4)	25 (55.6)
Residence	Urban	13 (19.1)	12 (26.7)
	Rural	54 (79.4)	33 (73.3)
	Suburban	1 (1.5)	0 (0)
Currently residing with	Spouse	8 (11.8)	5 (11.1)
	Immediate family members (with spouse)	53 (77.9)	15 (33.3)
	Immediate family members (other than spouse)	7 (10.3)	23 (51.1)
	With relatives other than family members	0 (0)	1 (2.2)
Education	No Schooling	9 (13.2)	28 (62.2)
	Primary Education	39 (57.4)	15 (33.3)
	High School	16 (23.5)	2 (4.4)
	Graduation	3 (4.4)	0 (0)
	Post Graduation and Higher	1 (1.5)	0 (0)
Current Employment status	Unemployed	48(70.6)	44(97.8)
	Part-time	4(5.9)	0 (0)
	Full time	1(1.5)	0 (0)
	Retired and pensioner	13(19.1)	1(2.2)
	Retired but not pensioner	2(2.9)	0 (0)
Monthly Household Income	0-1000	5(7.4)	3(6.7)
	1001-10000	47(69.1)	27(60.0)
	10001-20000	11(16.2)	15(33.3)
	20001-30000	0 (0)	0 (0)
	30001-40000	4(5.9)	0 (0)
	40001-50000	1(1.5)	0 (0)
Person(s) from whom help may be sought when needed (with multiple response)	None	4(5.9)	0(0)
	Spouse	34(50)	8(17.8)
	Children	51(75)	37 (82.2)
	Siblings	1(1.5)	0(0)
	Parents	1(1.5)	0(0)
	Other Relatives	4(5.9)	3(6.7)
	Friends	4(5.9)	2(4.4)

A large number of female stroke survivors (55.6 per cent) were widowed, separated or divorced at the time of the survey. This proportion was comparatively very small (7.4 per cent) among the male participants. In terms of residence, only 44.4 per cent women resided with their spouse while close to 90 per cent of stroke-affected men lived with their spouse. Further, 50 per cent of male participants reported that they were dependent on their spouses when in need of help; whereas only 17.8 per cent of female participants reported that they depended on their spouse when in need of support. Female participants were financially more dependent or vulnerable as most of them were unemployed (97.8 per cent) and a large number of them (62.2 per cent) had no formal schooling. In contrast, at least one-fourth of the men had some source of income and relatively higher levels of education.

In other words, men as stroke survivors were relatively better-off in terms of their educational level, economic independence and co-residence of and caregiving by their spouses. Women stroke survivors were in a much more vulnerable situation, being economically dependent and often without their spouses for support. This also suggests that most of the caregivers are women, an assumption corroborated by the qualitative component of the study.

Tables 2 and 3 are based on BI score for disability and various activities. The data shows that almost similar numbers of male and female participants suffered severe to mild disabilities with a few very severely disabled patients (Table 2).

Table 2: Information on Illness-related Characteristics and Treatment Seeking

Variables	**Categories**	**N (per cent) Male**	**N (per cent) Female**
Sex	Number patients	68 (60.2)	45 (39.8)
Barthel Index (BI) Score	Very severely disabled (0-20 score)	2 (2.9)	3 (6.7)
	Severely disabled (25-45 score)	10 (14.7)	6 (13.3)
	Moderately disabled (50-75 score)	24 (35.3)	15 (33.3)
	Mildly disabled (80-95 score)	24 (35.3)	19 (42.2)
	Not disabled (100 score)	8 (11.8)	2 (4.4)
Advised for Physiotherapy	Yes	60 (88.2)	36 (80)
	No	7 (10.3)	8 (17.7)
Accessibility to Physiotherapist	Yes	47 (69.1)	28 (62.2)
	No	13 (19.1)	8 (17.7)

Table 3: Sex differences on Barthel Index (BI) Activities

Barthel Index (BI) Activities		**Gender**		**Chi-Square Value p**
		N (per cent) Male	**N (per cent) Female**	
Feeding	Dependent	12 (19.1)	9 (20.0)	0.7811
	Independent	55 (80.9)	36 (80.0)	
Bathing	Dependent	28 (41.2)	16 (35.6)	0.5485
	Independent (Or in the shower)	40 (58.8)	29 (64.4)	
Grooming	Needs help with personal care	33 (48.5)	25 (55.6)	0.4644
	Independent face/hair/teeth/ shaving (Implements provided)	35 (51.5)	20(44.4)	
Dressing	Dependent	21 (30.9)	17(37.8)	0.3883
	Needs help but can do about half unaided	16(23.5)	6(13.3)	

Bowels	Incontinent, or catheterized and unable to manage alone	22 (32.4)	13 (28.9)	
	Continent	46 (67.6)	32 (71.1)	0.6966
Bladder	Incontinent, or catheterized and unable to manage alone	21 (30.9)	10 (22.2 per cent)	0.312
	Continent	47 (69.1)	35 (77.8)	
Toilet use	Dependent	14 (20.6)	8(17.8)	0.8157
	Needs some help, but can do something alone	19 (27.9)	15 (33.3)	
	Independent (On and off, dressing, wiping)	35 (51.5)	22 (48.9)	
Transfers	Unable/Major help	12 (17.6)	12 (26.6)	0.3815
	Minor help (Verbal or physical)	24(35.3)	17 (37.8)	
	Independent	32 (47.1)	16 (35.6)	
Mobility	Dependent	28(41.3)	19 (42.2)	0.912
	Independent (But may use any aid; e.g., stick) > 50 yards	40 (58.8)	26(57.8)	
Stairs	Unable	23 (33.8)	15 (33.3)	0.9569
	Needs help/Independent	45 (66.2)	30 (66.7)	

Differences across the dimension of sex on various BI activities were tested to assess the functional disabilities by Chi-Square test (Table 3), which showed that there were no significant ($p > 0.05$) differences across sex for ability to perform activities of daily living.

Qualitative component

Thirty participants were selected for in-depth interviews of which, 11 (37 per cent) were women, and 19 (63 per cent) were men (Table 4). In-depth interviews focused on physical, social and mental aspects of coping with the after-math of stroke in stroke-affected individuals and their caregivers. For those participants who were completely cognitive-impaired or who had expired following the survey, caregivers and other household members were interviewed to capture the dimensions of coping and caregiving, ‘as perceived and reported’ by them. Analysis of this data brought out many themes including changing social relationships, financial hardship, caregivers’ stress, coping strategies and access to rehabilitation services with a cross-cutting theme of ‘role of sex and gender in shaping the care-receiving/giving experience’.

Table 4: Profile of Participants Selected for Qualitative In-depth Interviews

Participants for in-depth interviews	N (per cent)	N (per cent) Male
Participants selected	19 (63)	11 (37)
Deceased	3 (15.7)	5 (45.4)
Completely cognition- impaired	1 (5.2)	2 (18.1)
Partially cognition impaired	3 (15.7)	0 (0)

Sex of the patient and experiences around care

As indicated by Table 4 among the 30 patients who were followed up for this component of the study 19 were men and 11 women. As we shall see through some of the narrations below, sex of the patient had a role in shaping who gets or provides care and the strategies of reorganisation adopted by households.

Table 4 suggests another important possibility. Out of the thirty patients who were followed-up from the initial survey, 11 had unfortunately expired before the qualitative study began. Three times as many women had expired as men. It is probable that age played an important role in this. The average- reported- age of women and men stroke-survivors were 74 and 69, respectively. The average- reported- age of patients who had expired was 81 for women and 76 for men. In addition, other factors like co-morbidities, the severity of stroke, families' economic status etc. may have played a role. Yet, the higher mortality observed among women patients could also indicate a difference in the quality of care received by women as compared to their male counterparts.

In the following paragraphs, we look at narrations from households with female patients and a few from households with male patients to illustrate the differences – if any - in care received by them respectively.

Harishbai

Harishbhai[4], age 70 years, had a stroke about 14 years ago and another one subsequently. He is paralysed on the left side of his body. He is being taken care of by his second wife and an unmarried son. Earlier he used to manage to go to the toilet by himself outside in the fields, but his condition had worsened over the past three years. He is bed-ridden now and has urinary incontinence and no bowel control.

> "Can't say about bowels (lacks control) … that's the only thing he can't tell. Even if we ask many times, he will still pass it (in bed) … earlier he was not able to eat 'roti,' but now he can eat it."

His wife does all the work for him, but cannot easily lift him; she therefore does whatever possible, and beyond that, she waits for the son to come. His son can lift him up to bathe him or wash him once in three or four days and massage. The son is still unmarried and in search of a wife who would be ready to come and live with his family. "I don't want to live separately. After my father dies, then I may I live (separately)".

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[4] All names are pseudonyms

His wife narrated:

> “I feel tired, not able to sleep in the nights and my limbs ache. But who will do for us? My daughter-in-law lives nearby but if we ask her ‘please give me some water,’ she would answer, ‘I have no water in the house how I can come to give to you.’ Then we have to help ourselves”.

“I don’t go to anybody’s house … Even if I went to my brother’s house; I would leave at 10 o’clock and would be back by 2 o’clock. I don’t even visit my children’s homes.”

One of their neighbours added,

> “His wife cares for him. Whatever he wants, she would make it for him. They keep his bedding separate, two pairs of bedding. Every day she washes the beddings and his bed. Sometime, if he has diarrhoea, she serves him all day. She uses nappies made up of clothes…like we do for young kids… On some days she would feel like resuming work in the fields, but she also has low BP problem. She feels dizzy… is it advisable to go and work?”

The above is a situation in which a patient had a stroke over 14 years ago, was bed-ridden and is still being cared for. He was clean, and his room and surroundings were hygienic. The presence of his wife and an unmarried son – who has been delaying his marriage – has made a big difference in the quality of care he has been receiving. His son attends to the economic needs and supports in tasks that require physically lifting the patient, while the patient’s wife attends to chores connected to his care.

Shankarbhai

Shankarbhai, aged around 70 years at the time of the initial survey, had expired when the team visited for the qualitative interview. He had a stroke over six years ago. The family is economically better off, owed land and ran a private higher secondary school. He was the founder-owner of the school.

During the initial survey, the team found this person left in an almost unattended state, in a room with a strong stench. Toilet bins were left un-cleared, and the person was in a dirty state. When the investigators reached the site, his daughter in law and grandson hurriedly got his room cleaned and washed him.

His wife had heart attack four years before his stroke and was not in a position to take care of him. She subsequently passed away after his stroke. After that, he was being taken care of by his daughter-in-law and his grandson. He used to walk without a need for a stick, but he fell and broke his hip and after that, his condition began to deteriorate. During the last six months, he was entirely bedridden.

According to his daughter-in-law,

> “My son and I have been taking care of him. Sometimes he would have diarrhoea. But my son and I would clean him. I would hold on one side and on the other side my son would hold and would make him stand by the support of the walker. … His daughters are there (in the village, a few kilometres away). So he used to go to stay for 10 to 15 days there in between.”

Here, the individual affected was economically affluent and commanding respect in the family. However, as he had lost his spouse and his married sons and daughters were not in a position to take care of him he was shunted between his son’s and daughter’s houses for care. Meanwhile, he became bedridden, and the situation became worse. He was left entirely unattended and didn't survive long.

Tulsiben

Tulsiben was 80 years old and had a stroke about four years prior to the survey. She had expired by the time the team went for an in-depth interview with her. She had been utterly dependent on her son's family that had a reported monthly income of Rs.1500.

At the time of her stroke, there was the family was in the midst of a wedding. Because the family feared that the marriage may be called off if her illness was known, they made her sit-up to greet the guests. She was not taken to a hospital. Instead, a doctor from a private clinic was called home to attend to her. The doctor had told the family that nothing could be done for the patient. Her son and daughter-in-law told us that because of the poor prognosis according to the doctor, they did not take her to a hospital.

The stroke affected Tulsiben on her left side and she was unable to walk independently. She used to drag herself around the one-roomed space she had been given under the government's free housing scheme.

She was not able to communicate properly, had mood swings and behaved erratically. She sometimes took off her clothing. She often woke up three or four times in the night asking for water, and was awake from 4 am onwards. She did not allow her daughter-in-law to touch her. She preferred to have her daughter, who lived nearby, or her grandchildren to come over to bathe her.

Her son and daughter-in-law narrated,

> "We faced many difficulties. … In everything…In feeding her, in lifting her…We had to feed her, give her a shower, and change her dress … We could not go for our farming work leaving her alone at home … The whole day we had to keep giving water to drink at frequent intervals."

Here, probably the economic situation of the patient's family and the severity of the stroke had shaped the caregiving situation. Yet, the fact that she did not have a living spouse and was completely dependent on children who had their own family responsibilities also appears to have made a major difference.

These cases illustrate the importance of the presence of the spouse or a male member who could attend to care; economic affluence of the household, and the household's ability to adapt to caregiving situation in shaping the quality of care received by the stroke patient. It is certainly difficult to tease out these factors. Nevertheless, it may be said that the sex of the patient and the presence of a female -principal caregiver did ensure better caregiving.

Changing social relations

Most of the narrations by participants and family members referred to changes in social relations following the incidence of stroke in a member of the household. The stroke caused severe stress in relationships especially with spouses and children and made a profound impact on the emotional well-being of patients and caregivers.

The IDIs captured the conversations about how families, friends, and neighbours supported or denied support to stroke survivors after the illness. In some situations, the patient experienced considerable discrimination.

A female stroke survivor who lived alone, described the discrimination she faced from her brother and other relatives,

> "In such times (when one suffers from a stroke), relatives are not going to do anything...if something happens to me, my neighbours help me... My brother visits only to check the house as I live in his house...and never helps financially for medicines or livelihood...rather he would say I should die."

Another female survivor, having her spouse as the principal caregiver, expressed intense guilt and a sense of helplessness. During the interview, her husband told us,

> "At times I feel like poisoning her food to get rid of her. I am tired of caring for her."

Contrary to this, in some households, stroke survivors were well taken care of irrespective of their gender.

A granddaughter, as a chief caregiver, described how her family cared for her grandmother, a stroke-survivor with cognition-deficit issues

> "My grandmother used to sell vegetables, but after her illness my mother sells vegetables...My grandmother is never quiet, and keeps talking on and on...we let her speak...we have to be patient with her because she is an elder, have to be patient as long as she lives."

A male stroke survivor shared his experiences about a change in his social role after stroke:

> "I used to sell vegetables earlier...but now my wife and son are managing the occupation... Earlier I was the decision -maker but now my wife and son...they do it. They usually ask me before doing anything...I have to guide them..."

The IDIs also captured societal attitudes towards aging-related diseases. We observed that society easily accepted age-related illnesses and gradually the survivors and their families started preparing themselves for the patients' death. In spite of such societal attitudes, most of the families sought immediate medical care after stroke to save their elderly. However, as an exception, an instance of a woman not being taken to the hospital was reported. Her son told us,

"We did not take her to a hospital as she was not able to speak or stand up and she was aged...one usually does not recover in old age...we asked my sisters also, they said that she will not recover even if we spent money."

Patients with communication difficulties due to loss of speech/slurred speech showed intense emotional reactions, perhaps because the ability to speak and express is an important factor in maintaining social relationships. The wife of a male stroke survivor who had been fond of singing bhajans (religious prayers), shared with us that he would often cry at his inability to speak.

Financial hardship

Nearly all households experienced significant financial impact of the catastrophe brought about by the stroke. As a stroke attack is usually sudden, most participants/families said that they were unprepared and were unable to manage the crisis. Due to the acuteness of the illness, priority was given to immediate treatment, which was generally very expensive. To meet the emergency, many families had to borrow money from relatives. Consequently, the families ran short of money for further medications and long-term rehabilitation services.

Some incidents were noted where women caregivers had to take up some form of employment to make ends meet, besides care giving. A daughter-in-law shared her financial problems after her husband went absconding, leaving her to take care of his mother.

> "My husband, who used to sell vegetables in market, ran away last year after his mother's illness....he left us and his mother and did not return even for her death ...so I started working to earn our living ... As I could not afford to spend on her medications, we stopped her medications after my husband ran away."

There were also situations where many women had to give up their jobs in order to take care of a stroke-affected member, causing economic vulnerability. The families were further burdened by societal norms requiring them to perform post-death rituals:

> "I used to work and earn Rs.5000-6000; but after my mother-in-law suffered a stroke, I had to leave my job, because my sister-in-law was not able to manage things alone...As per the custom in our caste, we performed some rituals after her death, the expenses for which were about Rs.15000 to 20000."

In another case, a woman expressed guilt at getting back to work with her husband in home after a stroke,

> "I went to work for three days as a labourer thinking that since he was better I could go out to work and earn to feed him better...but in the meanwhile he had an insect bite and developed boils on his back. I felt bad, and my sons also scolded me for going to work when he had to be taken care of. Then I decided to never work."

The immediate and long-term household economic impact of stroke are most often overwhelming. Many households are rendered impoverished and indebted. Depending on specific life situations, members have to reconfigure their roles vis-a-vis employment. Some give up their jobs, and some freshly take up employment, and the decisions are often mediated by caregiving roles and gender norms.

Caregivers' stress

This theme captured physical and mental stress that the caregivers had to endure as they carried out their care giving responsibilities, whether willingly or unwillingly. In most households, members mentioned that caregiving was the responsibility of women members of the household - wife, daughters-in-law, or granddaughters. Interviews with these members brought out the enormity of this responsibility and their feelings of helplessness because these responsibilities were seldom shared by other members of the family. As discussed in the previous section, some women were compelled to take up remunerative employment along with caregiving; while some had to give up their employment to meet the caregiving requirements. In both situations, the women caregivers experienced high levels of physical and mental health issues such as fatigue, body ache, sleep-deprivation, high blood pressure, infections, and depression.

Two daughters-in-law narrated their care giving experience for a bed-ridden mother-in-law,

> "We faced a lot of physical difficulties but what could we do? ...Being available for her all day, we used to get feverish, tired and dizzy...we were not getting adequate sleep….sometimes we used to think, 'when will the God call her now?'.. God should either free us or her. She would soil her clothes every day...We used Dettol soap for her and put some Dettol in warm water to give her a bath. We had a good relationship with our mother-in-law, but we feel good now (as she is no more)."

They also added that:

> "A male cannot do such things....if a male is disrespectful and insensitive; he may not take care of his wife but would rather get rid of her by throwing her out of his life." "Who will serve a female? ...only those who feel pity on them...their daughters and daughters-in-law [not sons or sons-in-law]."

Another daughter-in-law and a wife shared their experiences of taking care of a male stroke survivor in their family:

> "He used to remove his clothes and expose his body parts to all of us (in a luring manner) ... While taking him for a bath, we used to face great difficulties as he would never cooperate in removing his clothes...he would beat us and would use abusive words... Nobody would tolerate such behaviour, but we tolerated for eight years."

Although the study identified mainly women as the principal caregivers, in a few cases some male patients had their sons playing this role, and these men faced a similar burden. A man who had survived stroke had this to say about his son taking care of him:

> "I was suffering from [disability due to] stroke at that time too (when my wife was alive), but my condition was better...but I lost my courage after my wife's death... My son is a daily wage labourer...he comes in the afternoon and cooks food for me...Sometimes he gets frustrated...he comes from work and has to cook and take care of me so naturally, he gets frustrated."

Taking care of individuals affected by stroke is physically and emotionally intense and often a full-time responsibility. It can wear out the caregivers and other family members physically and psychologically, and in addition they may have to face financial vulnerability and indignity. Caregivers themselves need support to cope with such extreme yet enduring situation.

Coping strategies

During the interviews, patients and their caregivers commonly discussed patients' strategies to cope with the impact of post-stroke illness. Depending on their socio-demographic environment, patients developed their own coping strategies to deal with the physical and mental trauma. There were no significant gender differences found in coping strategies as elicited from structured instruments. Nearly all the participants accepted their stress and disabilities to retain their psychological and social wellbeing. Religious coping was one of the most frequently used strategies. Most of the survivors accepted their illness with an attitude of seeking forgiveness and spiritual support; however, a few patients showed extreme forms of negative religious coping.

> "I have lost my faith in God (crying)... I am a widow since childhood. God has done this to me. God has nearly killed me. I don't believe in God now. I don't worship God now."

Apart from these, self-distraction and substance use to ease the stress were also reported.

> "I drink alcohol. Monthly I spend 200-300 rupees on it... If my body starts aching, I ask someone to bring alcohol, and I drink a glass of it...I offer the children (who bring me alcohol) one rupee to buy it for me...What to do as I don't work now? I don't take medicines. I want to die and go to God's home."

Smoking or chewing tobacco or using snuff was reported among both male and female stroke patients. One of the daughters-in-law reported that her mother-in-law smoked regularly, and continued to do so till the day she died.

As far as physical coping is concerned, patients/families innovated their own ways as they received negligible help from the government. Post-stroke consequences caused loco-motor disabilities in survivors making them completely/partially dependent on others for daily activities such as defecation, transfer and walking. Such families reported the use of innovations like modifying a plastic chair/stool by cutting the seat from middle to use as a toilet chair and using a wooden/metal stick as a walking stick. However, innovations were very basic, and while they helped improve mobility to some extent, they hardly improved the quality of life of stroke-survivors.

Access to rehabilitation services

Affordability and availability were seen as barriers to accessing of rehabilitation services. Most people had to travel long distances and incur expenses on travel to access rehabilitation services. Households which were able to spend some money on rehabilitation continued it for some months after the stroke attack. For poor families, however, rehabilitation services were not affordable even from the nearest rehabilitation clinics. A lone woman patient, surviving on benefits from the government said,

> "I used to go for exercise for six months by taking an auto rickshaw and spent so much money for auto rickshaw, but it has made no difference. Now I have no more money, so now I do nothing. How can I manage treatment and my living expenses in just 750 rupees?"

Accessing rehabilitation services demand cooperation from patients as well as caregivers and other family members. Patients or their family members often lost their faith in rehabilitation services and gave up as they perceived very little or no progress in the condition of the stroke-survivor despite spending money that they could ill-afford.

> "My son earns 100-200 Rupees and he has four children to feed. I did not go anywhere for exercise ... I used to exercise for some days on my own, but then I got bored and stopped exercising."

Unaffordable rehabilitation services often compelled stroke survivors to stay at home, increasing their post-stroke complications and severity of disabilities. Post stroke-complications and severity of disabilities amplified their rehabilitation needs.

IV

Discussion

In India, stroke survivors and their families are faced with enormous challenges during the course of post-stroke continuum of care – from the management of acute phase of stroke to immediate rehabilitation services to care at home. The present paper expands our understanding of how stroke affects the lives of survivors and their families by changing their social role and responsibilities affecting their social dynamics, their financial conditions, and their physical and mental well-being. This study reveals gender disparities prevalent in society negatively affecting women, both as stroke survivors and as caregivers.

Along the lines of previous studies (Bonita, Solomon and Broad, 1997; Carmo, Morelato, Pinto and Oliveira, 2015; Lynch et al., 2008), the present study illustrates that social relations are one of the major determinants of the quality of life of stroke-survivors. It has a significant influence on patients' physical and psychological well-being. As many patients are dependent on their families for their day-to-day activities, surviving a stroke is not just limited to the physical effort, but it is a collective social effort as well.

Our findings are consistent with research that confirms the greater burden of illness among the female population as a result of longer life expectancy, resulting in a higher number of women stroke patients at an older age (Seshadri et al., 2006, Haast, Gustafson and Kiliaan, 2012). Further, the study highlights denial of immediate stroke treatment, rehabilitative services and home-based care for women stroke survivors especially when compared to support received by men stroke survivors. Like other studies, this study too brings out that gender disparities in stroke care are due to multiple reasons such as social values and norms around gender, residence, and economic situation of the stroke-affected individual and his/her family (Singla and Singla, 2016: 74).

Findings from this study illustrate gender differences in caregiving in a domiciliary setting. This has also been observed in previous studies (Das et al., 2010; Pinquart and Sorensen, 2006; Banerjee and Das, 2016). A majority of the primary caregivers are women, who consequently suffer from various physical and psychological hardships such as depression, disturbed sleep, fatigue, raised blood pressure, general body ache and financial stress.

Studies have also shown that there is a significant extent of unmet need for affordable stroke rehabilitation centres in India (Kamalakannan et al., 2016; Banerjee & Das, 2016; Pandian and Sudhan, 2013) and Gandhinagar district, Gujarat is no different from the rest. Although organised rehabilitation centres are available in the country, they are only limited to private hospitals in urban areas which are too expensive for the rural population who constituted our study sample.

V

Conclusion

In conclusion, our study shows that receiving emotional, physical and financial support from one's family is of greater importance to stroke-survivors than professional support. The study identifies women, as stroke patients and caregivers, to be in a more disadvantaged situation as compared to men. As caregivers, women are in dire need of other family members to share these responsibilities. Given the lack of rehabilitation services in Gandhinagar district in Gujarat, developing an affordable, accessible and patient-centred rehabilitative care is of utmost importance to reduce the post-stroke illness and burden of caregiving.

A major strength of this study is its mixed method study design which allowed us to obtain a rich understanding of stroke survivors' and their caregivers' needs. However, being a cross-sectional study, it does not provide insights into the process of coping with stroke and caregiving. A longitudinal or a more intensive ethnographic study may be useful as a follow up to this study.

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Perceived Barriers to Timely Postpartum Screening of Women with Gestational Diabetes Mellitus (GDM)

A Qualitative Study

K. Sakeena[1*], T. K. Sundari Ravindran[2]

Timely postpartum screening for diabetes following a pregnancy with gestational diabetes mellitus (GDM) is crucial to reduce the future risk of incidence of diabetes. This study explored barriers to timely postpartum screening for diabetes mellitus after a pregnancy with GDM, by assessing the concerned women's views and perceptions.

Data for this study pertains to fifteen respondents from among participants in a larger cross-sectional survey conducted in Malappuram District of Kerala among women affected with GDM during a recent pregnancy. The selection was based on detailed responses to open-ended questions asked in the quantitative study. The responses were transcribed and deductively coded. The findings were organized around major themes.

We identified five main areas of barriers in the management of diabetes during pregnancy. These were a) inadequate instructions from the healthcare provider who attended the pregnancy and delivery; health services related barriers; perceived difficulties of the oral-glucose-tolerance-test; lack of time owing to multiple roles as mothers and home-maker; and postponing the screening but unable to specify a reason for it. Of these, health-provider and services -related barriers and lack of time owing to multiple responsibilities were the most often- stated barriers. Participants had a general awareness of possible complications following GDM in pregnancy but often could not name specific effects on the woman or child during and after the GDM pregnancy. A majority of the participants were unaware of their elevated risk of developing Type 2 Diabetes Mellitus.

The barriers to postpartum screening identified in this study could help planning programmes to assist women in achieving timely postnatal screening for Type-2 Diabetes Mellitus.

Keywords : Gestational diabetes mellitus, postpartum diabetes screening for T2DM , Oral-glucose tolerance-test, procrastination.

Indians are living through a period of unprecedented economic inequality in more than a century, and this is largely true for most countries of the world. In 2017, 73 per cent of the wealth generated in India went to the top 1 per cent of the population, while the poorest 50 per cent were able to corner only 1 per cent. We as a country boast of having 101 billionaires, while 224 million people live below the poverty line of US$ 1.90 per day (Oxfam International, 2018).

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Gestational Diabetes Mellitus (GDM) is defined as the degree of glucose intolerance with onset or first recognition during pregnancy. According to the 2015 estimates of the International Diabetic Federation (IDF), globally 16.2 per cent of women with live births had some form of hyperglycemia in pregnancy and GDM accounted for 85.1 per cent out of this (International Diabetic Federation [IDF], 2015). In a systematic review of 28 epidemiological studies published between January 1961 and August 2001, with follow up times ranging from 6 weeks to 28 years after a pregnancy with GDM, the cumulative incidence of Type 2 Diabetes Mellitus (T2DM) after the index pregnancy ranged from 2.6 per cent to 70 per cent (Bellamy, Casas, Hingorani, & Williams, 2009). The maximum incidence was during the first five years after delivery, and the incidence appeared to plateau after ten years (Kim, Newton, & Knopp, 2002). But no standard GDM management protocol is being followed in India (Seshaiah, 2015).

An oral glucose tolerance test at 6-12 week postpartum in women with GDM is recommended by the American Diabetes Association (American Diabetic Association [ADA], 2013). Timely postpartum screening (i.e. between 6-12 weeks) and follow-up of women affected by GDM will help to prevent progression to Type 2 Diabetes Mellitus (Blatt, Nakamoto, & Kaufman, 2011). The onset of diabetes among women with a history of GDM can be delayed or prevented through lifestyle modifications (Buchanan & Page, 2011). Hence to modify natural history and reduce the risk of future T2DM, routine postpartum screening of women with GDM is necessary (Case, Willoughby, Haley-Zitlin, & Maybee, 2006).

Globally, postpartum screening rates for T2DM, of women who experienced GDM in the most recent pregnancy, are reported to be 50 per cent or lower (Kwong, Mitchell, Senior, & Chik, 2009). According to various studies, postpartum screening rate for diabetes in Indian women with a history of GDM ranged from 18 per cent to 57 per cent (Seshiah, 2015). In the Malappuram district Kerala, the comparable screening rate was only 29 per cent among the GDM women in (Sakeena, 2016).

The attendance rate of women for postpartum screening is very low the world-over, and ranges from 18 per cent to 57 per cent (Chamberlain, McLean, Oldenburg, Mein, & Wolfe, 2015). The reasons for low-rates of screening are unclear, and the majority of studies are from high-income countries. Besides, there are few qualitative studies that explore the experiences of women with previous GDM that delve into obstacles faced by women to postpartum screening for T2DM.

The objective of this study was to explore the barriers to postpartum screening for diabetes faced by women diagnosed with GDM, in the Malappuram district of Kerala through a qualitative investigation with the concerned women. The purpose was to obtain insights that could inform the development of interventions to improve the postpartum T2DM screening rates of GDM-affected-women.

Methods

Data for this paper is drawn from a larger cross-sectional survey of mothers with a history of gestational diabetes mellitus in Malappuram district of Kerala on postpartum screening for T2DM (Sakeena, 2016, Sakeena & Ravindran, 2017). Ethical approval was obtained from Sree Chitra Tirunal Institute for Medical Science and Technology, Trivandrum, Kerala (IEC Ref No: SCT/IEC/913/May 2016).

The interview schedule for the cross-sectional survey included a number of open-ended questions and recorded verbatim the responses by women. These included:

a) Please explain your experience of the postpartum period as a GDM mother? (overall wellness, breast feeding, diet, emotional status)

b) Did you get any specific instruction about postpartum screening for diabetes from any of your health care providers? If yes, what were you told?

c) (If the woman had said that she did not undergo postpartum screening) What are the main difficulties you experienced to go to a laboratory for doing postpartum screening for diabetes?

The author conducted these interviews during 2016 and lasted between 42 and 92 minutes. They were digitally recorded with permission from interviewees. Written informed consent was obtained from all interviewees.

From this larger sample, we purposively selected responses by 15 women, in such a manner as to have representation from diverse socioeconomic backgrounds and from among those who had delivered in private and public health care settings respectively.

Interviews were transcribed verbatim and checked for accuracy. Deductive coding was undertaken keeping in view the objective of identifying obstacles and barriers to postpartum diabetes screening by women. A priori themes had been identified from the quantitative study, and we added to these, as new themes emerged from our codes. In the findings below we present quotes to illustrate our themes.

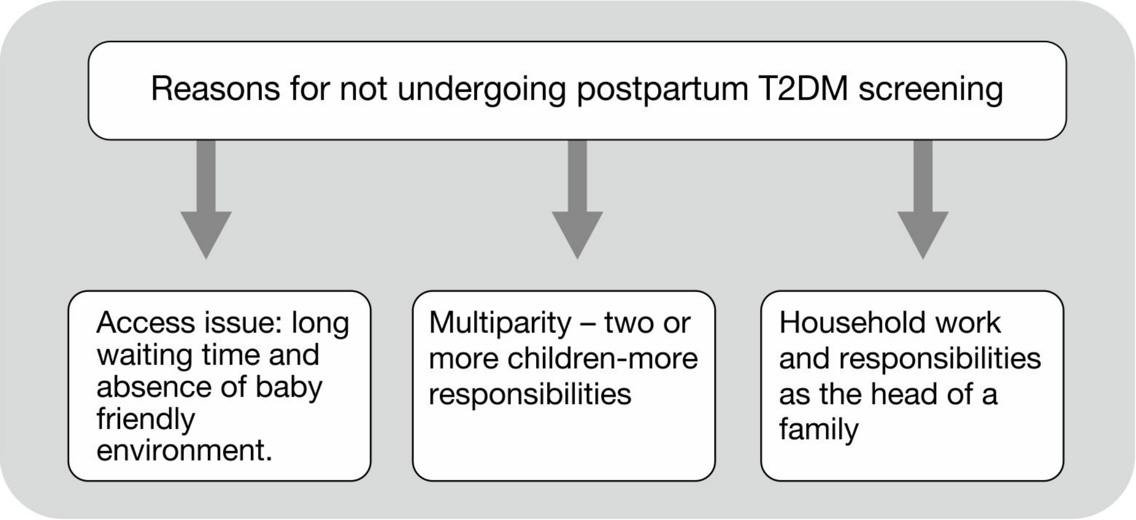
Results

Out of the 15 women whose responses were included in this study, six (40 per cent) were multiparas with more than three children, and above 30 years of age. Five women (33 per cent) had two or three children and 21-25 years of age, and three (20 per cent) women had one child and belonged to the same age group. One woman was less than 20 years old and had delivered her first child. Eleven of 15 women were wives of men who worked in 'Gulf' countries and were effectively the heads of their households.

Five themes emerged from the coding of the transcripts. These were: inadequate instructions from the healthcare provider who attended the pregnancy and delivery; health services related barriers; perceived difficulties of the oral-glucose-tolerance-test; lack of time owing to multiple roles as mothers and home-maker; and postponing the screening but unable to specify a reason for it. Of these, health-provider and services -related barriers and lack of time owing to multiple responsibilities were the most often- stated barriers.

Inadequate instructions from the healthcare provider attending pregnancy and delivery: According to the women, they did not often receive specific instructions from their attending-obstetrician on the consequences of GDM. A majority of the women were informed by the providers that GDM would subside after delivery. They were told about postpartum screening for T2DM only at the time of discharge from the health facility after child delivery, without an explanation as to why they had to undergo the test. Participants stated that they were not told that due to their history of GDM, they were at a higher risk of diabetes mellitus in the future. They knew that they had a postpartum follow-up visit scheduled with their obstetrician and thought of the screening as merely another test that the doctor had prescribed. According to one of the women: “The doctor didn’t tell me these things (that you may develop diabetes later on) … She only told me that my gestational diabetes would subside after the delivery.”

Figure 1: A Priori Thematic Framework Adopted



Barriers related to health services

Postpartum screening was rendered difficult by a number of health services-related barriers. One of these was the long queues and waiting time.

> “In the mornings, nearly 30-40 patients will be waiting for the lab test in the laboratory nearby. For me, it is difficult to wait outside the laboratory for that long, especially with the baby.”

The absence of a baby-friendly environment in the diagnostic centres and in health facilities, with no spaces or a room with privacy for breastfeeding, made the screening a difficult task.

The lack of breastfeeding facilities become especially challenging when the diagnostic centre is not close by:

> “It takes nearly 1 hour to reach the laboratory. After that, I have to wait with the baby … the baby gets restless. There are no private rooms to feed the baby in the lab.”

One of the participants told us that she was planning to get tested only after she had begun to wean her baby because of these difficulties. Leaving the baby behind at home to go for the screening, is not an option for many mothers who have no one who will take care of the newborn.

Perceived difficulties with the oral-glucose tolerance-test

For some of the women, the testing process was a dissuader. For example, one woman said that she was nauseated by the sweet solution that she had to consume and having to wait for a further two hours on an empty stomach was unthinkable. Another woman was afraid of the needle puncture.

> "I thought that the TT (tetanus toxoid) injection, needle puncture for IV (intra-venous) drips and all that would be over after the birth of my baby. I don't want to repeat all these painful procedures for the sake of screening for blood sugar. "

Lack of time owing to multiple roles as mothers and homemakers

A substantial proportion of GDM-affected women in the study area had husbands working abroad, mainly in countries of the Gulf. The women had to look after the spouse's elderly parents and shoulder all the family responsibilities. One of the participants said

"My husband is an electrician in Oman. He has a 62-year-old father and 59-year-old bed-ridden mother. I have to do all the household work and take care of the baby, when my older children are away in school. No time in a day to go to the lab for screening."

According to another woman with four children,

> "My first pregnancy was the biggest celebration ever in my life. But for subsequent pregnancies, there is nobody to take care of my older children. So immediately after the delivery, I have to get back to my familial responsibilities as a caretaker of my baby, a nurse for my aging parents, a caring father as well as loving mother of my older children, domestic worker and finally financial manager of the family (handling the bank account to which my Gulf-employed husband sends money)."

Even those who were aware of the importance of screening and wanted it done, could not find the time to get screened.

For example, a woman with three children told us that she was aware of the need for postpartum screening for diabetes and of her higher risk for T2DM. She was unwell and had to be on bed rest at home for the first three months after delivery. With her routine household tasks and care of her small baby, and also having to look after the older school-going children, she found it difficult to find time to go out and check for blood-sugar.

Another woman, a teacher in a private English Medium school, and a mother of two children, wished to undergo the lab investigation.

> "I conduct home tuitions for English and Social Sciences at 5 PM evening every five days of a week. I need to leave home for work at 8 am, after cooking breakfast for my children and mother-in-law, and also have to drop out my elder one in the Kindergarten. When will I get the time to do the lab investigations? My husband who works abroad brought a glucometer. My elder one damaged it."

It seemed to us that not going for postpartum T2DM screening was not just a matter of lack of time due to multiple roles, but also the tendency to consider their own needs to be of a lower priority. One respondent said this explicitly:

> "I am a mother. I should give priority to my family's needs. Only then can I think of my needs. That is the beauty of being a mother. I have an option to postpone my needs, but I cannot neglect my children. My mother taught me like that."

Postponing screening but unable to specify a reason

Some mothers could not explain the exact reason why they failed to go for postpartum screening for diabetes. One of the women said that she was aware of the consequences of failing to undergo screening and often worried about it. Another woman told us

> "They prescribed me a blood test after my second delivery … I am thinking about that, but haven't gone. I keep thinking I will go."

So here we can see the gap between intention and action.

Discussion and Conclusions

Among women with a history of GDM, timely screening and follow up were delayed owing to both, service delivery-related reasons and internalized gender roles. Our findings having a great deal of similarity to those by Rafii, Rahimparvar, Mehrdad and Keramat, (2017a) among Iranian women with a history of GDM.

Not receiving adequate guidance from the obstetrician about the importance of postpartum diabetes screening was an important reason for failure to go for screening among our study participants. Previous studies from India and elsewhere, have observed the same (Shah, Lipscombe, Feig, & Lowe, 2010, Kim et al., 2006, Tandon, Gupta, & Kalra, 2015). Seshiah (2015) suggested that there was an opportunity to carry out postpartum screening when the mothers attended health facilities for immunization of their babies. The vast majority of our participants revisited the hospital where they had delivered the baby, for getting their babies vaccinated. However, this again was a missed opportunity for carrying out screening for T2DM. Education of healthcare providers, especially obstetricians, on guidelines for postpartum screening and ensuring the implementation of these guidelines would go a long way towards improving timely postpartum screening rates.

In the absence of clear instructions from the treating obstetrician, women believed that the problem had been resolved once the baby was delivered. Although a majority reported symptoms of pain, myalgia, backache, fatigue, they believed these to be an after-effect of delivery and it did not occur to them that some of these may be symptoms of uncontrolled blood glucose level. It is therefore very important to provide information to women experiencing GDM on the signs and symptoms of uncontrolled blood glucose levels in the postpartum period, on experiencing which, they should seek medical attention.

Even though laboratories were available in the urban and semi-urban areas in the study district, access to laboratory services was constrained. The lack of a baby-friendly environment with privacy for breastfeeding in health facilities as well as in stand-alone laboratories is a significant barrier. Also, mothers with newborns could be triaged to be tested as soon as they arrive, rather than wait in a long queue along with others. These are simple measures that do not involve significant additional costs.

Another major barrier to postpartum screening for diabetes was women's heavy workload and absence of childcare support. Mothers whose husbands are employed in gulf countries faced many additional barriers. They had no one to lend a hand with the burden of day to day responsibilities, no one to consult regarding their healthcare needs, and no one to share their concerns and feelings with. Balancing the household budget within the monthly transfers received from their husbands was also a challenge. The vast majority of the mothers we interviewed had their husbands living abroad and appeared to be feeling alone and stressed.

A combination of limited understanding about the health problem and too many demands on their time and energy appeared to lead to a situation where there was a huge gap between intention to undergo screening and acting to make this happen. This gap was termed ‘procrastination’ in a study from Iran, which identifies this as the major underlying barrier to timely postpartum screening for diabetes (Rafii et al., 2017b). A meta-synthesis on barriers to breats-cancer screening also reported procrastination as an important factor that deterred women from availing breast-cancer screening (Azami-Aghdash et al., 2015).

In addition to interventions such as health-provider education; facilities for breast-feeding and triaging to give priority to mothers with newborns in diagnostic centres and health facilities, the following are a few simple steps that the public health services could take, to prevent the failure by women with a history of GDM to undergo timely postpartum screening for T2DM.

The Accredited Social Health Activist or ASHA could, during their routine postpartum visits, inform women with a history of GDM on the importance of postpartum screening for T2DM, and also send them reminders to ensure that the women undergo timely screening. The ASHA would be best-placed to follow-up subsequently to find out about the results of the test and action to be taken, and also advise and provide support on diet, physical activity and breast-feeding. A family-centred approach may be adopted to increase the family’s awareness on the need for follow-up care and routine monitoring following a GDM- pregnancy. The test and subsequent follow-up could be Primary Health Centre-based, rather than based in the secondary or tertiary public or private health facility, so as to be cost-effective and to minimize loss to follow-up.

Acknowledgement

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Gender Equity as a Dimension of Progress Towards Universal Health Coverage

Evidence from India's 71st Round National Sample Survey

Alok Ranjan[1], Adithyan G. S.[2], Daksha Parmar[3]

Universal Health Coverage (UHC) has emerged as a major health policy discourse across the world. Its proponents claimed it as the third grand transition in health after demographic and epidemiological transitions, whereas others have called it "old wine in a new bottle." UHC aims that everyone irrespective of their socio-economic status or gender should have access to essential healthcare facilities without facing any financial hardships. Equity is considered to be the central epithet in any UHC model, and in the Indian context, gender equity is a critical factor in the quest for achieving UHC.

This study aims to explore progress towards UHC in the dimensions of access and financial protection in India, and differentials in these by sex.

The current study is based on India's recently released data from the 71st Round of the National Sample Survey (NSS), 2014. The survey covered 65932 households (rural: 36480, urban: 29452) in India which included 3,33,104 individuals (men: 1,68,697 women: 1,64,407). Healthcare utilization, hospitalization rate, the proportion of the ailing population (PAP), insurance coverage, out of pocket expenditure (OOPE), catastrophic health expenditure (CHE) and impoverishment were calculated from the data set. By disaggregating the data set by sex, all the above indicators were analyzed through a gender lens. Various other equity dimensions (geographical location, caste, and economic category) were also analyzed in the sex-disaggregated data set. Descriptive statistics were used as the main data analysis technique.

Both, the hospitalization rate and the proportion of ailing population was higher for females as compared to males. The female hospitalization rate (per 100 population) was 3.1 as compared to 2.9 for male, and the proportion of the ailing population (PAP) per 1000 females was 110 as against 87 for males. There were significant inter-state variations. For instance, the hospitalization rate for males was higher than for females in states like Haryana, Maharashtra, Andhra Pradesh and Kerala. Public healthcare utilization for in-patient care was higher for women (50 per cent) than for men (37 per cent), and this pattern was consistent across all social groups and income quintiles. Insurance coverage was almost equal (women: 15.5 per cent, men: 15.0 per cent) for both men and women, but out of pocket expenditure (OOPE) was higher for men (Rs. 18,843) than for women (Rs. 11,251). Underlying many of the observed sex-differentials may be gender-related factors such as lower resource allocation within the household for female members.

In the current UHC discourse, sex/ gender is one of the important equity differentials which varies across the different States of India. This differential significantly increases for women belonging to lower socio-economic status. Public health facilities are major service providers for women, which is not the case for men. This signifies the importance of strengthening public health institutions in the country in its quest for achieving UHC.

Keywords : Universal Health Coverage (UHC), Gender, Financial Protection, Access

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As the world moves from Millennium Development Goals (MDGs) to Sustainable Development Goals (SDGs), Universal Health Coverage (UHC) has taken a central position in policy discourses (Vega, 2013). "Universal health coverage means all people receiving the health services they need, including health initiatives designed to promote better health (such as anti-tobacco policies), prevent illness (such as vaccination), and to provide treatment, rehabilitation and palliative care (such as end- of- life care) of sufficient quality to be effective while at the same time ensuring that the use of these services does not expose the user to financial hardship" (World Health Organization [WHO], 2015). MDGs were criticized for not considering equity while measuring the progress (Gwatkin, 2002), hence post MDGs, the agenda is committed towards equity, and is embodied in the acknowledgement that the future development agenda must "leave no person behind" (United Nations [UN], 2013). Thus, those who have higher needs should be able to receive more services (Witter, Govender, Ravindran, & Yates, 2017). Ideally, UHC is conceptualized to provide the full spectrum of comprehensive, quality health services to everyone irrespective of their socio-economic or gender status without facing any financial hardships (Boerma et al., 2014). Even though many equity dimensions hinder India's pursuit towards achieving UHC, 'gender' is highly significant and important to examine.

Indian society is diverse and stratified by caste, class, ethnicity, religion, and gender. The relations between men and women in India are highly unequal with significant power differentials (UN, 2009). Gender refers to structural inequalities marked by unequal access for women and men to material and non-material resources (Sen, George, & Ostlin, 2002). Inequalities coupled with increased poverty and gender bias results in creating multiple barriers to women's well-being (Larson, George, Morgan, & Poteat, 2016). Numerous studies have documented the influence of gender-based barriers on women's and girls' access to healthcare services (Barros et al., 2012, Houweling, Ronsmans, Campbell, & Kunst, 2007, Molina, Nakamura, Kizuki, & Seino, 2013). These gender-based obstacles can be either restriction on the mobility of women and girls to access the healthcare institutions, access to sources of income or in decision making in the household (WHO, 2011). In many cases, women suffer ill-health silently due to the way in which they are socialized, and pay less attention to their health because of the competing demands of work and care (UN, 2009). Other gender-based vulnerabilities in the Indian context such as, low marriage age, pregnancy at a younger age, repeated pregnancies and limited access to modern contraceptives results in increased morbidity and mortality for women (Raj, Saggurti, Balaiah, & Silverman, 2009). It is also to be noted that women have a wide range of health needs, apart from those related to pregnancy and maternal health (WHO, 2009).

In the World Economic Forum's (WEF) Global Gender Gap Report, 2017, India slipped 21 places to occupy the 108th position among 144 countries, which is among the lowest ranked nation in terms of gender equity (World Economic Forum[WEF], 2017). If this present trend continues, India will not be able to accomplish its SDG targets with regards to maternal health and women's empowerment.

Considering India's large landscape and cultural diversity, there is considerable variation in gender bias across various States and social groups. Further, the intersection of gender with other social stratification existing in the Indian society can exacerbate access and utilization of care (Ravindran, 2012). This can result in increased vulnerabilities to women belonging to different social groups. Furthermore, women and girls from a low socio-economic background and rural areas are more vulnerable to barriers to accessing healthcare than those from higher socio-economic status and urban areas (UN, 2006). For instance, a woman from Scheduled Caste (SC) community faces a double disadvantage (of being a woman and being a woman from an SC community) due to the patriarchal and caste system prevailing in the country (Mamgain, 2014). Hence, reduction in gender inequity is inevitable for good health and well-being of women in India (Witter et al., 2017).

India has one of the most commercialized health care system in the world (Bisht, Pitchforth, & Murray, 2012). It is one of the countries where the proportion of out of pocket expenditure on health is among the highest (Berman, Ahuja, & Bhandari, 2010). Out-of-pocket expenditure on healthcare impoverishes a large section of the population (Sundararaman, Mukhopadhyay, & Muraleedharan, 2016). Also, low public investment in health is the quintessential characteristic of India's health care financing. The under-funding of public health facilities and unregulated private health sector with a huge cost of care has led to many challenges in the delivery of effective health services to the population particularly those belonging to the marginalized section of the society including women (ibid). However, given the rising costs of medical care, it is likely that women may find it difficult to access the formal care and may thus experience high untreated morbidity (Sen, Iyer, & George, 2002).

In India, there are few studies which have explored the gender dimensions of access and financial protection in the context of UHC (Witter et al., 2017). The discussion of UHC in the Indian context is also timely considering the poor access to affordable and quality healthcare as well as the inequities existing in healthcare scenario. The current study has been conceptualized on the three-dimensional UHC Cube, proposed by WHO and World Bank (WHO, 2010a). Three dimensions of the UHC cube are; 1) Population- who is covered, 2) Services-which services are covered, and 3) Direct cost: the proportion of cost covered. In this context access and financial protection are the two most important components. In order to reduce health inequity, many governments have targeted the health system to improve access to healthcare and to distribute more equitable healthcare across the population (Allin & Masseria, 2009). Also, among various health systems reforms (governance, healthcare financing, health workforce, medical products and technology, information and research, and service delivery), WHO identifies that health financing system reform will have the greatest impact in improving equity (WHO, 2010b). The present study attempts to explore access and financial protection by sex-disaggregated analysis and also its interaction with other social stratifiers such as caste, class, rural-urban location and region.

Methods

This study is based on the 71st Round of National Sample Survey (NSS) data which was collected between January 2014 to June 2014, by National Sample Survey Office (NSSO), Ministry of Statistics and Programme Implementation. It was a cross-sectional survey which used a stratified sample design with two stages. In the first stage, census villages and urban blocks were sampled as first stage units for rural and urban areas respectively. The household was the second stage unit. A total of 65,932 households (Rural: 36,480: Urban: 29,452) were surveyed for the whole of the Indian Union, and 3,33,104 individuals (Men-1,68,697; Women-1,64,407) participated in the survey. Apart from socio-demographic information, the survey collected information related to inpatient care (in the last 365 days), outpatient care (in the last 15 days), nature of the ailment, types of service providers, and cost of care. The survey also collected information related to maternal health and geriatric care.

In the present study, we focus on the use of disaggregated data on sex and highlight the differences and similarities between men and women from a gender perspective rather than the biomedical perspective. Interaction of gender inequity was analyzed with other social stratifiers in the society based on caste, class (income) and geographical location from an intersectional perspective. Further, our analysis also attempts to bring in the discussion on gender-based questions on financial access and decision making power in access to healthcare (Morgan et al., 2016). Access and financial protection were considered. Healthcare utilization, hospitalization rate, and PAP were considered as access indicators for the study (Aday & Andersen, 1974), whereas insurance coverage, out-of-pocket expenditure (OOPE), Catastrophic health expenditure at 10 per cent threshold (CHE-10) and impoverishment were considered financial protection indicators (WHO, 2010b).

We categorized age into six groups: 0-5, 6-15, 16-30, 31-45, 46-60 and 60+ category. Social groups were categorized as Scheduled Tribes (ST), Scheduled Castes (SC), Other Backward Classes (OBC) and General Caste Category (GEN). Education was categorized as illiterate, up to the primary, up to secondary, and above secondary levels. The hospitalization rate was calculated based on the number of individuals who reported getting hospitalized (out of 100 individuals) in the last 365 days. The hospitalization rate for women was calculated after excluding hospitalization due to childbirth since it was considered as a wellness event. The proportion of the ailing population (PAP) in 1000 was calculated based on the number of individuals who reported getting out-patient treatment in the 15 days before the survey. Sub-centre, ANM, ASHA, primary health centre, community health centre, mobile medical unit and public hospitals were categorized under public provider, whereas private doctor or clinic, and private hospitals were categorized under private provider for the analysis. Household's usual monthly consumption expenditure was used for generating income quintile (poorest, poor, middle, rich and richest) for the study. Household's usual annual consumption expenditure was calculated by multiplying household's usual monthly consumption expenditure by twelve. Out-of-pocket expenditure (OOPE) was calculated by adding transportation costs to the total medical expenditure and subtracting the reimbursement amounts. Catastrophic health expenditure at 10 per cent threshold (CHE-10) was calculated if OOPE in last one year was more than 10 per cent of the usual annual consumption expenditure of the household (Limwattananon, Tangcharoensathien, & Prakongsai, 2007, Prinja, Kanavos, & Kumar, 2012). For calculation of impoverishment, Planning Commission Report, 2014 was used (Planning Commission, 2014). According to this, if household's usual per capita monthly expenditure was less than Rs. 972 in rural areas and Rs. 1407 in urban areas, it was considered as below poverty line.

Simple descriptive statistics were used to calculate hospitalization rates, the proportion of the ailing population (PAP), catastrophic health expenditure at 10 per cent threshold (CHE-10), impoverishment and utilization of healthcare from a public or private provider. STATA version 12 software was used for analysis of the dataset.

Results

The results section of this study is organized into two broad headings; 1) Access, and 2) Financial protection.

Access

For this study, access was examined through hospitalization rate for inpatient care, and proportion of the ailing population (PAP) per 1000 population for out-patient care.

Hospitalization Rate

The overall hospitalization rate in India was 3.0 (per 100), and it was slightly higher for women (3.1, excluding childbirth) when compared to men (2.9) (Table 1). Out of the 36 States and Union Territories (UT) in Indian Union, hospitalization rate was higher for women in 24 States and UTs. In ten States and UTs (Haryana, Delhi, Nagaland, Tripura, Meghalaya, Dadra& Nagar Haveli, Maharashtra, Andhra Pradesh, Goa and Kerala) hospitalization rate for men was higher than for women. This difference was highest in Dadra& Nagar Haveli and Andhra Pradesh where men's hospitalization rate was 55 per cent and 24 per cent higher compared to women, respectively. Among all the States, Kerala had the highest (9.2), and Meghalaya and Assam reported the lowest (1.2) hospitalization rate in the country.

Table 1: Hospitalization Rate (Per 100) And PAP (Per 1000) In States of India

		Hospitalization Rate			PAP			N
	State	Men	Women	Total	Men	Women	Total	
1	Jammu & Kashmir	2.2	2.9	2.5	49	70	59	6788
2	Himachal Pradesh	3.9	4.7	4.3	57	100	79	4392
3	Punjab	2.5	3.2	2.9	133	202	166	7797
4	Chandigarh	1.9	2.6	2.2	130	140	134	6026
5	Uttaranchal	2.0	2.0	2.0	70	100	84	3177
6	Haryana	3.1	2.8	3.0	58	67	62	8040
7	Delhi	2.6	2.3	2.5	40	40	40	5424
8	Rajasthan	2.4	2.6	2.5	55	70	62	16655
9	Uttar Pradesh	1.8	2.4	2.1	66	80	73	47083
10	Bihar	1.6	2.2	1.9	53	63	58	17596
11	Sikkim	1.3	2.4	1.8	34	49	41	2100
12	Arunachal Pradesh	3.0	3.1	3.1	81	95	88	2994
13	Nagaland	1.4	1.3	1.4	39	17	28	2651
14	Manipur	2.1	2.3	2.2	20	18	19	7187
15	Mizoram	1.9	2.7	2.3	29	27	28	3864
16	Tripura	4.3	4.2	4.2	29	49	39	5977
17	Meghalaya	1.3	1.1	1.2	26	35	31	4380
18	Assam	1.1	1.3	1.2	25	43	33	11411
19	West Bengal	3.4	3.5	3.4	142	193	167	22783
20	Jharkhand	1.4	1.7	1.5	52	73	62	8318
21	Odisha	2.9	3.1	3.0	89	117	102	11576
22	Chhattisgarh	2.1	2.3	2.2	44	37	41	874

23	Madhya Pradesh	2.3	2.7	2.5	53	64	58	19131
24	Gujarat	3.2	3.2	3.2	90	103	96	15211
25	Daman & Diu	3.3	4.5	3.8	36	336	165	537
26	D & N Haveli	4.5	2.9	3.7	89	126	106	641
27	Maharashtra	3.6	3.4	3.5	70	82	76	27124
28	Andhra Pradesh	4.7	3.8	4.3	165	175	170	10636
29	Karnataka	3.4	3.5	3.5	85	111	98	14727
30	Goa	3.8	2.7	3.3	190	171	181	916
31	Lakshadweep	4.3	7.0	5.5	179	245	208	836
32	Kerala	9.2	9.1	9.2	292	323	308	11229
33	Tamil Nadu	4.6	4.4	4.5	140	188	164	16090
34	Puducherry	4.6	4.7	4.6	242	171	207	1117
35	A & N Islands	4.3	3.6	4.0	127	235	178	1234
36	Telengana	3.4	3.6	3.5	83	111	97	6582
	Total	2.9	3.1	3.0	87	110	98	333104

Overall hospitalization rate in rural India (2.8) was lower than in urban (3.5) areas. However, the difference in hospitalization rate between women and men was relatively higher in urban areas (12 per cent) compared to rural areas (7 per cent) (Table 2). Across various social groups, hospitalization rate was highest among the general category (3.3) and lowest among the ST category (2.1). The difference in hospitalization rate between SC (3.0), OBC (3.1) and the general caste category (3.3) was relatively smaller compared to the difference between ST category (2.1) and all other social groups. Across all social groups, hospitalization rate in women was higher than for men (Table 2).

In both rural and urban India, hospitalization rates increased significantly from the poorest to the richest sections of society. The poorest section of rural India had the lowest (1.8) hospitalization rate among all. On the other hand, it was highest (5.0) in the richest section of rural India. Similarly, in urban areas, hospitalization rate in the richest section was 1.9 times higher than among the poorest. In all economic classes, hospitalization rate in women was higher than for men. However, in the rich population of rural areas men had marginally higher hospitalization rate compared to women.

Table 2: Hospitalization Rate and PAP Across Different Equity Differentials by Gender

	Hospitalization			PAP		
Total	**2.9**	**3.1**	**3.0**	**87**	**110**	**98**
Rural-urban divide						
Rural	2.7	2.9	2.8	80	99	89
Urban	3.3	3.7	3.5	101	136	118
Social Group						
ST	2.0	2.2	2.1	65	73	69
SC	2.9	3.2	3.0	79	106	92

OBC	2.9	3.1	3.1	87	110	98
GEN	3.2	3.4	3.3	99	125	111
Economic Class						
Rural						
Poorest	1.6	2.0	1.8	62	68	65
Poor	2.1	2.3	2.2	70	88	79
Middle	2.5	2.6	2.6	72	95	83
Rich	3.5	3.4	3.4	94	112	103
Richest	4.8	5.2	5.0	120	153	136
Urban						
Poorest	2.3	2.6	2.5	72	94	83
Poor	3.3	3.4	3.4	94	127	110
Middle	3.7	4.4	4.0	105	158	130
Rich	3.4	4.1	3.7	117	154	134
Richest	4.5	5.0	4.7	143	182	161

Proportion of ailing population (PAP)

In India, 98 people reported ailing (per 1000) in last 15 days due to any ailments (Table 2). PAP for men was 87 whereas it was 110 for women. In most States, PAP for women was higher than for men except in six States/UTs (Nagaland, Manipur, Mizoram, Chhattisgarh, Goa, and Puducherry). Kerala (308) reported the highest PAP whereas it was least for Manipur (19).The PAP reported by women was least in Nagaland (17) and maximum from Daman & Diu (336), followed by Kerala (323) whereas, for men population, it was least from Manipur (20) and maximum from Kerala (292) (Table 1)

The PAP reported in rural and urban areas were 89 and 118 respectively. As in the case of hospitalization, the difference between women and men in PAP was higher for urban areas compared to rural areas. PAP was highest for the general caste category (111) and lowest for ST population (69). In both rural and urban areas, PAP significantly increased from the poorest to the richest sections of the population. In rural areas, PAP increased from 65 (poorest) to 136 (richest), whereas in urban areas it increased from 83 (poorest) to 161 (richest). In all sections of the society, PAP was higher for women when compared to men (Table 2).

Healthcare utilization

Healthcare utilization was another measure to evaluate access. In this study, the focus of healthcare utilization was broadly categorized as those utilizing the services of the public or the private health care provider either for inpatient or outpatient care.

Hospitalization (In-patient care): In India, 45 per cent of total hospitalization was in public facilities (Table 3). This proportion was higher for women. Of all women who were hospitalized in the one year preceding the survey, 50 per cent went to the public provider. On the other hand, only 37 per cent of the male population went to the public provider. The proportion of women who went to public facilities was higher in rural (56 per cent) areas compared to urban (37 per cent) areas. A similar trend was seen for the male population, with a relatively larger proportion going to a public facility in rural areas (39 per cent) when compared to urban areas (32 per cent).

Examining across various social groups, 68 per cent of the ST population utilized public facilities for hospitalization during the one year preceding the survey, whereas among the general caste group, only 39 per cent went to public facilities. Among the male population, 56 per cent of STs and 33 per cent of general caste populations went to a public facility, but for the female population, this proportion was 73 per cent and 43 per cent respectively.

In rural areas, three in four (74 per cent) women from the poorest quintile utilized public facilities, whereas for men this proportion was two in four (56 per cent). In the richest income quintile (rural) 26 per cent of men and 33 per cent of women utilized public health facilities. In the richest income quintile (urban) only 16 per cent (men-17 per cent, women-14 per cent) patients utilized the public facility. Interestingly, in the upper two (richest and rich) quintiles in urban areas, utilization of a public facility is higher in men when compared to women, but the pattern is the other way around in all the other economic classes. The utilization of public health facilities in the poorest urban quintile was 3.3 times (men- 2.5, women-3.8) higher when compared to the richest income quintile.

Table 3: Public Healthcare Utilization Across Different Equity Variables by Gender

	Public healthcare utilization for inpatient care (hospitalization)			Public healthcare utilization for out-patient care (ambulatory care)		
	Men	Women	Total	Men	Women	Total
Total	**36.9**	**50.0**	**45.4**	**24.4**	**26.5**	**25.5**
Rural-urban divide						
Rural	39.5	56.1	50.4	26.5	29.9	28.3
Urban	32.1	36.8	35.0	20.8	21.5	21.2
Social Group						
ST	55.6	72.6	67.6	45.8	50.0	47.9
SC	48.8	61.3	57.0	30.1	30.6	30.4
OBC	32.3	45.3	40.7	24.6	27.0	25.9
GEN	32.8	42.9	39.1	17.6	20.1	19.0
Economic Class						
Rural						
Poorest	54.9	74.0	68.9	29.8	37.3	33.5
Poor	54.5	64.8	61.7	33.0	32.9	32.9
Middle	41.5	58.7	53.1	26.2	30.1	28.3
Rich	36.5	52.1	46.1	24.3	24.3	24.3
Richest	25.9	33.2	30.2	22.5	28.4	25.8
Urban						
Poorest	43.2	55.6	51.8	29.1	28.0	28.4
Poor	39.6	44.6	42.7	26.5	25.4	25.8
Middle	33.4	34.0	33.8	18.1	24.4	21.7
Rich	25.8	22.6	23.9	19.7	16.7	18.0
Richest	17.1	14.4	15.6	13.1	14.0	13.6

Outpatient care (ambulatory care): In India, one fourth (25 per cent) of the total out-patient (OP) care happened in public facilities (Table 3). This proportion was almost the same for men (24.4 per cent) and women (26.5 per cent). Like hospitalization, the proportion of OP care in public facilities was higher in rural (28 per cent) areas compared to urban (21 per cent) areas. Across social groups, utilization of public health facility was highest in ST population (men-46 per cent, women-50 per cent) and lowest in general caste population (men-18 per cent, women-20 per cent). There is a clear trend of higher public facility utilization among lower socio-economic categories. Also, utilization of public health facilities was higher among women than among men across all stratifiers.

When examining income quintiles, the gap between poorest to richest population was not so wide as was the case for hospitalization. In rural areas, utilization of public sector facility in the poorest quintile was 33 per cent (men-30 per cent, women-37 per cent) whereas in the richest quintile it was 26 per cent (men-23 per cent, women-28 per cent). In urban areas, surprisingly, utilization of public facilities among poorest and poor income quintile was marginally higher for men in the bottom two quintiles. In spite of poverty, two-thirds of OP care for the poorest population happened outside the public facility.

Financial protection

Overall insurance coverage in men and women population was equal in India. This is because of nature of insurance schemes in India, where the unit of enrollment is the household. Overall 15 per cent of India's population reported coverage under any insurance schemes. A majority of those covered by insurance were enrolled in publicly- funded insurance schemes. Across various social groups, insurance coverage was higher in ST/SC population compared to the general population which is a good indication, since the projected aim of the public insurance is to provide financial protection for the most marginalized sections of the society. On the other hand, across income quintiles, and more so in urban areas, insurance coverage was highest for the richest quintile (rural-20.2 per cent, urban: 36.1 per cent) and lowest in poorest quintile (rural-12.1 per cent, urban 9.8 per cent). This distribution of insurance coverage across income quintile was inequitable. This trend was similar for men and women. The insurance coverage in India covers only hospitalization cases and does not provide any financial protection for outpatient care (ambulatory care). The present study looks at out- of -pocket expenditure (OOPE), catastrophic health expenditure (CHE) and impoverishment in hospitalization. All these calculations were done for hospitalization alone since it is covered under insurance coverage.

On an average, Rs. 11,251 was spent out of pocket per hospitalization episode by women whereas men spent 67 per cent higher than this. The OOPE per hospitalization was higher in urban (Rs. 15,478) area compared to rural (Rs. 9292) counterpart. But the proportional difference in OOPE for men against women was higher in the urban area compared to rural area. For instance, in the rural area, OOPE by men was 49 per cent higher than women whereas in the urban area this was 79 per cent.

Across various social groups, OOPE increased from the ST population step-wise, through SC, OBC and the general caste category population. But the differences between men and women varied. For instance, among the ST population men had a 45 per cent higher OOPE compared to women whereas in the OBC and general caste categories the sex-difference was 73 per cent and 60 per cent, respectively.

The difference between men and women in OOPE was higher in rural areas than in urban areas across all income quintiles. For instance, in rural poorest quintile, the OOPE for men was 87 per cent higher than for women whereas among the urban counterparts it was 69 per cent higher for men. The difference in OOPE between men and women decreased from the poorest to the rich quintile. However, it then increased for the richest quintile. For instance, the difference between men and women in OOPE in rural areas decreased from 87 per cent (poorest) to 46 per cent (rich) and then increased to 73 per cent for richest quintile. In urban areas too, the difference in OOPE decreased from 69 per cent (poorest) to 17 per cent (rich) but again increased to 36 per cent for the richest population.

Table 4: Insurance Coverage and OOP Across Equity Indicators Disaggregated by Sex

	Insurance coverage		OOP per hospitalization		Proportion of household facing CHE at 10 per cent threshold	Proportion of household facing impoverishment	
	Men	Women	Men	Women		Before OOPE	After OOPE
Total	15.0	15.5	18843 (18196-19490)	11251 (10956-11546)	39.7	27.1	39.9
Rural-urban divide							
Rural	13.7	14.4	16593 (15797-17388)	9292 (8965-9620)	39.0	27.4	40.4
Urban	18.1	17.9	23097 (21995-24199)	15478 (14914-16042)	40.9	26.6	38.8
Social Group							
ST	18.5	19.7	10273 (8915-11631)	7054 (6343-7765)	25.8	42.8	52.3
SC	13.7	14.2	12140 (11350-12931)	7908 (7487-8328)	35.7	35.8	47.7
OBC	15.4	15.7	19290 (18318-20261)	11133 (10664-11602)	41.2	26.3	39.4
GEN	14.3	14.6	23968 (22501-25435)	15000 (14356-15646)	43.6	18.2	31.9
Economic Class							
Rural							
Poorest	10.9	12.1	10666 (9697-11636)	5712 (5249-6176)	36.2	100.0	100.0
Poor	11.2	11.6	11005 (9800-12210)	7326 (6717-7935)	34.4	43.5	76.1
Middle	12.4	12.3	12288 (11354-13223)	7520 (7116-7924)	37.3	0.0	20.3
Rich	16.8	18.1	14253 (13180-15325)	9789 (8721-10856)	38.4	0.0	10.4
Richest	19.4	20.2	26901 (24436-29367)	15486 (14677-16294)	47.1	0.0	5.4

Urban							
Poorest	9.6	9.8	13567 (12360-14775)	8019 (7488-8549)	37.9	100.0	100.0
Poor	12.5	12.5	16856 (15261-18450)	11031 (10380-11683)	39.3	20.2	53.4
Middle	18.9	18.2	20869 (18412-23327)	13624 (12823-14424)	43.6	0.0	10.8
Rich	22.3	24.1	29479 (26230-32727)	25203 (22980-27426)	45.9	0.0	9.4
Richest	36.7	36.1	35930 (32540-39320)	26309 (24003-28615)	38.0	0.0	4.0

CHE-10 and impoverishment were calculated on household basis since the whole household faces financial hardship even if a single member of the household gets hospitalized. In India, out of total hospitalized households, 40 per cent faced CHE-10. This proportion was almost same for rural (39 per cent) and urban (41 per cent) areas. Across various social groups, the proportion of household facing CHE increased as we move from ST (26 per cent) households to general caste category (44 per cent). In rural poorest quintile, 36 per cent household faced CHE-10 whereas in rural richest quintile this figure increases to 47 per cent. Similarly, in urban areas too, 38 per cent of poorest households faced CHE-10 whereas in rich and richest section of the population this proportion increased to 44 per cent and 46 per cent, respectively.

In India, 27 per cent of households who had been hospitalized were below the poverty line even before spending on health. This proportion increased to 40 per cent after expenditure on health. The proportion impoverished was almost the same for rural and urban areas. Between the ST population and the general caste category, the proportion impoverished increased from 22 per cent to 75 per cent. Across various income quintiles, both in rural and urban areas, the proportion impoverished consistently decreased from poorest to richest quintile. Ironically, both in rural and urban areas, all households of the poorest quintile were already living below the poverty line before spending for health (Table 4).

Discussion

The paper mainly explores the access and financial protection aspect of UHC through an equity dimension by analyzing the sex-disaggregated dataset of NSS 71st rounds. Through the gender lens, gender inequities in healthcare in India in context of access and financial protection have been explored in the current study.

Access to healthcare and gender

Hospitalization rate and proportion of the ailing population (PAP) was considered as a proxy indicator of access. Overall, as compared to the 61st NSS rounds (2004), the hospitalization rate in India has increased by 42 per cent in 2014 with the largest share in the increase for the rural women

(Ministry of Statistics and Programme Implementation, 2016). In most states of the country and on an overall basis, the hospitalization rate and PAP were higher for women compared to men. Both gender and sex play an important role in influencing the hospitalization rate and PAP.

Studies across the world show a higher reporting of morbidity in women than among men. The plausible explanation could be: a) a higher burden of chronic conditions in women; b) men tend to suffer more from conditions which have fatal outcome, whereas women suffer from non-fatal conditions, or c) differences in reporting behaviour where women tend to be less stoic about their health and seek care more readily than men (Case & Paxson, 2005). The higher hospitalization rate for conditions other than child delivery and the higher PAP among women in India could be due to one or more of the above reasons.

The higher hospitalization rate among women may also be viewed against the backdrop of the health financing model (government-funded health insurance schemes; demand side) operating in the country to achieve UHC as well the implementation of Janani Suraksha Yojana (JSY) under the National Rural Health Mission (La Forgia & Nagpal, 2012). The effect of JSY cannot be taken into account in this paper since childbirth was not included while calculating hospitalization rate in this paper. With regard to government-funded health insurance, there is growing evidence of irrational drug use and diagnostics which also include unnecessary surgical procedures (Ahmed & Khan, 2010, Handa & Davis, 2006). For instance, a large number of unnecessary hysterectomies was reported in Chhattisgarh among the most vulnerable sections which are under the insurance scheme (Nandi et al., 2016, Nandi, Schneider, & Dixit, 2017). Since hysterectomy costs are among the highest of all procedures under government-funded health insurance schemes, insurance coverage may have been a driving phenomenon (Kurian, 2015). It also shows that in the absence of quality public health systems (supply side) existing in the country, health insurance as the mode of financial protection (demand side) may sometimes lead to unnecessary hospitalization for non-serious illnesses and unnecessary medical procedures (Parkhurst et al., 2005, Schneider & Gilson, 1999).

Macintyre et al., (1996) in their review concluded that “the whole topic of gender differences in health warrants frequent reexamination” where gender differences across one society or time cannot be generalized for another society or time (Macintyre, Hunt, & Sweeting, 1996). In a patriarchal society such as in India, gender-based discrimination is common, and quite often family members ignore the health problems of the women, and the men get the priority in case of any illness event (Fikree & Pasha, 2004). Most often because of the limited financial access and the lack of decision making power among women, it further exacerbates and widens the inequities in accessing health services. Hence this finding of higher hospitalization rate among women should be explored further through in-depth qualitative studies. However, in India’s pursuit towards UHC, there is an important need to ensure universal access because the existing gender inequalities and the power relations between men and women determine who has access and to what services (Ravindran, 2012).

Public health facilities were the major healthcare provider for women and lower socio-economic population during hospitalization. The proportion of women who utilized the public facility for hospitalization was 35 per cent higher than their male counterpart, and this proportion was found greatest among lower socioeconomic category. Among the higher socio-economic group, this difference still persisted. Hence, the public health facilities were the most acceptable, accessible and equitable health delivery system especially when it comes to women and socio-economically deprived communities. This has also been echoed by many other studies (Marriott, 2009, Sundararaman, Muraleedharan, & Mukhopadhyay, 2016). The present findings indicate the importance of strengthening public health systems in the context of India's quest to achieving UHC.

In ambulatory care, only one fourth (25 per cent) of the population came to a public facility for treatment, but in all social stratifications (rural-urban, caste and economic quintile) the proportion of women in public facility utilization was higher than that of men. However, in the richest quintile of urban areas, public healthcare utilization was higher for men compared to women. Further in-depth qualitative studies are needed to explore this relationship. However, of the population living below poverty line (poorest quintile), 67 per cent of rural and 72 per cent of urban individuals went to a private provider (include informal care too) where OOPE was very high. One of the important areas to reflect for public providers is about the quality of care. Public health facility was found more equitable in nature across all socio-economic groups compared to the private providers.

Financial protection and gender

In our study, insurance coverage for both men and women was equal since in most of the insurance schemes households are the unit of coverage. However, there are studies which show that there is gender dimension in insurance coverage. In many situations where there is a cap on insurance coverage for the household, the healthcare needs of women members of the household are neglected. Also, women members of the household find it considerably more difficult to utilize insurance coverage during hospitalization than do males members (Cerceau, 2012). There is growing evidence showing the ineffectiveness of government-funded insurance schemes in providing financial protection to lower socio-economic groups (Ghosh, 2010, Prinja, Chauhan, Karan, Kaur, & Kumar, 2017).

The OOPE was relatively much higher for men than for women across all socio-economic categories. This is one of the crude indicators of gender-based discrimination in society where households are willing to pay out more to men than to women. Often, women forgo their treatment due to helplessness and lack of financial accessibility which is difficult to capture in this indicator (Sen et al., 2002). Also, the relative sex-difference in OOPE in lower socioeconomic status was higher compared to the higher socioeconomic status population. This indicates that when resources are scarce, vulnerability for women is significantly higher when it comes to access to healthcare. A study by Saikia, Mordhvaj and Bora (2016) also revealed similar findings and pointed out that there is a strong practice of gender discrimination in healthcare spending on women. Though the short-term and major morbidity is higher among women as compared to men, the health care expenditure incurred was significantly lower for women than men (Saikia, Mordhvaj & Bora, 2016). They also observed that significantly lower amount of money is spent on women's health because of the dominant understanding that women's health is not as important as that of men's health and women compromise their own health needs in most instances by prioritizing the health of the male members since they are viewed as the main bread-winners of the household (Saikia, Mordhvaj & Bora, 2016). These findings further reinstate the existence of deep-rooted patriarchal structures in the Indian society. The present study provides empirical evidence for this finding.

Also, the chances of facing catastrophic health expenditure by household increases as the socio-economic status of the household increases. This phenomenon of lower incidence of catastrophic payments among poorer quintiles compared to the richer is seen in many countries (Gotsadze, Zoidze, & Rukhadze, 2009, Van Doorslaer et al., 2007). This can be explained by the fact that poor people simply do not use health services due to their inability to pay since most of them already live below the poverty line before payment for health expenditure (ibid). The often forgo their treatment due to poverty which leads to a vicious cycle of poverty and ill health. The rich use more services and then suffer adverse financial consequences linked to paying for care.

The study also shows that among the poorest income quintile (both urban & rural areas), the whole population is below the poverty line even before spending on health. Hence, while analyzing CHE, it should be interpreted along with the indicator of service coverage among poor. Another reason for high CHE-10 among the rich could be because most often hospitals (private) charge families to their maximum capacity as well as they differentially charge patients according to their economic status. These instances have been seen in recent times where the private sector charged a family heavily until they expressed their inability to pay (Perappadan & Kumar, 2017).

This study tried to provide empirical evidence to examine UHC from a gender perspective. However, we have provided mainly sex-disaggregated data and have inferred gendered reasons underlying these. The study has a few other limitations. Access and financial protection are multi-dimensional concepts which may not be adequately captured in the given study. To do so may require sophisticated modeling or detailed qualitative study. Catastrophic health expenditure and impoverishment were presented from a household's perspective and had no scope for sex-disaggregation. There were many interesting findings whose explanation was difficult to provide, and it will require further studies. For instance, higher public utilization by men in upper two quintiles of urban areas needs further probing. Regarding the data set also, there were certain precautions which need to be considered. This study was based on self -reporting which could be biased depending on the demographic and background characteristics of the respondents. The NSS-71st rounds also have not collected data among the third gender. Hence, addressing the health inequities among the third gender population is beyond the scope of the current paper. Finally, UHC as a concept is not just about financing healthcare services. There are multiple aspects of UHC which are not discussed in the present paper.

Conclusion

While access in the form of hospitalization rate and PAP was higher for women compared to men in India, OOPE for women was significantly lower than for men. This may be indicative of gender-based discrimination in a society where the family is willing to incur a much larger expenditure for the healthcare of its men, as compared to its women. The proportion of use of public health facilities was higher among women especially from the poor and vulnerable sections of society which shows that government intervention is desirable to make healthcare accessible to women of all socio-economic groups. The paper reiterates the importance of strengthening public healthcare in India's quest for achieving UHC.

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The authors declare that there is no competing interest.

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All authors contributed to study design, interpretation of result and to the writing of the manuscript. AR analyzed the data and AG, and DP verified the results. AR, AG, and DP drafted the first version of the manuscript. All authors read and approved the final version of the manuscript.

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Publicly Funded Health Insurance Schemes (PFHIS): A Systematic and Interpretive Review of Studies

Does Gender Equity Matter?

Rajalakshmi RamPrakash[1] and Lakshmi Lingam[2]

With the announcement of the National Health Protection Scheme in February 2018 by the Indian Government, the policy direction based on an insurance-based model of health financing as a panacea for all ill-health has become even more evident than in the past. This is surprising, given that the evidence on the positive impact of a publicly funded health insurance scheme (PFHIS) is equivocal. There are only a handful of reviews of studies on national and state level PFHIS on equity dimensions, and none of them have applied a gender lens.

The current paper aims to provide a systematic as well as an interpretive review of available literature on PFHIS in India by employing a gender and health equity lens. It aims to understand the evidence on gender dimensions in process indicators (awareness, enrolment, and utilization) and impact indicators (health expenditures and coping mechanisms) of PFHIS. It also aims to answer why we do not know enough about the gendered aspects of PFHIS given their existence for more than a decade.

Using PRISMA techniques, a total of 80 papers covering 17 specific states in India were reviewed to aggregate the evidence on gender differences. For the interpretive review, the same studies were critically reviewed to understand the nature of gender analysis and to uncover the reasons for the thin evidence emerging on gender equity in PFHIS.

Except on awareness where women fared low, there was no conclusive evidence on gender differences in enrolment and utilization. As most studies used households as units of analyses, gender differences in process and impact were difficult to assess. The exception was the vulnerability of female-headed households. Many sexual and reproductive health illnesses which cause out of pocket expenditures for women were not included in schemes and concerns of over-utilization of certain procedures among women were found.

The review found that available evidence shows the need for improving programme design and implementation of PFHIS in order to fix existing gender gaps in addressing both vertical and horizontal health needs. There is need for a comprehensive framework to monitor and evaluate PFHIS using gender-based indicators which go beyond simplistic sex-disaggregation of data. Research using mixed methods and inter-disciplinary approaches with an explicit focus on gender are imperative.

Keywords : publicly funded health insurance, universal health coverage, gender equity, out-of- pocket expenditure, systematic review, interpretive review, India

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A growing body of literature points to increasing health insecurity leading to the impoverishment of households worldwide (Peters et al., 2002 & Wagstaff, 2002). About 150 million people globally suffer financial catastrophe annually because of out-of-pocket (OOP) payment for health services (Xu et al., 2009). According to India's draft National Health Policy 2015 (Ministry of Health and Family Welfare [MoHFW], 2014), every year over 63 million persons in India faced poverty due to escalating healthcare costs. The National Health Accounts for 2013-14 estimates that the largest share of health financing in India is through household OOP payments, constituting 69.1per cent of total health expenditure (National Health State Resource Centre [NHSRC], 2016).

The World Health Organization (WHO) defines Universal Health Coverage (UHC) as ensuring that all people have access to needed promotive, preventive, curative and rehabilitative health services, of sufficient quality to be effective, while also ensuring that people do not suffer financial hardship when paying for these services. Though India is committed to achieving UHC, there is no common understanding among stakeholders on what constitutes UHC and how to achieve it (Sundararaman et al., 2014). So far in India, social health protection has focused mainly on the formal sector employees through the Employee State Insurance card Scheme (ESIS) and Central Government Health Insurance card Scheme (CGHIS). A small proportion is covered under Community Based Health Insurances (CBHI), micro-insurances and voluntary household insurances. Since 2007, India has also been serving as an experimental ground for several Publicly Funded Health Insurance Card Schemes (PFHIS). The Rashtriya Swasthya Bima Yojna (RSBY) (translates to the National Health Insurance Card Scheme) introduced by the Central Government and many other state-initiated schemes targeting mostly the Below Poverty Line (BPL)[3] population captured national and international attention. RSBY was rolled out in 26 states (457 districts) in India (www.rsby.gov.in), with a few states like Kerala and Meghalaya expanding the original scheme. States like Andhra Pradesh, Telangana, Karnataka, Tamil Nadu, Maharashtra, and Goa initiated their own state health insurance Card schemes. These health insurance Card schemes mark a departure from a supply side health-financing model in the country to a demand-side financing model, and from the role of the Government as a direct provider of health services to a contractor funding the purchase of services. They are different from CBHIs and micro-insurance card schemes that are not tax-funded. Under the publicly financed schemes, vulnerable households are identified, enrolled and are entitled to avail cashless health services for select procedures from a pool of public and private health service providers in return for a premium usually paid by the Government to an insurer. These schemes allegedly contributed an increase from 55 million insured persons in India in 2003-04 to about 370 million in 2014, covering one-fourth of the population (MoHFW, 2014). They are also popularly considered an effective route to achieving UHC.

There are wide differences between different schemes with respect to geography, launch period, target population, premium contributions, packages, and terms of conditions with private parties, administration, and governance. Some schemes are administered through an independent society or trust established by the state government. Evaluation of schemes were carried out internally as well as externally. Studies carried out on PFHIS also differ in their designs, methods, and techniques. So far there have been two reviews of studies - Nandi, Holtzman, Malani, and Laxminarayana in 2015 and a systematic review of the publicly financed schemes in India based on experimental studies which used a control group by Prinja, Chauhan, Karan, Kaur and Kumar in 2017. Nandi et al., (2016) attempted a brief review of literature from a gender lens and found the literature to be limited to enrolment and inappropriate care. Apart from these, there have not been any systematic reviews of Indian PFHIS on social and gender equity dimensions.

WHO (2011) defines Gender Equity as 'a process of being fair to women and men with the objective of reducing unjust and avoidable inequality between women and men in health status, access to health services and their contributions to the health workforce.' PFHIS aim to improve access to healthcare services by removing the financial constraints because of which low income men and women may forego or delay seeking health care. It is well-established that gender is a crucial social determinant of health and healthcare access and yet the role of gender in studies on healthcare utilization does not receive explicit attention when compared to race, caste and economic class (Saha & Ravindran, 2002, Sen et al., 2002).

Gender and health-equity concerns surrounding women's access to healthcare treatments point to the following factors: (1) Biologically, some of the health needs of women are unique, while some others are similar to those of men, requiring integration of vertical and horizontal equity. (2) Gender power relations within the household allow women limited access to financial resources and affects healthcare utilization when it is determined by the ability to pay. (3) The vast majority of women work in the informal economy and in the lowest rungs of the formal sector. Current social security, and protection policies have to make special efforts to reach out to women workers. Hence the health risks, needs, and experiences of financial burden due to illnesses are likely to be different for men[4] and women. However, there is an absence of any systematic application of a gender lens in the evaluation of PFHIS to understand the impact on gender equity at the policy and programme levels.

The current paper aims to review evidence from studies on Indian PFHIS on gender and health equity. The review was undertaken by the first author as a part of her doctoral dissertation.[5] The following research questions guided the literature review:

1. What are the focus areas of different studies on PFHIS?
2. What are the findings on process indicators such as awareness, enrolment, and utilization that relate to gender and health equity from studies on PFHIS?
3. What are the findings on outcome indicators such as health expenditures and coping mechanisms that relate to gender and health equity from studies on PFHIS?
4. What are the frameworks and methodologies used in studies to unearth gender and health equity?
5. What are the emerging knowledge gaps in the scholarship on gender and health equity in PFHIS and what could be some of the reasons for these?

This paper is structured as follows: methods and results of the literature review are presented first and discussed, followed by the rationale and methods for conducting an interpretive review. A discussion on gender equity dimensions from both these reviews is followed by suggestions for changes in policy, implementation, and research on PFHIS.

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[4] A benchmark used by Government of India and its states on economic grounds to identify possible beneficiaries for various schemes.

[5] The Ph.D. dissertation explored the different gendered dimensions of equity in the design, processes, and outcomes of PFHIS.

Literature Review: Methods

We closely followed the PRISMA guidelines 2009 (Moher et al., 2009) in searching and selecting studies for review. Internet-Based research was done using search engines like Google (Scholar), MEDLINE, Science Direct and other e-resources. Key words used for the search were combinations of:

- "universal health coverage" and "social health protection" +"gender" and/or "women"
- "health insurance card", "health care financing"- + "India" and + "gender" and/or "women"
- "Government Sponsored Health Insurance card," "Publicly Funded Health Insurance card," Rashtriya Swasthya Bima Yojna" (and state-specific scheme names)+ "India" and + "gender" and "women."

Official websites of the various schemes were searched, and experts were contacted to expand the literature-base. Research papers, as well as commentaries, reviews, working papers, essays, conference papers and abstracts published in English between 2010 to April 2017 on national and state-specific PFHIS in India, were downloaded. Out of the 112 items downloaded, literature exclusively on community-based or employer-based insurance card was excluded and so were articles that focused on principles of management. Studies that singularly focused on design, governance and political economy aspects of PFHIS were also excluded. After removing duplicates, the full text of a total of 80 papers (including 18 from RSBY website) which focused on the process level indicators (awareness, enrolment, and utilization) or impact (expenditures, methods of coping) was finally selected for detailed review. A total of 17 states in India were covered through this review.

A proforma for capturing and categorizing data from the studies was developed. Initially, this included details such as year of publication, type of research design, sources of data, location, duration, sample size, results and key findings. Later more categories were added from the interpretive review. The summary of characteristics of the selected studies is presented in Table 1 and Table 3.

Table 1: General Characteristics of Reviewed Studies on PFHIS in India

Claims data	**Large surveys** NSSO, IHDS
Selvavinayagam & Vijayakumar (2012) - Tamil Nadu Yelliah (2012) - Andhra Pradesh Krishnaswamy & Ruchismita(2011) - National Rao et. al. (2012)- Andhra Pradesh CBPS (2015) - Karnataka Jain (2011) - National Grover &Palacios(2011) - National Dudala et. al. (2013) - Andhra Pradesh Reddy et. al. (2011) - National La Forgia &Nagpal (2012) - National Reddy &Mary (2013) - Andhra Pradesh Sharan (2014) - National Jain (2014) - National Kurian (2015) - National	Narayana (2010) – National Fan, Karan ,Mahal(2012) - Andhra Pradesh Sood et al.(2014) - Karnataka Selvaraj & Karan(2012) - Andhra Pradesh, Tamil Nadu, Karnataka Sharawat & Rao (2012) - National Ravi & Bergkvist (2014) - Andhra Pradesh, Tamil Nadu, Karnataka Sahoo& Madheswaran(2014) - National Shoree & Ruchismita (2014) - National Rao, Katyal et. al. (2014) - Maharashtra, Andhra Pradesh Katyal et. al. (2015) - Maharashtra, Andhra Pradesh Dror &Vellakal (2012) - National Raza et. al. (2016) - Uttar Pradesh, Bihar
Primary (Survey only) Yelliah (2012) - Andhra Pradesh Mitchelle, Mahal, Bossert (2011) - Andhra Pradesh Joseph & Rajagopal (2011)-Tamil Nadu Pughazendhi et. al. (2014) - Tamil Nadu Nandi et. al. (2016) - Chhattisgarh Gupt et. al. (2016) - Himachal Pradesh Devadasan et. al.(2013) - Gujarat Ghosh (2014) - Maharashtra Nandi, Nundy, et. al. (2012) - Chhattisgarh Dhanaraj (2015) - Andhra Pradesh Das & Leiono (2011) - Delhi Mazumdar et. al. (2016) - Jharkhand, West Bengal Rana et. al. (2016) - Gujarat Neena et. al. (2016) – Kerala Bhageerathy et al. (2016)-Meghalaya	**Mixed Methods** Rao (2009) – Andhra Pradesh Rent & Ghosh (2015) - Maharashtra Vijay (2012) - Karnataka Rao et. al. (2011) - Karnataka Wagle& Shah (2017)- Maharashtra Sabharwal et. al. (2012) - Madhya Pradesh, Uttar Pradesh Nair (2015) – Kerala Mishra & Sebastian (2014)- Chhattisgarh
Primary (qualitative - interviews, focus group discussions, participant observations) Cerceau (2012) - Haryana Dasgupta et al. 2013-Chhattisgarh Narasimhan et. al.(2014) - Andhra Pradesh Karpagam et. al.(2016) - Karnataka Virk & Atun (2015) - Delhi Virk & Surinder(2016)- Delhi	

Source: Authors

Literature review: Results

In this section, results of the review attempt to answer Review Questions no. 1, 2 and 3. Findings are organized based on the common themes around which the studies presented their findings. Under each parameter, the findings from studies reviewed are presented and their implications for gender and health equity are discussed. Any finding with implications for gender equity, even when not accompanied by sex-specific data, is also discussed in this paper.

Process Indicators in PFHIS and Gender Equity

Tracking the process level indicators in health programmes help to focus on the implementation process, assess how well a programme is being implemented, how much the implementation varies from one location to another, if and how it achieves the target and quality dimensions. This allows for understanding the equity dimensions, the processes of inclusion/exclusion and how policy translates itself into implementation levels through written and unwritten norms. In the context of PFHIS, awareness and enrolment are key process indicators. Utilization could be conceptualized as an output or impact indicator, but in the current paper, it is a process indicator.

Awareness

Awareness of available health services and social health protection schemes is considered in health research as an important determinant of utilization of available services. Reviewed studies tried to assess the levels of awareness, sources of awareness and the determinants of awareness related to PFHIS mostly through primarily survey research though some studies used qualitative methods like focus group discussions (FGD), in-depth interviews and participant observations with the general population, subgroups or beneficiaries who utilized the schemes.

Awareness of PFHIS among men, irrespective of which aspect was being measured, was consistently found to be better than women. According to Yelliah (2012), when compared to men, awareness among women was low in Andhra Pradesh. Cerceau (2012) in a qualitative study found women to lack awareness of benefits and empanelled hospitals in Haryana. In Uttar Pradesh, women were less aware (37per cent) compared to men (44per cent) (Amicus Advisory, 2011). According to Thakur (2014), educational level, economic activity and political connectedness of households in Maharashtra were positively associated with awareness while being urban, Hindu, Scheduled Castes (SC) /Scheduled Tribes (ST), female, illiterate or households headed by female or were nuclear, were negatively associated. Nandi et al., (2016) also found that awareness of PFHIS was low among slum women in Chhattisgarh though the study did not measure men's awareness. Karpagam et al., (2016) through a qualitative study found that women in Karnataka lacked information on the scheme cards, and on where to get the information or lodge grievances. According to these studies, factors that were responsible for awareness or lack of it centred around absent or ineffective awareness campaigns by insurers and enrolment agencies. For example, written materials were distributed among an illiterate population, or the population was left to rely on unofficial sources of information (friends, neighbours, etc.).

Under most PFHIS models, awareness generation is the responsibility of the insurer. The findings indicate that awareness-raising strategies of the scheme have been poorly implemented (Amicus Advisory, 2011, Rathi et al., 2012, Thakur, 2014, & Ghosh, 2014) and the channels and materials used for information education communication campaigns (if any) may not have been gender-sensitive.

Poorer awareness on PFHIS among women can have serious implications on utilization, impede informed decision making and subsequently lead to poor or nil financial protection for themselves as individuals, as well as for other family members when women are primary caretakers. NFHS-3 data showed that 35per cent of women had no regular exposure to newspapers or television when compared to 18per cent of men (IIPS Macro, 2007 as in Jain, 2013). Thus, the scheme itself accentuated women's access barriers by failing to create awareness which in turn resulted in poor utilization for themselves and others. Other studies such as Das and Leiono (2011), Rajasekhar et al., (2011), Aiyar et al., (2010-11), Rathi et al., (2012), Rao et al., (2014), Ghosh (2014), Rana et al., (2015), Rent & Ghosh (2015), and Neena et al., (2016) pointed at poor awareness on PFHIS but do not provide any insights on gender differences.

Enrolment

Enrolment refers to the formal inclusion of households and its members in the PFHIS after being screened for eligibility. Enrolment is most often represented by possession of a smart card which entitles the household and its members for benefits under the scheme. Levels of enrolment were researched in many of the studies reviewed, using secondary data from the scheme as well as primary surveys. Findings related to enrolment tend to swing either way - sometimes in favour of female-headed households and other times indicating poorer enrolment for women.

Grover and Palacios (2011) analysed the determinants of enrolment and found that while age and education of head of household, and linkage with politicians and local authorities were significant, gender was not a significant determinant. With RSBY data showing higher male enrolments, Swarup (2011) and Krishnaswamy and Ruchismita (2011) reasoned that male enrolment might seem higher because BPL lists used for enrolment in PFHIS usually have males as head of households. Sun (2010) observed that if the sex of head of household and spouse was not considered, there were no differences in male and female enrolment.

Some studies identified a clear gendered risk in intra household exclusion based on gender, age and marital status due to the ceiling of maximum five members per household in schemes like RSBY. They pointed out the possibility of intra-household exclusion of women to resources guaranteed by social health protection mechanisms. Intra household exclusions in enrolment were found in RSBY by Sun (2010), Das and Leino (2011), Nandi, Nundy et al., (2012), Ghosh (2014) and Nair (2015). Some of these studies reported the specific vulnerability of women to be excluded from enrolment either due to design aspects of the scheme or requirements for documents (Sun, 2011, Cerceau, 2012, Jain, 2013, Rana et al., 2015, Raza et al., 2016 & Karpagam et al., 2016).

Nandi, et al., (2013) found a positive association between female-headed households and enrolment in RSBY. Ghosh (2014) in a study of 6000 households covered by RSBY in Maharashtra found that those with female-headed households, SC/ST, Muslim were more likely to be enrolled. Using RSBY scheme data, Jain (2014) observed that though low to start with, female enrolment increased with time. Nandi et al., (2016) found a slightly higher percentage of women (68per cent) enrolled than men (65per cent), though in the age groups 6-18 and above 45, men overtook women. Thus, examining the sex of the head of household provided inconsistent results. It is not clear whether the higher enrolment of female-headed households or females in general, is due to the better targeting in the scheme, or because of other factors like availability of women during enrolment camps and women being substituted for men as head of households for convenience (Sun, 2010). Overall, the evidence is inconclusive on gender differences in enrolment except for the design-based exclusion of women.

Other studies which discuss enrolment used households as a unit of measurement and analyses (for example Narayana, 2010, Shoree et al., 2014) or did not provide sex-disaggregated data. In schemes like Rajiv Arogya Sri (RAS) or Rajiv Gandhi Jeevandhayee Arogya Yojna (RGJAY) or Chief Minister's Comprehensive Health Insurance Card Scheme (CMCHIS) all members of the household are automatically enrolled, and hence gender-disaggregated enrolment data was not available.

Utilization

Utilization refers to the use of PFHIS by an enrolled person for a particular surgical or medical treatment. Because PFHIS like RGJAY, CMCHIS, Vajpayee Arogyasri Scheme (VAS) and RAS provide exclusively for tertiary level care, the terms utilization and hospitalization became interchangeably used in studies on PFHIS. However, not all hospitalizations came with PFHIS coverage, and due caution was necessary during interpretation of results and findings. Studies gauged utilization levels mostly through scheme (claims) data, hospitalization data from National Sample Survey Organization (NSSO)[5] and primary surveys. Unlike enrolment, utilization takes place at an individual level.

Utilization estimates mostly indicate a pro-male bias when assessed through claims data. Selvavinayagam and Vijayakumar (2012) in Tamil Nadu using scheme -claims -data reported a slightly higher percentage of utilization by males in the first year of the scheme (55per cent). Krishnaswamy and Ruchismita (2011) found hospitalization to be higher for males in the second year of RSBY reversing the trend of the earlier year. However, the claim amount was higher for women. Rao et al., (2012) analysed the claims data from the RAS (undivided Andhra Pradesh) scheme and found that 53.6per cent of the beneficiaries were men. Only 40per cent of beneficiaries of VAS in Karnataka were women (CBPS, 2015). Wagle and Shah (2017) found that only 40per cent of beneficiaries in the RGJAY claims were from females. Vijay (2012) found, based on a sample of 30,000 beneficiaries drawn from RAS data, that women and children under 15 were under-represented. Jain (2011) found a higher hospitalization rate for men under RSBY than women in Chhattisgarh. Rent and Ghosh (2015) reported that 59per cent of respondents who utilized RGJAY were males during an exit survey in Maharashtra. Gupt et al., (2016) in a cross-sectional study in Himachal Pradesh found more males than females were represented in the beneficiary group.

However, some studies showed that in certain age groups (Selvavinayagam & Vijayakumar, 2012) or during some stages of scheme cycles (Jain, 2014), utilization tilted in favour of women or female-headed households. For example, Grover & Palacios (2011) found more women than men being hospitalized under RSBY in Delhi. In Haryana, though fewer women were enrolled, utilization was more among women than men (Cerceau, 2012). Devadasan et al., (2013) found higher utilization among women, elderly and lower caste individuals in Gujarat. The reasons for higher utilization by females in these areas are not elucidated in the studies. Jain (2014) also observed an increase in female hospitalization in RSBY over the years at a national level. Katyal et al., (2015) found that utilization among female-headed households in Andhra Pradesh increased following the PFHIS. Ghosh (2014) using multivariate analyses of survey data in Maharashtra found that gender was

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[5] NSSO, however, combines PFHIS with other Government funded schemes like ESIS and CGHIS

not a factor influencing hospitalization rates under RSBY. Thus, there is no clear direction in the evidence on whether women are at a disadvantage or not when it comes to utilization of PFHIS. Other studies, however, did not apply equity metrics on hospitalization data to gender but income quintiles, geographic location, religion or caste with households as units of analysis.

Regarding specialties and commonly utilized procedures, a higher share of claims in Obstetrics and Gynaecology was noted indicating largely reproductive health related morbidities. Women's claims were also found in non-reproductive ailments such as burns, dermatology, cardiology, medical and surgical oncology reflecting utilization for cardiovascular diseases, cancers and even treatment for violence (Dudala et al., 2013, Wagle & Shah, 2017, CBPS, 2015).

However, the higher share of claims in Obstetrics and Gynaecology specialty across many schemes need to be interpreted cautiously. Most studies did not disaggregate the procedures under Obstetrics or General Surgery to understand if the schemes were used for for reproductive ailments other than hysterectomy. Reports from Indian states of Bihar, Andhra Pradesh, Rajasthan, Chhattisgarh, Gujarat and Karnataka (Jain & Kataria, 2012, Human Right Law Network, 2013, Mamidi & Pulla, 2013, Xavier et al., 2017) showed that women were vulnerable to misinformation and fear tactics, resulting in provider-induced hysterectomies within insurance-based health systems. Caesarean deliveries were irrationally employed by private medical providers for profit motives (Varma, 2012, Neuman et al., 2014, Marathe & Mukadam, 2017). No benchmark is available for an acceptable prevalence of hysterectomies, and no standard treatment protocols are available to assess rationality and appropriateness of such procedures. In this context, it is difficult to interpret utilization figures as indicative of rational care or 'access' or as indicators of vulnerabilities of women who lack awareness and negotiation skills to be victims of moral hazard. Studies on whether and to what extent being enrolled in health insurance empower women with improved decision-making both within and outside the household, and with control over their treatment and facility choices are absent barring a few qualitative studies (discussed later).

Impact Indicators and Gender Equity

Since PFHIS were introduced in response to increasing financial burden for health expenditures, their impact is typically studied by looking at household health expenditures, specifically out of pocket health expenditures (OOPE) and in some cases Catastrophic Health Expenditures (CHE) whereby the expenditures exceed a threshold of overall household consumption in order to assess if they lead to impoverishments. The presence and extent of distress coping is another measure of the impact of PFHIS.

Mitchelle, Mahal, & Bossert (2011) in a large survey administered in rural Andhra Pradesh to close to 5000 women on health-seeking behaviour including reproductive illnesses found that households with scheme membership in RAS incurred higher expenditures than non-enrolled households. Rao et al., (2012) found that female-headed households did not receive coverage under PFHIS when compared to male-headed households in Andhra Pradesh and Maharashtra. Sabharwal et al., (2014) found that while 76.8per cent of male-headed households incurred OOPE as compared to 66.7per cent of female-headed households, this was not a statistically significant difference. They also found that among households that did not use a scheme card, a higher proportion of female-headed households depended on borrowing. Ravi and Bergkvist (2014) concluded that maternity care caused catastrophic health expenditure for poor households without insurance, but the nature of expenditure and other details were not provided in their paper. Dhanaraj (2015) measured coping strategy at the household member level and found that female-headed households had a higher probability of facing welfare loss and were seen to cope by sending children to work due to health shocks than male-headed ones with an overall finding that PFHIS did not have a significant effect in reducing the loss. Nandi et al., (2016) surveyed hospitalized women in a Raipur slum and found that among women who utilized the PFHIS in Chhattisgarh, 96per cent of the enrolled women experienced OOPE due to fees, medicines, and transportation which are meant to be covered under the scheme.

Available evidence from reviewed studies shows the vulnerabilities of female-headed households to OOPE irrespective of being enrolled in PFHIS. OOPE tends to occur for meeting expenses related to outpatient care, drugs, diagnostics (covered under the scheme) and indirect costs such as transportation (covered under the scheme), food and boarding, loss of wages and companion costs(not covered).

Qualitative studies were better-able to capture gendered aspects of OOPE, distress coping among women and the non-financial barriers faced by women. Narasimhan et al., (2014)'s case study approach showed how the exclusion of maternity care and mental illness in RAS, as well as fear, mistrust, and the perceived poor quality of public health facilities caused high OOPE for women. Karpagam et al., (2016) found poor awareness among women, denials by hospitals to accept the card, women's difficulties in dealing with paper work, preauthorization delays affecting women's access, and lack of childcare facilities during hospitalization to be some pathways that particularly affected women's utilization. They found that women who were elderly, single or had chronic problems faced additional barriers to timely care under the PFHIS.

Sex-disaggregated data on impact of PFHIS were not reported in studies by Fan, Karan and Mahal (2012), Selvaraj and Karan (2012), Shahrawat and Rao (2012), Devadasan et al., (2013), Ravi and Bergkvist (2014), Sood et al.,(2014), Sahoo and Madheswaran (2014), Rent and Ghosh (2015), Rana et al., (2015) and Gupt et al., (2016). The limitation of not looking at intra-household differences was acknowledged in the study by Fan, Mahal, and Karan (2012). Another study overcame this limit and took individual household members as units of analyses and brought out the differential impact on female-headed households (Dhanaraj, 2015). The lack of sex disaggregated data on health expenditures is thus not a matter of availability but of being aware and sensitive to gender issues.

Literature Review: Conclusion

The results of the review presented a mixed picture with no conclusive evidence on gender differences on the various aspects of PFHIS barring awareness viz. enrolment, utilization and financial risk protection. Female-headed households sometimes were seen to fare better in certain indicators like enrolment but poorer in terms of experiencing financial burdens due to health expenditures. Studies, however, did not look at vulnerabilities of women within male-headed households, a limitation that arose out of considering the household as the unit of measurement.

Conducting the systematic review in a conventional method was ridden with limitations of not being able to aggregate studies that differed widely based on research design, methods, and geography. Wherever the household was considered as the unit of measurement, subsequent analysis through disaggregation based on intra-household stratifies such as sex, marital status and age could not be done. Overall, equity was assessed more along location (urban/rural), income/class and sometimes caste in the studies reviewed but rarely on gender. Few studies looked at user perspectives, reasons for no use, especially that of women and other qualitative elements like decision-making within the household. Not much is known from these studies about the relevance of the PFHIS across the different life stages of a woman - childhood, adolescence, middle age and old age. Thus, the reviewed studies were most often silent on gender differentials, and even when available, were not interpreted for possible implications on gender and health equity.

Critical Interpretive Review: Methods

The second stage of the review attempted to go from merely aggregating findings on gender and health equity to a qualitative inquiry, to exploring reasons for why we know so little about gender and health equity implications of Indian PFHIS in spite of compelling evidence on the health vulnerabilities of women. It has been over a decade since the first PFHIS was introduced in India, and yet the gender-based evidence remains sketchy. Sometimes they were 'present' in the data but not 'picked up.' The interpretive review employed a critical interpretive approach based on principles proposed by Dixon-Woods et al., (2006). Interpretive reviews involve induction and interpretation compared to aggregation and comparisons in conventional reviews. This paper, however, does not come up with a new theory as proposed by Dixon-Woods et al., (2006). The aim was to critically look at a large body of complex evidence on PFHIS containing both quantitative and qualitative studies (though so far interpretive reviews are confined to qualitative data only) from a gender perspective.

The same sets of studies were reviewed using a critical interpretive approach. In addition, Research questions no. 4 and 5 were addressed. Some additional categories were added to the proforma such as the use of the conceptual framework particularly gender analytical, and the representation of women as individuals or household members in the studies. Analysis of evidence was based on some recurring themes and identifying the assumptions and biases in the studies. Three such major assumptions or biases found to be underlying most of the studies on PFHIS are described next.

Critical Interpretive Review: Results

The unitary household model and gender neutrality

Though health shocks affect individual members, the burden of expenditures is supposed to affect the household budget. Hence health economics, in general, is concerned with household expenditures, household financing options and does not automatically look into intra-household allocations of resources. Decisions on medical expenditures and coping are 'negotiated' within the family but acknowledged to be rising from different bargaining positions (Russell, 2004).

Insurance policies define a household as consisting of the household head, spouse, and certain dependents. As commercial insurers underwrite PFHIS, the schemes adopt the same definition and maintain data and records with the household as the unit of analysis. Taking household as the unit of enrolment has the advantage of not leaving out any women, elderly or disabled, lest when the ceiling is capped at five members per household (Ravindran, 2012). However, research studies also uncritically applied the same model and factors like awareness or coping mechanisms measured in aggregate as 'household awareness' and 'household coping' (For example, Das & Leino 2011, Vaishnavi & Dash, 2009).

The household model thus leads to lack of disaggregated data at the scheme- level and when collecting large survey data (such as the NSSO). It also leads to uncritical primary research. Even though some studies capture gender differentials initially, they later succumb to aggregating their findings at the household level (for example Mitchelle et al., 2011 and Mazumdar et al., 2016). Feminist economists criticize the household model as it reinforces the assumption of a male breadwinner and that all members of the family are equal and get to share the benefits provided equally (Macdonald, 1998). Farrington (2005) as in Holmes and Jones (2013) found that intra-household relationships did not allow insurance benefits to befall on women though they were involved in unpaid household work. Fan et al., (2012) acknowledged in their analysis of RAS that they did not look for the impact of insurance on intra-household allocation of resources, which household members used health services, whether they used public or private care or the level of provider used. Dhanaraj (2015) did successfully challenge the unitary household model, used household members as units of analyses, and found that the coping strategies were different when male and female members lost their lives in a household.

Some studies that exclusively used women as participants of the survey reverted to discussing findings in terms of the "household." Others lacked comparative data for male counterparts (Mitchell et. al., 2011, Karpagam et al., 2016 & Nandi et al., 2016). Many findings did not capture sex-specific differences yet indicated intensified vulnerabilities of women because of intersectionality with a social group, location, age or disability status. For example, when the distance between empanelled facility and villages are discussed as a determinant, it becomes evident that women who lack mobility would be worst affected (as in Sun, 2010). Or as in Grover and Palacios (2011) who found political connectedness as key to enrolment, women may be assumed to be automatically disadvantaged. Gender is implied when PFHIS design excludes costs for outpatient care, attendant costs, and child care. When primary and public care services were undermined by PFHIS, women were likely to be the worst hit, as poor and marginalized women were most dependent on them. However, such interlinkages with gender issues were missing from the discussion of such findings.

The consistent application of the household model appears to be oblivious to an already established pool of research studies proving the vulnerability of women within the household in terms of access and control over household resources, and the unequal burden that befalls them when a health shock strikes any member including themselves (UN Millennium project, 2005, Asfaw et. al., 2008, Gosoniu et. al., 2008, Desai et. al., 2010, Xu et. al., 2009 & Rout, 2010). Unfortunately, there is little evidence emerging from the PFHIS studies on gender differences in health expenditures as well as in the extent of financial risk protection.

A closely related factor to the unitary household model is the assumption that social health protection policies that cover the entire household are gender-neutral and hence unbiased. Gender-neutral policies are those that routinely use generic, non-gendered categories and do not challenge the existing divisions of roles, resources, and responsibilities between men and women (Kabeer and Subrahmanian 1999). Cerceau (2012) reports key policy makers of RSBY claiming that RSBY is a 'gender-neutral' policy as it provided coverage for the entire household. While gender neutrality at the level of enrolment in PFHIS is to be welcomed, it cannot be assumed that this alone would translate to neutrality at all other levels of scheme implementation.

Gender Biases in Frameworks and Methodologies

Another reason for the absence of discussion on gender equity found in this review could lie in the frameworks and methodologies used in the studies (See Table 2). Some studies used the WHO's UHC cube framework of 1) Breadth denoting the population covered, (2) Depth denoting the services covered and (3) Height denoting the direct costs of health and what proportion of costs are covered (Reddy et. al., 2011, Shoree et. al., 2014 & Seshadri et. al., 2012). Some studies using the social exclusion or access framework gave better insights on vulnerabilities of women in the different process indicators which in turn affect the impact indicators (Sabharwal et al., 2014 & Thakur, 2014 use social exclusion while Aiyar et al., 2013 use Tanashi's Access framework).

No framework is inherently gender biased. However, compared to location and income, the review found that gender was assigned a lower priority in equity analyses. Only a few studies used specifically a gender analytical framework (Cerceau, 2012, Jain, 2013, Gothoskar, 2014, Karpagam et al., 2016 & Nandi et al., 2016). Some of these studies (except Nandi et al., 2016) were based on secondary data or a limited sample. However, they were able to highlight the mismatch between women's morbidities (specific to their paid and unpaid work) and procedures covered in PFHIS, access barriers at the time of enrolment and hospitalization, delays in seeking treatment, gender blindness in design, gender insensitivities in scheme implementation and lack of respite from catastrophic health expenditures. Studies employing a social exclusion framework were also able to highlight some important gender issues. Ravindran (2012) applied a gender analyses framework to different social protection schemes across countries and observed that 'universal health coverage' could only to some extent result in 'universal access' for women.

Table 2: Frameworks Used in Studies on PFHIS India

Frameworks used	
Gender lens/ Analytical	Ravindran 2012, Cerceau 2012, Jain 2013, Gothoskar 2014, Karpagam et al. 2016, Nandi et. al.2016
Access to health	Aiyar et al. 2013, Jain 2013, Narasimhan et al. 2015
Social Health Protection	Vijay 2012, Jain 2013, Gothoskar 2014,
Social Exclusion	Sabharwal et al. 2014, Thakur 2014
WHO's UHC Cube	Reddy et al. 2011, La Forgia & Nagpal 2012, Shoree et al. 2014, Seshadri et al. 2012

The dominant method of calculating OOPE and CHE was the econometric method followed by Wagstaff and van Doorslaer (2003). WHO defined catastrophic OOPE as health expenditure that exceeds some fixed proportion of total household expenditure. This threshold level is set arbitrarily, say 10per cent irrespective of the level of income and irrespective if the household is rich or poor (Shahrawat & Rao, 2012). These methods are not without criticism (See, for example, Gupta, 2009 & Russell, 2004). One such criticism is that because households can cope with healthcare costs through borrowing, or sale of assets (Flores et al., 2008 as in Joe, 2015) their non-food consumption may not reflect any change thus shifting them to the non-catastrophic category. The traditional calculation of OOPE and CHE can be considered arbitrary and also gender- biased. In large surveys like NSSO, only transportation costs were included as indirect costs. Ghosh (2014) found that when OOPE for indirect expenditures like attendant costs is included, the proportion of households incurring financial catastrophe increased. Calculations of direct and indirect costs in studies on PFHIS also reflect a gender bias where biological and social reproductive roles performed by women within the home are unaccounted for. For example, in a study on wage-days-lost for persons living with AIDS in Tanzania, it was found that women's loss was much higher than that by men (Russell, 2004). In the wake of health shocks, women's assets, especially jewels, were more likely to be depleted to cope with them (Quismbing et. al., 2011 as in Holmes & Jones, 2013) yet the reviewed studies focused on 'household' and not sex-disaggregated coping strategies.

The overemphasis on quantitative approaches across PFHIS studies additionally renders many of women's experiences with access to healthcare using PFHIS, invisible. For ex, Narasimhan et al., 2014 and Karpagam et al., 2016 using a qualitative approach were able to bring out different gendered barriers faced by women. Gender, thus missed many opportunities to come to the forefront of equity discussions in the PFHIS studies.

Balancing women's vertical and horizontal health needs

While on the one hand gender neutrality can work against gender equity, on the other hand focusing narrowly on women's needs surrounding their reproductive roles could also adversely affect gender equity. The literature search on gender and social health protection turned up several studies on maternity and safe delivery. The financial burden caused by vertical or sex-specific health needs of women no doubt requires priority, but these are not limited to pregnancy and childbirth alone. Financial and other barriers operate in determining women's access to a range of sexual and reproductive conditions including maternity, childbirth, contraception, abortion, menstrual/ gynaecological problems, reproductive tract illnesses and sexually transmitted diseases. The availability and acceptability of such sexual and reproductive health services in public health systems are limited, forcing women to either forego care or seek private services and face financial burden (Balasubramanian & Ravindran, 2011, Mohanty & Srivatsava 2013). It must also be remembered that women in Above Poverty Line households may be in the same or even position in their access to household financial resources when compared to women in BPL households (Witter et al., 2017).

Many of the PFHIS, such as that of Andhra Pradesh/Telangana, Tamil Nadu, and Maharashtra, do not cover maternity and childbirth, based on insurance principles that these are not non-random health events. Other forms of social protection such as cash transfers may be available to meet expenditures for maternity/childbirth but with questionable equity impact (Balasubramanian & Ravindran, 2012). Studies on PFHIS found that exclusion of maternity and childbirth was a serious lacuna (Ravindran, 2012, Ravi & Bergkvist, 2014). Gothoskar (2014) raised the concern how deliveries were included when RSBY was implemented in Maharashtra but was later withdrawn when it was replaced by RGJAY. Similarly, hysterectomy was included in the PFHIS of Tamil Nadu when introduced, then withdrawn and then reintroduced (La Forgia & Nagpal, 2012 p. 324). The rationale and circumstances under which these policy decisions were taken are not adequately captured in any study. Many of the PFHIS did not provide for access for gynaecological morbidities at early stages but provided for removal of uterus once the untreated morbidities increased in severity. As seen earlier, unnecessary caesarean deliveries and hysterectomies show how women are vulnerable to provider-induced moral hazards masquerading as 'utilization' and 'access' while jeopardizing women's health.

Women's health risks extend beyond their reproductive roles. There is little recognition of the horizontal needs of women such as vulnerabilities due to infectious, chronic and non-communicable diseases that can disproportionately affect women because of their increasing life spans much of which is spent as single or dependent. The Global Burden of Disease Report states that diarrhoeal diseases, iron deficiency anaemia, lower respiratory infections were higher among females (ICMR, PHFI & IHME, 2017). Women are also vulnerable to cardiovascular diseases, different types of violence, mental ill health and substance abuse (Holmes & Jones, 2013).

As seen earlier, PFHIS are able only to address a narrow set of illnesses that women suffer from, especially after it escalates into a serious or life-threatening condition such as cancers and removal of the uterus. Both cases are avoidable if adequate prevention and screening were also incorporated into policy design such as in Thailand and Mexico's universal health insurance schemes. The high utilization of certain procedures at certain ages also raises concerns, given the risk of moral hazard. For example, in a study on utilization patterns from the CMCHIS in Tamil Nadu, a consistently higher number of claims were observed by men in every age-group except for 41-50 where women overtake (Selvavinayagam & Vijayakumar, 2012, a pattern also seen in VAS in Karnataka (CBPS, 2015)). The reasons for this pattern were not discussed in detail in the paper as disaggregation of procedures performed on women of those ages were not given. In the same scheme, a higher share by males in total claim costs and average claim size was attributed to sex differences in health risks ('cardiac diseases more common among males than females in 41-60 age group') in another paper (La Forgia & Nagpal, 2012, p.328). It is not clear whether this pro-male difference in claims is due to purely sex-differences or also reflect gender and social barriers for women. In fact, the perception of heart diseases as a man's disease was found to cause delays in diagnosis of cardiac distress among women (Doyal et al, 2003.) Claims analyses by CBPS (2015) in Karnataka and Wagle and Shah (2017) in Maharashtra show that women's share is higher in burns which actually could be the result of violence inflicted on women.

Thus, PFHIS incorporates a narrow understanding of women's specific sexual and reproductive health needs as well as general health needs and are ridden with more exclusions than inclusions of conditions known to cause financial burdens for access for women. Disturbingly, the included procedures were seen to be over-prescribed at the cost of women's health.

Conclusions

Women constitute a majority of the world's poor, the informal and unorganized economy. Women have some specific health needs due to their biological roles, intensified needs that manifest differently in women as compared to men and have imposed vulnerabilities and risks arising from their social positions. A health insurance scheme aimed to improve healthcare access by removing the financial constraints needs to take into account the multiple levels of marginalization faced by women compared to men. The paper aimed to look at the extent to which PFHIS in India address the differential needs of women in a way that overcomes existing barriers to ensure gender and health equity. By combining two approaches, one deductive and another inductive - to review existing studies on PFHIS, the paper has brought out three key issues:

(a) There are gaps in the approach and methodology of the evaluation studies in analysing gender inequities. The uncritical application of household as the unit of measurement and analysis in the studies rendered much of the gender differences invisible and reinforced the myth of the household as a non-discriminatory unit and the PFHIS health policy as a gender-neutral one. Unless power inequalities between men and women within the household and in health system settings are taken into account, a purely economic analysis of the scheme will yield misleading results and findings. The review proved that health research influenced by deep-seated gender bias creates a vicious cycle combined with lack of well-articulated evidence (Sen et al., 2002). Research approaches need to go beyond health economics to incorporate interdisciplinary approach including psychological, social, anthropological and qualitative approaches that are best suited to unravel some unexplored dimensions such as decision-making, user perspectives, quality of care and non-financial barriers to accessing health under PFHIS.

(b) Current evidence on gender issues calls for improving programme design and implementation of PFHIS in India. The review found that women were disadvantaged in being aware of, included in and impacted by PFHIS. The findings strongly underline the need for PFHIS to improve awareness raising strategies and relook at the design elements that tend to exclude women and conditions that cause financial burden, to ensure benefits of financial risk protection reaches individual women irrespective of their marital or social profile. The different kinds of ‘costs’ associated with a woman’s hospitalization and treatment need to be acknowledged and covered under the scheme.

(c) There is a need to put in place a comprehensive monitoring framework for publicly financed programmes, for tracking gender-specific indicators. So far there is insufficient attention to gender issues in routine evaluations of PFHIS, especially for gender inequity indicators. The study shows that this has to go beyond sex-disaggregated data to a comprehensive application of gender lens in scheme design, processes and impact along with health service organization and delivery. Gender analysis of not only PFHIS but health financing strategies and UHC frameworks are also urgently needed.

This paper unmasked India’s PFHIS policy, which maintains a gender-neutral language providing a seemingly “gender-equal” form of social protection to the marginalized populations. The findings assume greater significance in the context of the announcement of the Government of India of the National Health Protection Scheme during the budget session in February 2018. The plans to expand the population as well as monetary coverage without relooking into gender and health equity implications is likely to only usher more hurdles for women and the marginalized. As publicly funded health insurance is a complex subject involving multiple stakeholders and the current political economy allows profit-oriented and market-based institutions to influence policy decisions, no time should be wasted in bringing explicit and committed attention to gender equity.

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Class and Gender Dynamics of Outsourcing Manpower in the Health Sector

From Formal to Informal work

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Estimates by academicians have pointed out that salaries appropriate as much as 70 – 80per cent of state budgets, leaving a minuscule share for health infrastructure and other inputs. A solution to the problem has been offered through reforms which have propagated alternative mechanisms of recruiting workforce. These include hiring staff on short-term renewable contracts and outsourcing tasks to a contracting agency. The following paper is a case-study of a tertiary-care hospital which has adopted such hiring practices.

This study on contract-hired and outsourced workers aims at documenting the dynamics and implications of reforms in recruitment on the conditions of work of those recruited on such work arrangements, and on the quality of healthcare.

This paper draws on a larger qualitative study which examined the implications of health reforms for services provisioning within a tertiary -level government hospital. Between September 2016 and June 2017, in-depth interviews were conducted with 85 health workers including both permanent and casual staff. Prior consent from the Delhi Health Department was solicited for conducting the study.

Reforms in recruitment have advocated outsourcing for the lowest rung of employees, while for technical, nursing staff and physicians, the system of contracts has been introduced. Both groups of workers were paid lower than regular employees carrying out the same tasks and had to contend with long-term job insecurity. However, the experiences of outsourced workers revealed a more humiliating working environment. The process of 'casualization' of workforce showed a class dimension, further marginalising the already vulnerable sections of society. Also, it was women from the groups who were concentrated in the lowest paid jobs.

There appears to be class, caste and gender-based discrimination of employees in the health sector through contracting and outsourcing.

Keywords : health reforms, contracting, outsourcing, feminization of work, public hospitals, India

Since the 1990s, economic reforms aiming at fiscal discipline have seen many governments try various strategies to reduce health expenditures. These reforms were based on the tenets of improving efficiency, effectiveness, and quality of care in public health services. Besides, reforms often presumed a more dominant role for the private market in healthcare financing, provision, technology, and research. Advocates for privatisation/outsourcing argue that a distinction should be made between the provision of public services and the production of public services. The former is

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seen as an example of government responsibility, and the latter is viewed as best left to the private sector. This view of the state as 'enabler' rather than 'provider'underpinned outsourcing in health policy (Lochlainn & Collins, 2015, p.2).

The present paper focuses on human- resources -reforms that have aimed at reducing the burden of salaries in India's health budget. Estimates by academicians have pointed out that salaries appropriate as much as 70 – 80per cent[1] of state health budgets, leaving a minuscule share for health infrastructure and other inputs. The high proportion of budget claimed by salaries has not prompted an increase in budgetary allocations for healthcare, which remains at a dismal 1.1per cent of GDP[2]. On the contrary, there is evidence that cost-cutting measures are being implemented. Such measures include a slowdown in permanent recruitment and stepping up of alternatives like contract hiring and outsourcing of health personnel. Through these measures, the government has reduced its obligations of paying salaries on par with the market, and of pension payments.

The idea of outsourcing public health services had its roots in the paradigm of New Public Management (NPM). Hodge (1999) describes outsourcing as stemming from the privatisation movement, particularly in the US and the UK. In the UK, introductory competitive tendering was a key component of the Thatcher government's privatisation programme[3] (Lochlainn & Collins, 2015, p.1). NPM was a market-driven model, where quality, costs, and efficiency, ensured by competition between providers and informed consumers, was the formula to ensure the optimal provisioning. Public sector bureaucracies were regarded as bulky, corrupt and resource- inefficient. Although public servants and bureaucrats did not have a profit motive, they were perceived to be fulfilling self-interest, which came in the way of public or national interest (MacDonald, 2010, p. 27). NPM is also called the "public choice" approach, which offers competition with private providers as the solution for attaining efficiency in the public sector, disregarding the inherent differences between the public and private sectors.

Another dominant approach, the transaction costs (TCE) suggests that activities which are frequently conducted and exhibit high degrees of uncertainty and asset specificity have high transaction costs which are likely to exceed the benefits of transacting. They are therefore best produced in-house. Activities that incur low transactions costs are outsourced. Following this strategy, core functions of patient- care are retained within government production and provision, and it is the ancillary services that have been outsourced.

The present paper draws its data from a qualitative study carried out by this author, on implications of health reforms within a tertiary hospital in New Delhi. The study brings to fore the plight of those who work as a contract or outsourced workers, and documents clear discrimination of lower class and women employees, who perform non-clinical work such as cleaning and sanitation, laundry, catering, ambulance drivers, security guards and nursing orderlies.

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[1] As reported in 'The Hindu' dated December 1, 2016, "Wages and salaries account for 86per cent of the total public expenditure in Punjab, 72per cent in Maharashtra, 65per cent in Kerala, 52.5per cent in Madhya Pradesh and 35per cent in Odisha"

[2] India's low allocation for health is in sharp contrast to high-income countries, where health reforms have a deep penetration, and yet allocations to healthcare are very high. Of the total health spending in India, the Indian government contributes just 29per cent. In the UK, the government's share is 83per cent. For others, this figure ranges between 45 and 55per cent

[3] As early in 1982 we find evidence of Health authorities introducing competitive tendering for support services, such as catering, cleaning, portering and estates maintenance in the NHS, United Kingdom

The paper is divided into five sections. Following this introductory section, the second section presents the study methodology. The third section describes the dynamics of working as contracted and outsourced workers through experiences of employees. The fourth and fifth sections contain the discussion and conclusions, respectively. These sections are enriched through excerpts from interviews[4] conducted by the researcher which bring out the real picture of contracting and outsourcing, as experienced by different categories of hospital staff.

Methodology

The larger qualitative study that examines the implications of health reforms for services provisioning within a tertiary level hospital was designed as an institutional ethnography of a tertiary hospital under the Delhi government. We aimed to draw on the perceptions and experiences of hospital staff to understand how health reforms have impacted the employees, and service provisioning. Essential areas of reforms within the hospital -setting included computerisation of all hospital departments and systems, user fees for specific services and procedures, reforms in the recruitment of health personnel, outsourcing of ancillary services, and public-private partnerships in the delivery of certain core functions.

Selection of the hospital: Since the study aimed at documenting changes brought about through health reforms, we needed hospitals that were functioning before the reforms, i.e., earlier than the 1980s. Of the four hospitals, the present hospital[5] was selected on the basis of convenience for conducting an ethnographic study. The study hospital is a 714- bedded super- specialty tertiary hospital with seven clinical and five para-clinical departments. The ease of getting permission from the hospital director and Medical Superintendent also aided in the choice of this hospital where resistance was minimal.

Prior written consent was solicited for conducting the study from the Health Secretary of the Government of Delhi. Individual consent was taken from all participants before conducting the interviews. Unstructured in-depth interviews with all categories of hospital staff – doctors, nursing staff, technical staff, nursing orderlies, and cleaning staff, as per the terms of their contract, i.e., permanent, contracted, privately outsourced, was done.

Sample size and selection: A total of 85 hospital employees were interviewed between September 2016, and December 2017[6], including permanent, contracted and outsourced staff. Of the 85 employees interviewed, 45 had permanent government jobs, 20 were on one-year renewable contracts, and 20 were outsourced employees. The selection of employees was through snowballing, more often depending upon their willingness to be a part of the study. Most government employees had inhibitions in consenting for interviews, as their service contracts rule against sharing of official information with outsiders. We, therefore, maintained the complete anonymity of participants. Observation of the day-to-day activities of the hospital supplemented the data collected through interviews. The researcher had long and in-depth informal conversations with union workers and leaders on the issues of contract-hiring and outsourcing.

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[4] In the quotes used for description Cleaning staff has been denoted by CS, Nursing orderly by NO, technical staff by T, Nursing staff by N, and Doctors by D

[5] The name of the hospital has been concealed for maintaining the anonymity of respondents.

[6] Further interviews were conducted from August 2017 till December 2017, and a total sample of 156 hospital staff had been interviewed for the larger ethnographic study.

The researcher also visited sites of protest and observed their meetings, where informal conversations with members from other hospitals helped to understand the magnitude of the issue. It was through these meetings that the researcher met union members of ASHA workers' and Anganwadi workers' unions, who had been demanding regularisation of their employment. The section on feminization was brought to limelight through these informal meetings on how mass casualization of grassroots female workers has happened during the last decade. Since these interviews were informal and unplanned, they have been supplemented through review of the literature, which remains very scanty. The present paper thus builds from the data collected within the hospital but can capture the trends of casualisation of labour beyond the hospital boundaries through literature emanating from workers' groups, newspaper reports, and a few published studies.

The inspiration for the present study comes from the scarcity of studies on reforms and their implications in healthcare institutional settings such as hospitals. Most research on reforms discusses the concepts and critiques them. However, studies examining the implementation of reforms and the every-day manifestations of reform, remain very few. This paper focuses exclusively on human resources reforms in the public health sector, where we identify newer recruitment modes of outsourcing and contract employees.

The present study uses Yeheskel Hasenfeld's conceptualisation of healthcare facilities as human services organizations, which are unique, as 'people' are their raw materials – both in the form of service providers and patients to be worked upon. Organisational effectiveness is a function of the complementarity and congruency between the goals of the organisation and personal needs of the workers. (Hasenfeld, 1992, p.27) This implies that if the personal needs of the staff members are not met by the organisation, and when they are dissatisfied with their job, they will take it out of their clients. This approach thus holds health workers as central to the health seeking experience and views health reforms critically for the divisions it has created in public health workforce.

Dynamics of contracted and outsourced work: A critical inquiry

Before the 1980s all staff was permanent - selected either through Union Public Service Commission (UPSC) or Delhi State Selection Board (DSSB). The outsourcing[7] of services in the study-hospital was first initiated during the 1980s with the outsourcing of cleaning services. The hospital has gradually privatised security services, laundry, cafeteria, ambulatory services (contracted out) and deployment of nursing orderlies (contracting in). The outsourced workers are recruited and remunerated by a contractor – selected through a tendering process for a fixed budget. In both these forms, the responsibility of the government as an employer becomes minimal. They have no liability to provide any social security or job security cover, or pension. According to its advocates, outsourcing allows the government to retain overall control over the quality of service through contract specification, monitoring, and evaluation of performance. Unlike the privatisation of assets, outsourcing is easier to reverse (Lochlainn & Collins, 2015, p2).

For all other employees, the Delhi government has since the late 1990s introduced recruitments through temporary contracts instead of permanent selections. Initially, these recruitments were seen

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[7] The Eighth (1992–1997) and Ninth (1997–2002) Five Year Plans introduced the system of contracting out of primary level services, and consequently, in the Tenth (2002–2007) Plan, there were talks of both contracting in and contracting out of clinical and non-clinical services. (Basu, 2016). However, these strategies were already in experimentation, and here we find outsourcing of cleaning services had begun in the 1980s

as temporary measures to meet the hospital requirements until the permanent selection process was conducted by UPSC/DSSB. However, since the late 1990s, DSSB has also hired hospital employees on contract basis at all levels of the hierarchy. Within these arrangements, the employees are recruited for a fixed term of 11 months, at a fixed monthly salary. The system of contracts carries no allowances, or pension- cover. The first batch of contracted staff in the selected hospital was recruited in the year 2003, and the practice continues till today.

In this section, we describe the results of our interviews and observations with contracted and outsourced workers and their colleagues within the study hospital.

Contractual workers: Working as a contract-worker was revealed to be an exploitative experience. The remuneration scales of contract staff were remarkably low when this system was initiated, finding parallels in the private sector. For example, when contract nurses were first inducted, their salary was fixed at Rs 6,000 per month. This was later increased to Rs 11,000 per month, and finally to Rs 16,000 per month through successive pay commissions. However, when a large number of contract workers united, they filed a case against the discrimination by Delhi Government and made the demand of "equal pay for equal work." This was premised on the logic of the same quantum of work being done by contract staff as permanent staff, while differential salaries were being paid. In a landmark October 2016 judgment, the contract workers won their demand, and their monthly salary was increased at par with the basic salary of permanent staff, which is now Rs 45,000. This has led to a significant boost in morale of contractual staff. However, there are a few categories of contract-staff who do not come under the purview of this judgement. Also, other postulates of the contract, i.e., a fixed term of 11 months, no allowances, no promotions, no pension, leave disparity, etc. continue.

The dynamics of insecure jobs affect contract-staff considerably. Not knowing how long the system of contracting would be practiced, whether and how it would be discontinued, and for how long they would have to continue performing the same tasks because of no promotional avenues, were sources of worry for all contractual employees. In the private sector, contracts are the normal form of recruitment, and all staff is employed under the same contract rules. In the study hospital, the experience of being a temporary worker was heightened due to the presence of permanent peers, who worked without any worries. One Assistant professor (doctor) who had worked on contract in the past said (D3, Personal communication, October 15, 2016) –

> "The contract system is abusive. There is nothing for the employee – no quota of leaves, dismal salary structures, and no scope for the future. I used to be very depressed when I was working on a contract. I was so uncertain about my future (thinking about)– how long will I continue like this, or what will I do if someday my contract is not renewed."

Contract-staff also reported that they were often exploited. For example, a contract- staff nurse is expected to do all the work that a permanent nurse performs. Both contract nurses and permanent nurses have the same or equivalent qualifications. However, contract nurses had a much greater workload because permanent staff would leave their share of work for their contractual counterparts to carry out. Most permanent staff were reported to keep themselves occupied with administrative work, leaving patient -care to contract nurses. As one of the contract nurses (N27[8] , personal communication, January 25, 2017) shared:

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[8] To maintain the anonymity of hospital employees, they have been denoted by a reference code for all personal communication

> "Since our jobs are not secure, we cannot say no to any task. However, permanent staff nurses have no fear of anyone. They conveniently ask us to take care, while they do their work. And we can't even complain, because we fear that if our report shows negative remarks, our contracts may not be renewed next time."

The general perception about contract workers was very negative. They were seen as outsiders, and not as part of the system, and often excluded from social forums and discussion groups, leading to their alienation. The contract staff is popularly characterised by the permanent staff as temporarily placed, and not belonging in the hospital. In the words of a permanent staff nurse (N2, personal communication, October 21, 2016) - "Today they are working here, tomorrow if they find a better job, they will go there." Since their jobs are not permanent, it is presumed they don't develop a sense of belonging to the hospital.

The permanent staff – whether junior or senior, appeared to assume superiority over contract staff. They expected the contractual staff to demonstrate respect and do as they were bid by the permanent staff. Because promotional avenues are reserved for permanent staff, there is a strong notion that only the permanent staff would continue in the hospital in the long run. As a consequence, senior staff attributes greater credibility to permanent junior staff. A Nursing Sister said (N22, Personal communication, December 13, 2016):

> "We cannot leave the responsibility of handling high-end-equipment to contract- workers as we have found them very careless in their approach. Since the accountability for all stock and machines lies with me, I have to be careful in distributing the work. I can be questioned if anything goes wrong. They have nothing to lose; their jobs are already contractual."

The consequence of these dynamics was multiple hierarchies being created within hospital wards and departments, where all permanent staff emerges as one cohesive group. The contract staff often lacked solidarity, and they were unable to trust even other contract staff. There is a constant fear of negative reporting, even from fellow contract workers. As one contract staff nurse shared (N27, Personal communication, January 25, 2017):

> "I can't talk to any of the nurses the way I am talking to you. They don't spare any chance of complaining about us and becoming good in the eyes of seniors."

The dynamics of interpersonal relations varied with different occupational groups. Among doctors, there is absolute disenchantment with the system of contract hiring of doctors, and the remuneration is seen highly inadequate[9] They not only feel it as discriminatory but also counterproductive, because doctors hired on a contract never stick to their jobs. All the permanently employed doctors who we interviewed, felt highly protective of the few contract doctors, whose productive years were seen as wasted. A contractual position for a doctor is seen as a temporary job taken by either women doctors who have home responsibilities and therefore cannot fulfil the job obligations of the private sector, or by doctors who are just waiting to find a better job. An interesting comment was made by a senior professor (D20, personal communication, January 31, 2017):

> "if a contract doctor is sticking in the hospital for a long time, then you can infer that he is not a well-trained doctor; doctors with a sound background will find a better job very soon".

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[9] Contract doctors receive Rs 63,000 per month. Senior residents doing their Masters get close to Rs 1 lakh. Thus more qualified doctors get paid lower than students who they have to supervise.

Administratively, the induction of employees on differential contracting terms has led to a fragmentation of authority and accountability systems; creating operational problems in governance. Since there are no clear rules for the protection of contract -staff, and because there is no contract- staff at senior positions to speak out on their behalf, they become answerable to permanent staff across the hierarchy, who were often biased in their opinions about contract-staff. Functionally authority becomes distributed to the lowest levels of permanent staff, and abuse from junior permanent staff was also shared.

Outsourced staff

Outsourced staff members faced a double burden of authority as they had to report both to the hospital administration and to the contracting agent. Constant and strict surveillance; poor pay; denial of fundamental rights to safety at work; humiliation by permanent staff across all levels of the hierarchy, and insults by their supervisors publicly for minor mistakes eroded their capability to render efficient work.

Outsourced cleaning staff earned RS 13305 per month and an outsourced nursing orderly earned RS 13584 per month. The corresponding basic pay of permanent staff was RS 35000-40000 per month. Outsourced workers do not even have a union to voice out their concerns. In the words of the Supervisor (Supervisor of Contracting Agency, Personal Communication, May 15, 2017) –

> “They will be removed by the contractor if they engage in union activities. Who will listen to them?”

Interviews with outsourced employees revealed that often there was not even a written agreement between the contractor and the workers, which led to discrimination and human right violation. The conditions of work are poor, and the salary paid is low. The contractor may replace a worker at any time, delay payment of salaries, and often.

Their vulnerabilities and exploitation are demonstrated in the following episode shared by the outsourced cleaning staff. For many months the outsourced cleaning staff was not given a salary, as the contractor had himself not received his payments from the Delhi government. When there was considerable delay in government payment continued for a lengthy period, the contractor made all the outsourced employees sign a statement declaring that they were willing to wait for their salary till the contractor received his payment, and in case he did not, the workers would not demand any money from him for the services they had rendered. As a fallout, many outsourced workers left the job.

Another serious discrimination reported by the outsourced cleaning staff was the denial of Hepatitis-B vaccination, which is administered to all permanent cleaning staff once in three months. Exposure to Hepatitis B Virus is an occupational hazard for all healthcare workers. However, cleaning staff are at a higher risk since they deal with hospital waste, and can be exposed to contaminated needles. Outsourced cleaning staff in the study hospital had been denied this preventive cover despite repeated requests. According to the Supervisor from contracting agency, the hospital administration was unwilling to spend the RS 5000 per outsourced cleaning worker required for the vaccination.

Harassment by permanent staff was a regular feature in the lives of outsourced workers. The following is an account by outsourced nursing orderly: (NO5, personal communication, May 11, 2017)

> "Working side by side with a permanent orderly is in itself a demeaning experience, as he can say anything to me. Whether he is present or absent from workstation, it does not matter, but the nurse in charge will question me for everything".

An outsourced cleaning staff member shared (CS2, Personal Communication, August 22, 2017)

> "If the permanent orderly is not present, the nurse will not bother, rather ask me to do his work as well. The nurses make us do any work they require – bringing tea from the canteen, getting photocopies from outside, etc. Even changing patient bed sheets, and patient's urine bag – which is strictly a nurse's job. But since we have to work with them, we have to comply with all their demands. If someone says no to such tasks, they will pick the phone and complain to the supervisor – what kind of person you have posted here, how he can argue with us. So we are like their servants."

The management of outsourced work also becomes very tedious. This is because functionally, the hospital administrators are responsible for ensuring that the work is done, but they lack any authority over outsourced staff or the contractor. Union members told this researcher that the contractor showed a higher number of employees on paper than those deployed by him (T2, Personal Communication, September 12, 2017) –

> "He will get all the work done by less number of persons, so these workers are overworked. But he will claim the salary of all persons on paper. So that amount gets pocketed by the contractor."

Discussion

The exploitation and discrimination of workers through contract-hiring and outsourcing have been voiced through writings of trade unions.[10] The authors of a study noted how the restricted career growth, high turnover, and low salary of contractual staff in comparison to regular colleagues working in the same organization for the same purpose has led to a conflicting environment in organizations (Kumar & Khan, 2013, p.67). The 2009 Comptroller and Auditor-General (CAG) report on NRHM highlighted significant staff shortages despite contract recruitment and pinpointed to the difficulty in retaining contract workers as a crisis in the system. Despite these observations, there has been no change in the processes of contract recruitment.

The main consequence of these newer modes of recruitment has been large-scale casualization of health workers, and their deployment in the informal economy. The workers employed through outsourcing and on contracts have temporary jobs with no employment guarantee, no promotional avenue, or any long-term wage security. This creates immense psychological stress for workers who are always conscious of the insecure nature of their jobs. Far from the government's promises of job creation in the formal economy, we find a significant number of posts which were already regular being transformed into temporary positions. While at one level this amounts to a violation of workers' access to government jobs, it does more damage by justifying the 'hire and fire' practices of the private sector by emulating them.

Two important and inequitable consequences of the human resources-reforms merit detailed discussion. These include the disproportional impact of the human-resources reforms in the health sector in Delhi on the poor and Dalit populations, and on women.

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[9] Public Services International (PSI) is a global trade federation represented by over 700 unions across 154 countries. PSI released a Booklet series on Healthcare Workers in South Asia titled - Non-Standard Work in the Healthcare Sector in South Asia.

Marginalising the marginalised – bearing a greater load of cost-cutting practices

The outsourcing of non-clinical activities shows clear discrimination against lower class employees, who are seen shouldering a greater burden of these cost-cutting strategies. All non- clinical activities – namely cleaning and sanitation, laundry, cafeteria, security guards, ambulance drivers, and nursing orderlies come under Group D employees, the lowest in the bureaucratic hierarchy. And it is precisely these services which have been handed over to the private contractors. The employees who took these jobs came from poorer households and often had only 8 to 10 years of schooling. One cleaning worker appointed through outsourcing shared how they are trapped because of limited job opportunities (CS6, personal communication, 24th August 2017)

> "We have to fill our children's hunger, and so we are working like this. Otherwise, there is no respect, no status. I couldn't complete my education, so this is my only option. I have been working like this for the last seven years, and not once any permanent vacancy has been announced. The earlier generation of cleaning staff was lucky; they got permanent jobs."

Many of the cleaning and sanitation workers were not only financially poor but belonged to socially disadvantaged sections, as cleaning and sanitation work is caste-identified in the Indian society. The supervisor of the outsourcing agency reported that 90per cent of the 216 outsourced cleaning staff belonged to the Valmiki community (Supervisor of Contracting Agency, Personal Communication, May 15, 2017)

> "No one else comes for this work - it is only Valmiki people who do this work. The remaining ten percent are from very low-income families and willing to do any work".

Thus, the loss of permanent government jobs through outsourcing has systematically excluded the socio-economically disadvantaged sections of society. The permanent jobs provided an avenue for better financial security to these marginalised sections, as well as health benefits, improved access to better nutrition for women and girls; increased the chances of a girl child completing elementary schooling and an overall general upward mobility through respect achieved with the status of a government job. As shared by a permanent nursing orderly (N01, personal communication, October 18, 2017) –

> "My daughter is doing graduation from Delhi University; she is the first in my family to achieve this. Not even boys of our community study this much. I wanted her to become a nurse, but she wants to become a teacher."

Permanent government jobs were a more important type of positive discrimination compared to quota reservations for SC, ST, and OBCs as it employed unskilled work – largely fulfilled by persons from socially backward sections who could not complete schooling or technical education. Permanent government jobs made it possible for the subsequent generations from these families to compete for higher services, which is now lost altogether. Interviews with outsourced workers revealed how present incomes were insufficient to fulfil the needs of a family. In most cases, these incomes merely support family incomes earned by the workers' fathers or brothers engaged in alternative work like farming or some petty business. A few outsourced employees came from far off places, often from neighbouring states by travelling a significant distance up and down, as their salaries could in no way pay the rents of the national capital (CS1, personal communication, 22nd August 2017) –

> "It is impossible to run a family on this income. My brothers are engaged as agricultural labourers; together we can meet the ends. When they don't have work, our entire family of eight manages in my salary. Sometimes we have to borrow even for meeting daily expenses."

The reason for outsourcing non-clinical work, according to retired directors of the hospital, was excessive union activities, leading to disruption of hospital work. Recurring protests by Group D staff crippled hospital functioning, and a complete solution was sought through privatisation of such services. This is why outsourcing of cleaning work happened much earlier in 1980 (in the present hospital) while contracting began in 2000. However, the shift to outsourcing merely reflects government's apathy towards the needs of Group D employees, since trade union participation was always strong among public health workers. Unions for doctors, nurses and technical staff still engage in protests when their demands are not addressed by the administration. Outsourcing of ancillary services has iniquitous implications for the already less skilled and marginalised workers.

Feminisation of low paid work

The general trend towards hiring temporary workers for public health has at one level discriminated against the lower level employee. But at another level, we chart a higher proportion of women occupying these low paid positions. In the hospital where the study was conducted, there were only two doctors on contract, who were both women. Even among pharmacists, dieticians, social workers, a significant number of female staff had been appointed on contract. Looking beyond the hospital system, at the level of primary care a significant number of women have been deployed without fixed salary structure. These include the large army of ASHA workers, who have constantly been demanding regularisation and a fixed salary. The National Rural Health Mission (NRHM) introduced ASHA workers in 2005 as honorary volunteers with a provision for performance-based-compensation for work like assisting a low-income woman for institutional delivery and collecting samples for different tests. Their job requirements are not only physically demanding but often pose security threats to these women, who have to make regular home visits. As Nanda comments, this kind of volunteerism perpetuates the perceived low status of women workers within the system since an overwhelming majority of male staff belong to the salaried group. (As cited in Baru, 2005, p. 283)

After ASHA workers, ANMs and Anganwadi workers constitute another army of women workers who have been denied the rightful compensation of their labour – and are now constantly negotiating with the governments to increase their salaries. The trio of ASHA, Anganwadi workers, and ANMs have been most important in India's achievements on Infant mortality and maternal mortality rates, but this trio has also been most neglected and victimised - their conditions exemplify gross feminisation of lowest paid work. Informal interactions with members from these groups revealed the extensively laborious nature of their work which requires them to visit each home in the village, participate in the census and other government programmes, and frequent exposure to verbal abuse and harassment they endure in fulfilling their duties. In return, they don't even get paid government-prescribed minimum wages, rather a meagre honorarium.

Rama Baru who presents a synthesis of studies on conditions of health workers finds that most of these workers come from the poor socioeconomic background.

> … a majority of these workers are women belonging to the lower class/caste combine. An important reason for choosing women of this social background was that women belonging to upper castes would rarely participate outside their houses. Thus one sees that social hierarchy both in terms of caste and gender play an important role in the choice of female health workers [...] the working conditions and wages earned by community-level workers are poor. They are often paid only an honorarium that barely covers their travel costs. (Baru, 2005, p. 283).

She further quotes a 1995 study by Iyer, which reported that while ANMs may belong to upper and middle castes, they were not from landed sections. About 64 per cent of ANMs belonged to landless and poor peasant families. (as cited in Baru, 2005, p. 292)

Thus, here gender combines with class and caste to produce systematic discrimination of women and their labour. In the tertiary hospital where the present study was conducted, interestingly not a single outsourced cleaning worker was a woman. On probing, it was revealed that there were instructions from the hospital authorities not to appoint women workers, because they take more leave of absence. Thus, women suffer on all counts – they are discriminated in getting work, ghettoised in casual or informal occupations, and lastly, denied ethical compensation of their labour. As Amiya Bagchi asserts, with globalisation, all labour has been casualised in larger proportions, but the intensity of casualization has been even greater among women. (Bagchi, 2004, p.11).

Conclusions

Outsourcing and contracting are both fraught with serious violations of workers' rights and dignity. Greater workload accompanies intense job insecurity as there are no avenues for growth, either professionally or financially. It is interesting how contract positions for doctors become smart choices for entry into better jobs, while this advantage is lost to other contract workers. At the lower end of the bureaucracy, outsourcing has become a trap. The exploitation of lower-level workers is intense.

The processes of contracting and outsourcing have produced a staggering array of different terms and conditions under which the three-tier workforce is functioning. At one level it creates operational problems due to multiple layers of administration, control, and governance. It also forces workers with different entitlements to work together, making hospitals into spaces where exploitation becomes institutionalised, and there is little scope for workers' empowerment.

When we take note of the population groups who are engaged in contract and outsourced jobs, the caste, class and gender-based exploitation associated with these 'human-resources' reforms become evident.

The most ironical aspect of these reforms is that despite having initiated outsourcing and contracts for more than 15 years, recent estimates continue to show the high proportion of salaries in government budgets. Evidence shows increasing salary slabs of the residual permanent staff through successive pay commissions. R. Nagaraj's analysis, using data for six years from 2005–06 to 2011–12, shows that during this period, for all categories of central government employees, on average, real wages rose by 7.9 per cent per year – compared to per capita income growth of 6.8 per cent per year (Nagaraj, 2017, p. 165). Thus, human resources reforms have merely removed the lower hierarchy, and the white collar continues to absorb more benefits.

A serious inquiry is needed into the human-resources-related reforms which are translating into iniquitous structures within institutions. Government jobs and institutions, which were means for empowering the society, have become spaces where the marginalised become further excluded, and their exploitation becomes normalised. As C.U. Thresia writes introducing unequal labour standards and dividing the workforce within an organisation and the system threaten the concept of building an integrative, social- development-oriented workforce and health development. (Thresia, 2016, p. 11)

Note: The figures for salaries of permanent and casualised staff pertain to the hospital where the interviews were conducted. These vary across centre/state, across state governments and also according to the level of care – primary, secondary and tertiary.

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Integrating Gender in Medical Education
A Step in Addressing Health Inequities

Sangeeta Rege[1] and Padma-Bhate Deosthali[2]

Medicine, as a field, has been critiqued for being gender biased and not accounting for social determinants that shape health conditions, access to healthcare, and health outcomes. Gender bias permeates many aspects of medicine in India: clinical practice, research, health program delivery, and medical education. In 2007 the World health organization (WHO) acknowledged the imperative of systematic integration of gender in the curricula of undergraduate medical students.

This paper is a case study describing the process of implementing the 'Gender in Medical Education (GME)' project in Maharashtra by the Centre for Enquiry into Health and Allied Themes (CEHAT), the Department of Medical Education and Research, Maharashtra (DMER) and the Maharashtra University of Health Sciences (MUHS). The paper aims to illustrate the complex steps involved in integrating gender concerns into an undergraduate medical curriculum.

The GME project consisted of five components, some implemented sequentially and others taking place simultaneously. Three of the components are relevant to this paper. The first component involved ascertaining interest and support for the project from the concerned authorities. The second component consisted of identifying from among medical educators in the state, a core group of champions for the integration of gender into the undergraduate medical curriculum and building their capacity for gender-analysis of health issues. A third component involved the core-group of-medical-educators working with experts to revise the UG medical curriculum and make it gender-sensitive.

Medical educators were found to be unaware of the differences between the terms gender and sex. They relegated the issue of gender to the discipline of community medicine and did not think that gender should be integrated into other subjects of the medical curriculum. Capacity-building of medical educators from seven medical colleges under the Department of Medical Education and Research (DMER) exposed educators to ways in which gender gaps led to health inequities. The team prioritised five disciplines for integrating gender concerns: gynaecology and obstetrics, community medicine, forensic science and toxicology, internal medicine and psychiatry. Our team reviewed the undergraduate medical curricula of each of these disciplines from a gender-lens and identified topics for gender-integration. The core-group of medical educators worked with experts to weave-in gender issues as an integral part of what was already being taught. Innovative teaching methods and the fact that the revised gender-integrated curriculum did not increase the number of mandated teaching hours made the revised curriculum acceptable to teachers and students.

Working with a team of dedicated and trained medical educators as champions is an effective strategy to integrate gender into the undergraduate medical curriculum, and to successfully implement the revised curriculum in medical colleges.

Keywords : gender bias, gender gaps, medical curriculum, training of medical educators, integration of gender content in medical education

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I

Introduction

Scholars have critiqued the field of medicine as being gender-blind (Verdonk P et al., 2009) and male-biased because the body of medical knowledge views the male body as the norm, with men's experiences forming the basis for describing signs and symptoms of illness. Gender-based inequalities between women and men have not usually been factored-in as critical social determinants of health and disease. One of the consequences of gender-blindness in medicine is the limited gender-sensitivity among medical practitioners, contributing to the compromised quality of care. The World Health Organization (WHO) acknowledges the imperative of integrating gender in medical education specifically in the pre-service-training curriculum (World Health Organization (WHO), 2007) to reduce gender inequities in health. Globally, there have been efforts to integrate gender in the pre-service training of health professionals for at least two decades, in High-Income countries such as the US, Canada, Australia and Germany, and in LMICs including the Philippines and Thailand, among others.

In the context of India, systematic critiques of medicine and public health curricula have highlighted many lapses related to the inclusion of social determinants of health in medical education (Qadeer and Nayar, 2011). Evidence from studies points to gender biases prevalent amongst medical professionals and medical students. For example, a study among medical interns in Maharashtra found that almost 25 per cent of nearly 2000 students considered abortion to be morally wrong (Sjöström et al., 2014). Two-thirds of 75 undergraduate medical students in Pondicherry believed that spousal consent was essential for the provision of abortion services to women (Hogmark et al., 2013). Further, although health providers are the first point of contact for victims of violence against women, and can help women through their sensitive response, providers appear to be reluctant to acknowledge intimate-partner-violence as a health issue (Garcia-Moreno et al., 2015).

Early efforts to integrate gender in medical education in India were made by the Achuta Menon Centre for Health Science Studies, Sree Chitra Tirunal Institute for Medical Sciences and Technology in Trivandrum, Kerala. As a part of this initiative, systematic gender-reviews of medical textbooks for gynaecology and obstetrics, forensic science, psychiatry and community medicine were published in the *Economic and Political Weekly* (2005); and two-week-long workshops were conducted to build the capacity for gender-sensitive teaching in medicine among mid-level medical educators from several Indian states.

Several efforts have also been made in India to address in-service training of medical professionals to respond to the issue of violence against women (Government of India 2016). In Maharashtra, Dilaasa has been an evidence-based crisis centre located in a public hospital to respond to gender-based violence. In 2014, the National Urban Health Mission (NUHM) replicated this model in 11 additional hospitals of Mumbai. Other states have also adopted the model of Dilaasa.

The National Health Policy of 2017 has acknowledged the adverse effects of gender-based violence on women's health and urged states governments to take steps to provide dignified, free and comprehensive services to such survivors/ victims both in private and public-sector health institutions. Although the National Health Policy also makes a passing reference to the urgent need to review and revise the medical and nursing curricula, it does not explicitly mention the integration of social determinants of health and especially gender and other axes of social vulnerabilities (Government of India, 2017).

Against this backdrop, our paper describes an intervention to integrate gender concerns in the undergraduate medical curriculum of one state of India, viz., Maharashtra. The intervention was carried out by Centre for Enquiry into Health and Allied Themes (CEHAT), Mumbai in collaboration with the Directorate of Medical Education and Research (DMER), Maharashtra, and the Maharashtra University of Health Sciences (MUHS).

II

Approach to integrating gender in medical education in Maharashtra

This section describes the implementation of different components of the collaborative project related to integrating gender into the curriculum.

Winning support for and conceptualising the project

Building on past efforts in India and abroad, CEHAT embarked on the 'Gender and Medical Education (GME)' project which aimed to integrate gender in the undergraduate medical curriculum.

The first component of our strategy was to win the support of the concerned authorities in the state of Maharashtra. We used the gender review of medical textbooks, published in 2005, to highlight to the Maharashtra University of Health Sciences (MUHS) and DMER, the gender gaps in the undergraduate medical curriculum. During discussions with DMER and MUHS, we discovered that the MUHS has the mandate to implement curricular changes to integrate gender concerns. The team, therefore, decided to implement GME as a joint project of CEHAT and DMER. We also agreed that medical educators from selected medical colleges in the state, trained by us on gender issues in health, will play a key role and be centrally involved in the rolling out of the project. This would ensure that there was ownership from medical educators for the revised curriculum and besides, we would be able to test the revised curriculum in the medical colleges, to ascertain the feasibility of implementing it.

To ensure that the integration of gender in the curriculum could be done without increasing the teaching load significantly, we had to decide on core disciplines and themes to include. A series of meetings and discussions led to identifying five disciplines taught in MBBS as the subjects in which we would integrate gender concerns. These were: gynaecology and obstetrics, forensic science and toxicology, community medicine, internal medicine, and psychiatry. We chose these disciplines because they are considered to be core disciplines of the undergraduate (UG) medical curriculum. These disciplines also offered significant scope for integrating gender perspectives in teaching UG students. Regarding themes through which we would introduce gender, we zeroed-in on public health concerns such as access to abortion, the challenges in ensuring access to safe abortion while also preventing sex selection, and impact of violence on women's health. These themes were found to be conspicuously absent in the existing undergraduate medical curriculum.

Seven rural medical colleges were identified to participate in the project, and medical educators from the five selected disciplines were to be trained in gender issues in health. We envisaged that champions for gender-integration would emerge from among this group.

Perspectives of medical educators on gender in medical education

Before identifying medical educators who would receive training on gender, we wanted to understand how medical educators perceived the role of gender and other social determinants in medical education as well as practice. A situational analysis exercise was conducted by CEHAT in 2014 with the seven participating colleges.

The situational analysis aimed to understand the gender perspectives of the medical educators and to elicit their opinions, suggestions, challenges, and apprehensions related to integrating gender in medical education and practice. As part of this study, we interviewed 60 medical educators, 24 other staff, and 12 medical students.

The findings of this study indicated that gender was understood by the medical educators in a variety of ways, from a demographic category to health issues of women, to violence against women or increased presence of women in the workforce. A few of the professors referred to gendered social systems and structures. Most of them were of the opinion that gender as a social determinant was irrelevant to the medical curriculum. They also opined that sexual harassment was an outcome of increased women's work participation. The study revealed stereotypes commonly held by educators about women patients. Some of these were that women gave vague histories while men provided clear histories; and that women reported more somatic complaints than men, which implied the presence of intentional hysterical syndrome among women.

The study further found that gender-biased-notions influenced how healthcare providers dealt with women seeking abortion care, or those seeking contraception. Doctors had no qualms stating that they did not offer medical termination of pregnancy to married women unless women had the consent of their spouse or family members. Healthcare providers firmly believed that decisions on abortion and contraception ought not to be the woman's alone. All requests for second-trimester abortions were suspected to be sex-selective and often refused or provided conditionally on women undergoing post abortion sterilisation. Several medical educators had encountered women subjected to violence and were able to list numerous adverse health consequences that women suffered as a consequence. And yet, all of them perceived violence as a legal issue and not a health issue. They could not see any role that medical professionals could play beyond providing medical treatment to a survivor of violence. (John, Bavadekar, Hasnain & Karandikar, 2015)

Building capacity among medical educators

A key component of incorporating gender concerns in medical curricula is the availability of medical educators in the form of trainers and for them to become "change agents" to make revisions in the curriculum and spearhead the implementation of the revised curriculum.

We chose to recruit middle-level faculty such as assistant professors and associate professors who had a fair amount of autonomy and many years of service ahead. They were from six rural government medical colleges and one private medical college and drawn from the five core disciplines in which we were to implement curricular changes.

We developed a two-week course for medical educators for Integrating Gender in Medical Education. The content of the course drew on the earlier courses for medical educators run by Achutha Menon Centre for Health Science Studies in Trivandrum in the early 2000s and on CEHAT's course on the role of health professionals in addressing violence against women. Through intensive training, medical educators learnt about the social construction of gender and its interaction with other axes of privilege such as economic class or caste; examined assumptions about men and women that lead to discrimination in health care settings; discussed exclusion of disadvantaged communities from quality health care; and gained insights into the ways in which power and privileges operate in the provisioning and receiving of healthcare. We used participatory methods, which engaged the medical educators in co-construction of knowledge. Such training enabled them to understand how sex and gender relate to causation and response to health and illnesses. It assisted them in critically reviewing aspects of medical research that upheld gender biases or gender blindness, and led to health disparities.

The course also equipped medical educators with an understanding of client centred care and skills for planning for gender-sensitive services within hospital settings and for mainstreaming gender in undergraduate teaching. Specific emphasis was laid on contraceptive information and services; access to safe abortions while preventing sex selection, domestic violence, sexual violence, ethical issues such as informed choice and consent and issues related to privacy and confidentiality amongst others.

The course was conducted in two stretches of one-week each because it was not possible for medical educators to be away from their hospitals for any longer than that. We also had to organise an additional ‘bridge’ course to bring in new participants because of drop-outs from the original batch.

One way in which we sought to facilitate ongoing learning by these medical educators was to create a support group consisting of gender-sensitive subject-experts from each of their disciplines. Most of the mentors participated as resource persons in the course and continued to support the core-group of ‘champion’ medical educators (to be called the ‘core group’ of medical educators, from here-on) during the process of gender-mainstreaming the curriculum.

The entire training process resulted in a dramatic change in the mind-sets of the core group. They said that they could not now teach in the same gender-blind or biased manner as they used to before the GME training. They raised concerns over abuse of women in the labour room and said that all labour wards ought to have a poster on the human rights of women in labour. Before the training, they had not been introduced to the idea that rude behaviour, derogatory comments about women’s sexual activity, scolding the women, pushing women to be in lithotomy positions, etc. amounted to obstetric violence. The trainees said that the session on Population Policy had opened their eyes and convinced them of the need to focus on rights-based contraceptive services rather than family planning which only looked at married couples.

Evolving the gender-integrated curriculum

The core-group of medical educators who participated in the capacity-building played a crucial role in determining the process of curricular revision to integrate gender concerns. Some of the critical decisions they contributed to, were:

- A few stand-alone lectures on gender would not be adequate to bring about gender-sensitivity and awareness among undergraduate medical students

- The original plan (at the start of the project) of restricting the gender-content to issues of abortion, sex selection and violence against women would not be adequate to build a gender perspective of medical students.

- Gender aspects would be interwoven into the academic curriculum of the five disciplines for all the nine teaching semesters. Each topic would be reviewed, and gender aspects would be developed for integration into the lecture on that topic.

We accepted the recommendations of the core-group, although this vastly increased the scope of the curriculum change. A review of the curricula in the five disciplines indicated the need to integrate gender concerns in 31 topics for gynaecology, 27 topics for community medicine, 11 topics of internal medicine and eight topics in forensic medicine and toxicology, across seven semesters of the MBBS curriculum.

Besides these topics, two foundation lectures were to be introduced, one on understanding gender and sex and the second on recognising the health consequences of gender-based violence. The first foundation lecture on gender and sex was to be introduced at the end of the para-clinical phase when medical students would have developed an understanding of anatomy, physiology, and biochemistry. The second foundation lecture on gender-based violence was to be introduced in the clinical phase, during the sixth semester, because undergraduate students would be attending clinics and would have the scope to respond to women seeking care following an incident of gender-based-violence.

For the curriculum revision in the five disciplines, we identified five focus areas to be woven into the teaching content. These were [a] Social construction of gender: Sex and gender [b] Gender as social determinant of health, [c] Gender-based violence [d] Abortion, contraception and sex selection and [e] Ethics in practice. We agreed that these focus areas were critical to gain a comprehensive understanding of gender and health.

The following section illustrates with examples how these focus areas were included in the five disciplines. The next step, and the most challenging one, was ensuring that the newly developed content fit the actual hours of teaching allocated to lectures. Efforts had to be made to ensure that there is an element of innovative teaching techniques, but at the same time, it had to fit in the time slot of a given lecture.

III

Weaving gender into the five disciplines through five focus areas

1. Focus Areas One: The social construction of gender

The aim was to help medical students understand the social construction of gender, how gender operates as a system and defines roles of men and women based on expectations of society and accords a secondary status to women. We also decided to include the concept of transgender identities and alternative sexual orientations. None of these concepts were being taught in the five disciplines.

To cite a few examples, the discipline of community medicine comprises of topics such as general epidemiology, social psychology and social factors affecting health but fails to articulate gender as a social determinant of health. Psychiatry includes topics such as affective disorders, anxiety disorders but does not look at gender as a risk factor for such illnesses. Forensic science and toxicology cover topics such as sex verification tests. But there is no content on the various gender identities and the fluidity of gender. It also does not carry any critique of the current tests being carried out, from an ethical perspective. Also, teaching in forensic science is restricted to male models, and hence students cannot visualize injuries and trauma caused to women and their bodies. The discipline of internal medicine is silent on how gender mediates communicable and non-communicable diseases. In the subject of gynaecology, there is no reference to gender-power inequalities and how it influences contraceptive use, medical termination of pregnancies and intimate partner violence. All the five disciplines are silent on health problems of transgender and intersex persons.

We give below a few examples of how this focus area was integrated. In **gynaecology and obstetrics,** the health needs of intersex persons was introduced within the topic of development of genital tract, congenital anomalies and chromosomal abnormalities. The topic on gynaecological and surgical conditions in pregnancy, genital prolapse and tumours included gender-related factors contributing to prolapse, such as lack of rest and heavy work-load in the postpartum period and multiple pregnancies. **Forensic medicine** and toxicology integrated gender as a social construct in the topic of personal identity. The limitations of sex verification tests to ascertain the sex of a person and how such tests are used against women were highlighted. Topics on medico-legal aspects of sex, marriage and infant death discussed the concept of "virginity" and lack of conclusive scientific evidence to determine virginity in women. The concept of virginity was challenged not rooted in science but in socially constructed notions of women having to be chaste or a virgin until marriage. International evidence and doctors statements against virginity tests were introduced.

2. Focus Areas Two: Gender as a Social Determinant of Health

Gender as a social determinant of health included the teaching on gendered nature of health conditions, diseases and treatment, gender bias in diagnosis, the stigma and other consequences of certain illnesses on women. Gender issues in current health programmes and policies and the gender differences in access to resources and health care were also included.

We found gaps in addressing gender issues across all the five disciplines. The teaching of aetiology and factors causing diseases does not discuss gender as a determinant that may predispose women to certain conditions. Topics on the manifestation of pulmonary disorders do not make a connection to women's role in cooking with wood/charcoal stoves in poorly ventilated kitchens, or to passive smoking. Community medicine lectures do mention gender but only when discussing family planning methods. Gynaecology too is silent on gender, and there is no mention of how gender is associated with maternal mortality or problems related to accessing abortion services.

In the revised curriculum, gynaecology and obstetrics integrated gender as a social determinant in topics such as contraception, physiology of conception and ovulation amongst others. It familiarised students with concerns such as a disproportionate focus on women's use of contraception as against no programmatic efforts towards male contraception, and the social pressure on women to prove their fertility. In forensic medicine, the topic of medico-legal aspects of sex, marriage and infant death integrated gender as a social determinant of health through a discussion on existing differential and biased treatment towards individuals such as sexual minorities. It introduced students to violations such as lesbians being made to undergo 'corrective rapes' while 'conversion therapy' was used on gay men, which have far-reaching impact on their health and violates their sexual rights.

In **community medicine,** topics on nutrition and environmental health integrated gender as a social determinant of health. The topic of nutrition introduced a lifecycle approach to dealing with anaemia for girls. It enabled them to understand how gender plays a role in lack of access to nutritious food right from the birth of a girl child to her old age and how factors such as neglect and secondary treatment lead to anaemia, osteoporosis and a host of other preventable health conditions. **Internal medicine** integrated gender dimensions in the introduction to infectious diseases such as Malaria, HIV and TB. Gender-related vulnerabilities were also connected to topics such as Irritable bowel syndrome (IBS) in case of gastrointestinal diseases .How decisions related to kidney transplantation are influenced by patient-gender was discussed in nephrology.

3 Focus Area Three: Gender-Based Violence (GBV)

There is considerable global and local evidence of health consequences of different forms of gender-based violence. WHO's clinical and policy guidelines (WHO, 2013) specifically articulate the role of doctors in recognising health consequences associated with violence against women and offer survivors treatment and psychological first aid. Our focus was to include information on the definitions and prevalence of various forms of gender-based violence and their linkages with health, the role of health providers in responding to GBV, the various laws, guidelines/ protocols and their mandate for doctors and health facilities.

In the gender-integrated curriculum, Gender-based violence (GBV) is integrated across all the disciplines in the context of physical, psychological and sexual health consequences for women, transgender, and intersex persons as well as gay men and lesbians. Two foundation lectures on gender-based violence were added to the disciplines of obstetrics and gynaecology and community medicine, one in the first semester and one in the sixth semester. The foundation lecture in Obgyn was about responses to different forms of sexual violence and recognising their effects as health issues while the foundation lecture in Community Medicine looked at gender-based violence from a public health perspective and thus focused on primary, secondary and tertiary care strategies to respond to health consequences of violence.

We integrated this theme into the **gynaecology** curriculum in topics such as puberty and menopause, antenatal care, pregnancy and infections of genital tract amongst others. It explained to the students that as healthcare providers, they should detect and respond to violence in pregnancy. It also pointed out that girls in their puberty /adolescence might experience sexual violence and that doctors should remember to ask about violence during history-taking. Health problems such as urinary and genital tract infections and prolapse of the uterus may be associated with violence, and so doctors needed to probe into these concerns sensitively.

In **community medicine,** information on health consequences of different forms of violence was included in the topic on sociology. The content dealt with physical, verbal, sexual as well as 'structural violence' and how those led to adverse health consequences amongst women The content also imparted skills in recognising signs and symptoms associated with violence and asking about abuse as part of clinical enquiry. In the **internal medicine** curriculum, integration of gender-based violence was done within the topic on 'poisoning'. Medical students were instructed to seek history related to consumption of poison and assess whether this was an accident or an attempt to end one's life. In **forensic science and toxicology** medical students were alerted to examining the correlation between burns and domestic violence. The curriculum stressed on the importance of systematic medico-legal documentation and especially in cases of sexual violence was highlighted.

4 Focus Area Four: Abortion, Contraception and Sex Selection

The focus in this theme was on providing a nuanced understanding of the laws- on Medical Termination of Pregnancy (MTP) and on Prevention of Misuse of Pre-conception and Pre-Natal Diagnostic Techniques (PCPNDT) and clarifying that the PCPNDT Act does not restrict access to abortion services for women. Various issues concerning access to safe abortion and contraception were included, such as several current practices related to provision of contraceptive and safe abortion services that are significant barriers to women's access to these services. The topics have been integrated in two disciplines namely gynaecology and obstetrics and community medicine.

We adopted a human rights-based approach in both disciplines. In **gynaecology**, medical students are familiarised with gender as a risk factor to maternal morbidity and mortality. The reasons for women seeking abortions in the second trimester have been included to stress the fact that all delayed abortions should not be misunderstood to be sex-selective; women may have delayed the process because of other reasons such as lack of money, time and someone to escort them. Topics on permanent and temporary contraception methods provide students with an insight into coercive and poor-quality services related to tubal ligation. In **community medicine**, the topic on Family Planning Programme of India has been extensively revised. It now uses a gender-lens to address issues such as the continuing fear of population explosion, emphasis on targets, and over-reliance on camp-based approach for sterilisation. Students were encouraged to critique the term 'family planning' and the need to replace it with a more inclusive term 'contraception' which addresses needs of all individuals including those who may fall out of the traditional family unit and marriage. Students are enabled to carry out critical reviews of the National Family Planning Programme as these focus on female sterilisation as the main method of contraception and does not sufficiently focus on male contraception.

5 Focus Area Five: Ethical Issues in Practice

The focus area on ethical issues in practice included concepts of informed consent/refusal, privacy and confidentiality, recognition of patients' rights, and gender sensitivity in history taking and examination. It also encourages reflecting on the various biases prevalent in the medical discipline and to be aware of provider biases. Though ethical principles and values are covered in the first phase of MBBS curriculum in Semester 1 and 2, the content is restricted to very basic principles of doctor-patient relationships and dos and don'ts in medical research. Dilemmas and challenges encountered by doctors and ethical decision making find no mention in the curriculum

In **internal medicine,** we covered this theme within concepts and objectives of history taking. Emphasis was laid on implementing privacy and confidentiality and enabling patients in general and women patients, in particular, to be at ease to disclose their health concerns. Examples of situations such as disclosing HIV status and ethical principles involved were included. In gynaecology, we incorporated this theme within the topic of temporary and permanent methods of contraception. The inclusion enabled medical students to learn about ethical concerns such as those related to advising women to accept tubectomy, forced sterilisations of women and persuasion to opt for postpartum IUDs. The issue of obstetric violence was also introduced in the topic on normal labour and physiology, highlighting concerns such as unnecessary C-sections, routine episiotomies and physical /verbal abuse in labour rooms.

In community medicine, the theme was integrated with the topic of family planning. It familiarises students with the concept of informed consent in the context of post-delivery contraception use by women and trained medical students to help women make an informed decision as compared to opting for routine sterilisation after two children.

The theme of ethics in f**orensic medicine and toxicology** was introduced in topics such as medico-legal aspects of sex, marriage and infant death, wherein concerns of virginity testing and its ethics are highlighted. Similarly, the subject of personal identity provides an alternative perspective on the scientificity of sex verification tests. Ethical dilemmas related to surrogacy and assisted reproductive technologies are also dwelt upon. Further, the curriculum discusses medico-legal care for rape victims/ survivors in the light of the therapeutic role of doctors. Students are made aware of unscientific examination aspects such as the one finger test and comment on the hymenal status, which is a violation of norms of ethical conduct of doctors.

V

Moving forward

Through the strategy of developing a core-group of champion medical educators who were gender-sensitive and equipped to carry out a gender analysis of health issues, we were able to bring about curricular revisions that were woven integrally into the current undergraduate medical curriculum and were acceptable to medical educators.

CEHAT-DMER's initiative for integrating gender concerns in the medical curricula has been a success.

The Academic Council of Maharashtra has approved the gender-integrated curriculum. A directive for implementation of the gender-integrated curriculum has been issued in 2018 to medical colleges across Maharashtra.

A positive beginning has been made. Moving forward will require champions within each medical college who would ensure and sustain the implementation of the revised curriculum. For these champions to maintain their interest, efforts need to be made at an institutional level to continually update and upgrade their knowledge on gender and health concerns. Further, for the gender-integrated-curriculum to be taken seriously, gender concepts should be embedded in the assessment and evaluation of undergraduate medical students.

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Unmet Health Care Needs Among Urban Poor Population of Thiruvananthapuram, India

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In recent times, a significant proportion of the global population lives in an urban context, as cities offer unparalleled opportunities for livelihood. In an urban setting, when a majority of programmes, data, and services focus on urban averages, the intra-urban differences are often missed, rendering urban health inequities invisible. The objective of this paper is to examine the unmet health care needs of the urban-poor population, through examining the many steps involved in having one's health care need to be met, from finding a suitable health provider through to having the health problem resolved. After providing an overall picture of unmet needs and associated barriers, we delve deeper into the pathways to unmet need for care for acute morbidity conditions.

A cross-sectional epidemiological survey was conducted to assess the health care needs of the urban- poor population and a series of case profiles to identify those people who get left behind within the poor urban section. The study population comprised the urban-poor population of Thiruvananthapuram Municipal Corporation. Households enlisted in the 'Below Poverty Line' (BPL) list ward-wise for urban Kerala were the study universe, and the sample was selected using multi-stage cluster sampling. The most recent episode of illness or health care need in the sample household within the reference period was documented, and five categories of health care needs were captured. We examined the outcome variable 'unmet health care needs' through a sequential five-step process: Sought health care; Consulted health provider; Started treatment; Completed/ On-going treatment; Health problem resolved.

The study covered 529 household members whose age ranged from one month to 90 years, with a mean age of 34 years. Among the 236 (39.9 per cent) study participants with a health care need, 123 (52.1 per cent) had an unmet need for health care. Amongst the different categories, unmet health care needs for acute morbidity conditions were noticeably higher (74.3 per cent). More than half of those with chronic conditions (53.9 per cent) or need for hospitalization (56.5 per cent) had unmet health care needs. Truncation of health care- seeking before resolution of the problem seems to be more drastic for acute conditions when compared with other types of health care needs. Of those with acute morbidity conditions, larger proportions were females (76.3 per cent) and those in the age group of 60 years and above (86.7 per cent). Both patient-related factors such as age, gender and occupation, and health system related factors such as availability and quality emerged as potential barriers to health care access. Both sets of factors played a role in creating urban health inequities. Case profiles depict the circumstances that result in unmet need and how multiple disadvantages play out creating intersectional inequities in an urban setting.

Documenting unmet health care need is a way of moving towards more equitable health care provision and reducing urban health inequities in the long run. This further helps a welfare state like Kerala to meet its Sustainable Development Goal (SDG) commitment to 'leave no one behind.'

Keywords : urban poor, unmet health care needs, health inequities

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In recent times, a significant proportion of the global population lives in an urban context as cities offer unparalleled opportunities for livelihood (Muggah, 2012). Urban living is a double-edged sword though bestowing on or depriving many people of conditions for healthy life. As more people migrate to urban areas, the process of unplanned urbanization gives rise to numerous health challenges. A study on the changing urban environment identifies five major types of health threats in urban areas. These are: infectious diseases that result from crowding and poor living conditions; acute and chronic respiratory illnesses related to air pollution; chronic, non-communicable diseases related to unhealthy lifestyle; injuries related to accidents and crimes; and problems associated with climate-change, such as heat strokes and flooding-related communicable diseases (Bai, Nath, Capon, Hasan & Jaron, 2012, p. 466). Bai et al., (2012) observe that these threats are unevenly distributed across the urban population.

Stephens (1996) draws attention to the inequitable distribution of health risks in the urban setting. She comments that many studies focus on urban poverty and its consequences but not on urban inequality. The author considers health as a fundamental measure of urban inequality and health indicators as a reflection of policy approaches. When some groups benefit at the cost of others, leading to a higher burden of risks and diseases in the second group, this is in fact, health inequity, i.e., a lack of justice. Health inequities are produced when one social group does not have control of their exposure to risk and ability to treat their health effects (Stephens, 1996, p.13).

In an urban setting, when the majority of programmes, data, and services focus on urban averages, the intra-urban differences are often missed, rendering urban health inequities ‘invisible’. Urban health inequities mainly arise from unjust differences in the social determinants of urban health, which operate not only at the individual and household levels but beyond. The role of governance, among other social determinants, is highlighted by Vlahov et al., (2007). They observe that growth of slums in both developing and developed countries is the result of poor urban governance, which does not provide primary housing, infrastructure, water supply and sanitation services to the urban poor. The illegal nature of slums excludes the slum dwellers from getting legitimate health and social services.

The urban health system also plays a significant role in contributing to urban health inequities. A paper introducing a framework for examining urban health observes that urban dwellers have to contend with poor public health infrastructure and a private sector of variable and unpredictable quality. Informal providers operate at one end of the spectrum, while large corporate hospitals with the prohibitive cost of services operate at the other end. Services that are good quality, as well as affordable, may be hard to come by (Butsch, Sakdapolrak & Saravanan, 2012). Public preventive health services in India – such as child immunization – often do not reach the most disadvantaged households in urban slums (Agarwal, Bhanot & Goindi, 2005). For example, a 2015 study from Delhi found that utilization of reproductive health care among urban poor households was much lower than the urban average (Devasenapathy et al., 2015).

This paper attempts to examine the paradox of high health care availability with poor health outcomes through the concept of unmet need. This concept was used in many European countries to examine the achievement of universal health care, wherein unmet need was ascertained by directly questioning individuals to find out whether there was a time that they needed health care but did not receive it, or whether they had to forego health care (Allin & Masseria, 2009).

Unmet need is also defined as “the differences between services judged necessary and services actually received.” This may also be interpreted as an indicator of health inequity. In the words of Andersen, “equity in access to health care is best considered in the context of whether people in need of medical care receive it or not” (As cited in Pappa, Kontodimopoulos, Papadopoulos, Tountas & Niakas, 2013, p. 2018).

Barriers to care for the urban poor can be either due to inadequate urban health infrastructure affecting the urban population as a whole or can be due to marked marginalization related to geographical and financial constraints as well as due to pure discrimination against the poor (Matthews et al., 2010, p.3). The purpose of identifying such barriers to health care at multiple levels will enable us to make policy recommendations on how these can be effectively addressed.

Kerala has a long history of well-organized public health services as well as a wide network of private health institutions. However, there still remain barriers to accessing health care, especially for urban poor, who are often left with a limited number of affordable health care options (Levesque, Haddad, Narayana & Fouriner, 2006). This paper aims to examine the unmet health care needs of the urban poor population in Thiruvananthapuram city of Kerala, by examining the many steps involved in having one’s health care need to be met. These steps range from finding a suitable health provider to having the health problem resolved. After providing an overall picture of unmet needs and associated barriers, we delve deeper into the pathways underlying the unmet need for care for acute morbidity conditions.

Methods

Study design and setting

This paper is based on a larger original study on the ‘Development of an urban primary level health care services package based on the assessment and prioritization of health care needs of the urban poor population.’ Data were collected through a cross-sectional epidemiological survey, which assessed the health care needs among the urban poor population in Thiruvananthapuram. The paper also reports findings from a series of case profiles of people who get left behind within the urban-poor section. Thiruvananthapuram Municipal Corporation of Kerala, India was chosen as the study setting. The percentage of urban population in Thiruvananthapuram district is 47.7 per cent (Census of India, 2011) and Thiruvananthapuram city alone accounts for 68 per cent of the urban population in the District (Government of Kerala, 2005). In 2014, under the National Urban Health Mission (NUHM), eleven Urban Primary Health Centres (U-PHCs) were started within Thiruvananthapuram Municipal Corporation. The distinct areas served by each U-PHCs were considered as our study setting. The study population comprised of the urban-poor population of Thiruvananthapuram Municipal Corporation. Households enlisted in the Below Poverty Line (BPL) rank list ward-wise for urban Kerala were the study universe.

Sample selection

The sample was selected using multi-stage cluster sampling, to reach the estimated sample size of 130 urban poor households. From the eleven U-PHCs, five were randomly selected, and two wards each were randomly selected from the five U-PHCs. We chose the first household in each ward with a random start from a list of urban poor households. We interviewed the female head of the household or the adult woman of the household next in seniority to the head. Five hundred and ninety two (592) individuals from 130 urban poor households were included in the study.

The cross-sectional survey was carried out from January to April 2017 and data was collected using a survey tool in the local language (Malayalam) developed by the principal investigator. The study obtained ethical clearance from the Institutional Ethics Committee of the concerned Institute.

Outcome variables: Met and unmet health care need

The last episode of illness or health care need in the sample household within the reference period was documented. Five categories of health care needs were captured. The categories of health care needs are:

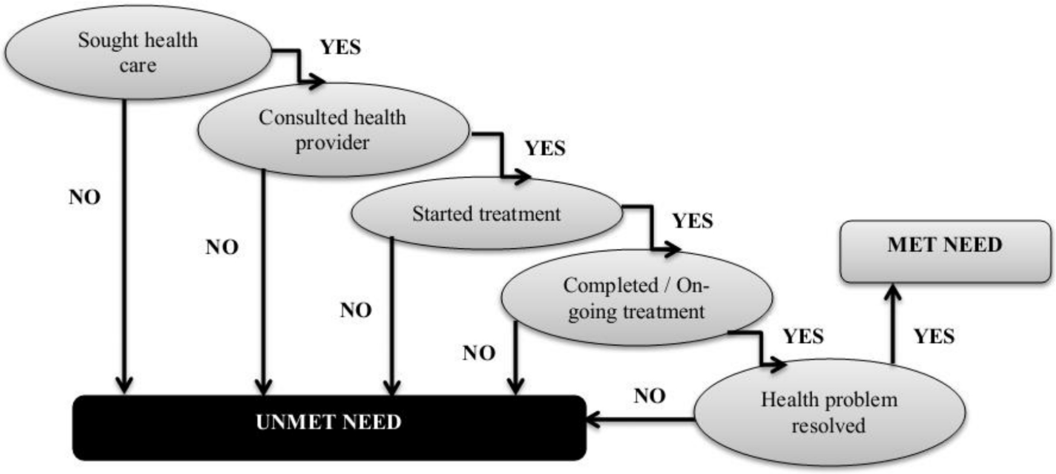
- Unwell with acute conditions in the past two weeks which led to the disruption of daily activities; not requiring hospitalization but requiring out-patient care.
- Suffering from any chronic condition requiring regular check-ups and medications in the past one month.
- Hospitalized in the past one year for any illness.
- Sought care for any maternal and reproductive health care need in the past one year.
- Sought care for any child health care needs in the past one year.

In this paper, the outcome variables of interest, namely met and unmet health care needs were defined as follows. A health care need was operationally defined as ‘met need’ when the person successfully sought and obtained health care, completed treatment and reported that the problem was resolved, or if the person subjectively considered his or her need as met even while undergoing treatment. Likewise, a need was operationally defined as ‘unmet need’ if the need was not met either because of not accessing health care or discontinuing before completing the course of treatment or if the person reported that his/her need was unresolved even after completing treatment or with continuing treatment.

We used a five-step process outlined by Tanahashi’s approach, which is principally a model to assess the health system bottlenecks, emphasizing the importance of the actual performance of the service as expressed by people who had received the service (Tanahashi, 1978). The steps (see Figure 1) are:

- Sought health care
- Consulted health provider
- Started treatment
- Completed/ On-going treatment, and
- Health problem resolved

Figure 1: Five-step Process of Identifying 'Unmet Health care Needs.



The first step in identifying unmet health care needs was documenting who sought care, who did not seek care and what were the barriers they faced during the process of seeking health care. In the second step we identified, among those who sought health care, how many consulted the appropriate health provider, and if not, what were the reasons. In the third and fourth steps we documented among those who consulted health provider, how many started their treatment and how many completed treatment or were undergoing treatment respectively; and if they did not complete treatment, what the reasons were. In the final step, we identified how many considered their health problem or need as resolved and the whys and wherefores underlying it. Through this sequential process based on our operational definition, we classified health care needs into met and unmet health care needs.

Results

Overall morbidity profile

The study covered household members whose ages ranged from one month to 90 years, with a mean age of 34 years. In our study population, 327 (55.2 per cent) of the urban poor household members were females, and 265 members (44.8 per cent) were males respectively. The proportion of those who had any health care need was 236 members (39.9 per cent). Eighty- four males (35.6 per cent) and 152 (64.4 per cent) females reported having one or more health care needs. The percentage distribution of the five different categories of health care needs across the study population is shown in Figure 2.

Figure 2: Distribution (per cent) of Diverse Categories of Health care Needs in Study Population.

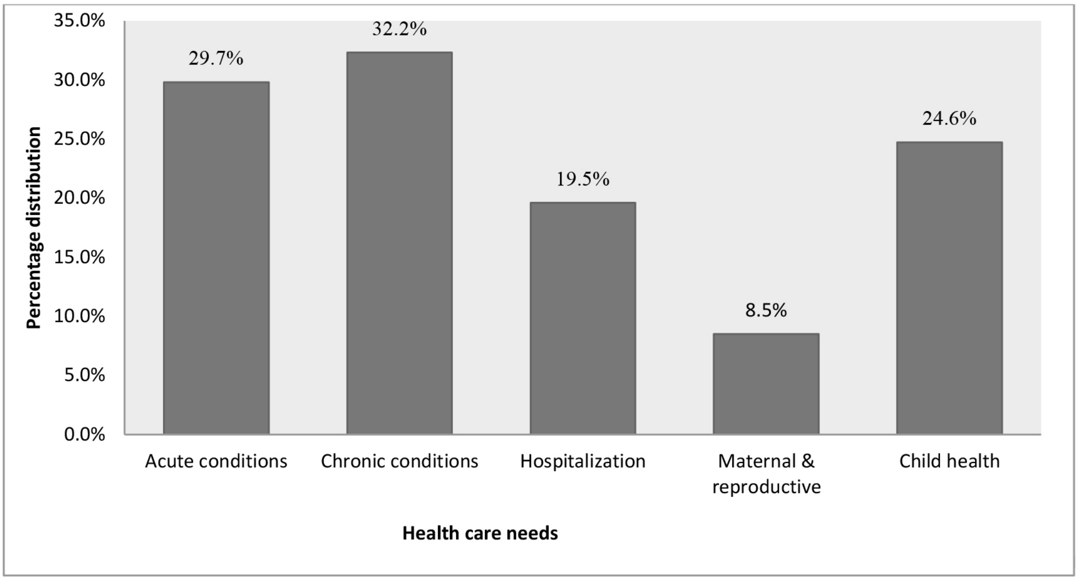


Table 1: Details of Ailments in Different Categories of Health care Needs

Categories of health need	N (per cent)
Acute conditions	**70**
Body pain, knee & joint pain	17 (24.3)
Headache	6 (8.6)
Vomiting, gastritis	2 (2.9)
Poisoning, Bites, Stings, Trauma, Minor injuries, Fracture, Burns & Corrosions	6 (8.6)
Fever & other infections	22 (31.4)
Acute episodes of Non communicable diseases	11 (15.7)
Occupational diseases	1 (1.4)
Skin & autoimmune diseases	2 (2.9)
Dental health problems	3 (4.3)
Chronic conditions	**76**
Non communicable diseases	57 (75)
NCD-Cancer	9 (11.8)
NCD-Mental health	4 (5.3)
Skin & autoimmune diseases	4 (5.3)
Eye & ENT diseases	2 (2.6)
Hospitalization	**46**
Gastritis	1 (2.2)
Poisoning, bites & stings	1 (2.2)
Injuries & fractures	5 (10.9)
Fever	8 (17.4)

Chronic communicable diseases (TB)	2 (4.3)
Non communicable diseases	22 (47.8)
NCD-Cancer	5 (10.9)
Eye & ENT diseases	2 (4.3)
Maternal & reproductive health	**20**
Pregnancy	9 (45)
Need for family planning	2 (10)
Disorders of menstruation	2 (10)
Uterine fibroids & cancers	1 (5)
Inability to conceive	5 (25)
Anaemia	1 (5)
Child health	**58**
Immunization	25 (43.1)
Post-natal health care	2 (3.4)
Common childhood illness	20 (34.5)
Chronic diseases	7 (12.1)
Allergic reactions	4 (6.9)

Notes: N (per cent) – Number (percentage), NCD – Non Communicable diseases, ENT – Eye Nose & Throat, TB – Tuberculosis.

Among those with any health care needs, chronic conditions were the most reported. Seventy members (29.7 per cent) were unwell with acute conditions in the past two weeks which led to disruption of daily activities requiring out-patient care; 76 members (32.2 per cent) had chronic conditions requiring regular check-ups and medications in the past one month, and 46 members (19.5 per cent) were hospitalized in the past one year for any illness. Maternal, reproductive and child health care needs were recorded separately. Twenty members (8.5 per cent) had maternal and reproductive health care needs, and 58 members (24.6 per cent) had child health care needs in the past one year.

Table 1 displays the distribution of ailments among different categories of health care needs. Among those who were unwell with acute conditions; 31.4 per cent suffered from fever and other infections followed by 24.3 per cent with body pain, knee and joint pain and 15.7 per cent suffered from acute episodes of Non-Communicable Diseases (NCDs). It was found that NCDs were the leading cause of health care need for chronic conditions (75 per cent) and hospitalization (47.8 per cent). NCDs in the study population included conditions such as hypertension, diabetes, hypercholesterolemia, stroke, hyperthyroidism, kidney complaints and breathlessness. In maternal and reproductive health care needs, pregnancy (45 per cent) and inability to conceive (25 per cent) were commonly observed followed by the need for family planning and disorders of menstruation. In child health care need, immunization (43.1 per cent) followed by common childhood illness (34.5 per cent) was predominantly seen. Common childhood illness broadly covered viral infections, fever, diarrhoea, cough, cold, worm infestations and other infections.

Unmet health care needs across different health categories

Out of the 236 people with a health care need, 123 people (52.1 per cent) reported an unmet need for health care; a larger proportion of those with unmet needs were females (65 per cent). In this section, we examine the 'unmet health care needs' through a sequential five-step process across five domains: Sought health care→Consulted health provider→Started treatment→Completed/On-going treatment→Health problem resolved. Figure 3 displays a stacked bar-chart showing the distribution of met and unmet health care needs across the categories of health care needs. Results show a wide variation in met and unmet health care needs across the various categories. Met health care needs for acute conditions were significantly lower at 25.7 per cent when compared to other categories. This implies that a larger proportion of 74.3 per cent of needs were unmet during the course of health care seeking. More than half of those with chronic conditions (53.9 per cent) or with a need for hospitalization (56.5 per cent) had their health care needs unmet. Unmet health care needs for maternal and reproductive health as well as child health were considerably low at 40 per cent and 13.8 per cent respectively.

Barriers to health care access

Study results show that respondents faced various barriers while accessing health care. These included both health system and personal factors. We classified the barriers to health care access encountered in each of the five steps for met need (see Table 2). For hospitalization and maternal and reproductive health needs, a major proportion reported no barriers while accessing health care (Figure 3). Among those who were unwell with an acute condition, 18 people (25.7 per cent) did not seek health care, because they faced either accessibility, acceptability or multiple barriers while accessing health care. On the contrary, among those who were hospitalized, 31 people (67.4 per cent) faced a barrier during the course of hospitalization. Of all the five steps for met need, barriers to seeking health care was a predominant category and acceptability issue related factors emerged as the predominant one.

Figure 3: Distribution of Met and Unmet Health care Needs Across Categories of Health care Needs.

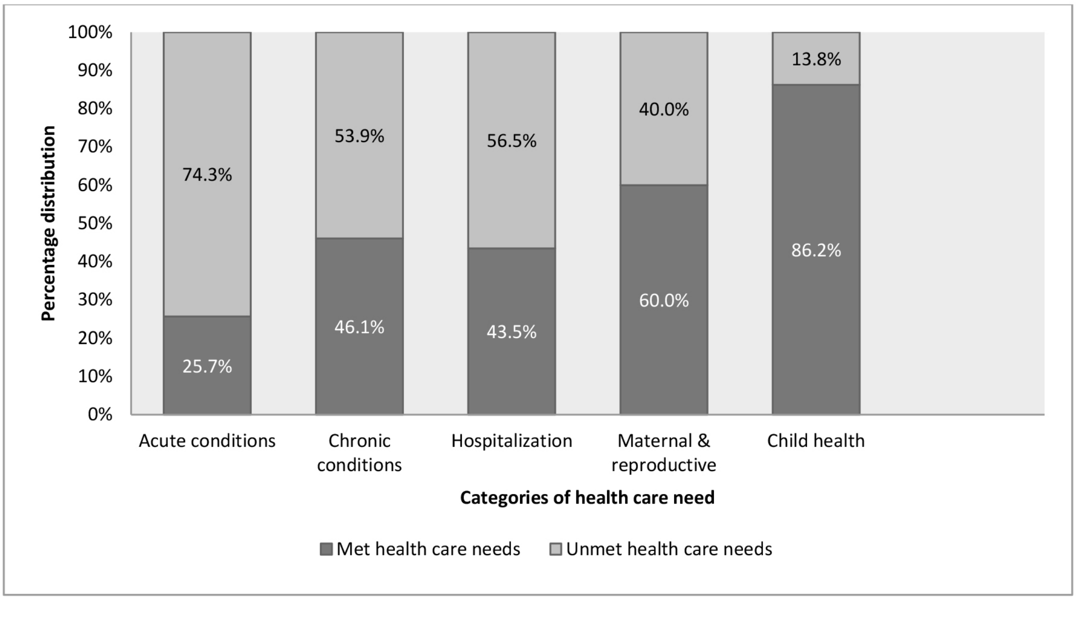


Figure 4: Truncated Health Care Seeking Pattern Across Different Categories of Health care Needs.

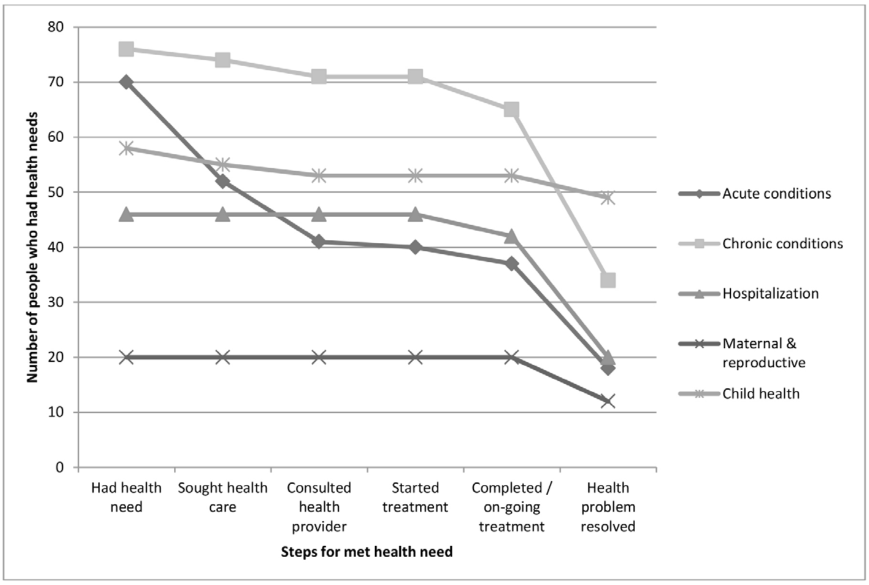


Table 2: Types of Barriers to Health Care Access Encountered at Each of Five Steps

Identified barriers
I. Barriers to seeking health care • Non availability of attached laboratory facility • Non availability of preferred AYUSH health facility • Non availability of doctors and health care staffs in the facility • Non availability of qualified staffs for specific health needs • Non availability of drug supplies • Non availability of other supplies and equipment's • Health facility located far away • Financial cost of accessing care • Transportation difficulties • Health facility located far away • Long waiting hours • Non-availability of accompanying person • In-convenient working time • Inability to take time off from routine tasks • Need to take leave for accessing care • Reluctant to receive medical treatment (personal preferences, religious beliefs) • Lack of privacy • Ways of treatment procedure not advanced according to personal preference • Indifferent behaviours of health care providers • Absence of doctors of preferred sex (male/female) • Distrust the quality of care provided • Do not consider treating ailment as important • Past negative incidents associated with the health facility • Stigma associated with such hospitals (Example: TB hospitals)
II. Barriers to consulting a health care provider • Prefer buying medicines from medical shop • Long waiting hours • Reluctance to take medical treatment from a hospital • Past negative incidents associated with health facility • Ways of treatment not advanced according to personal preference
III. Barriers to starting treatment • The financial cost of treatment
IV. Barriers to completion or continuation of an on-going treatment • Treatment was considered expensive / financial crisis • Could not continue treatment as health facility was located far away • Difficulty in adjusting to drugs and treatment instructions • Fear factor • Irregular supply of medicines • No other treatment option available (terminal stage) • The absence of a caretaker or accompanying person

V. Barriers to considering health problem as resolved

- Unable to access referral care
- Unable to bear the high cost of drugs and treatment in the continuum of care especially for chronic diseases
- Treatment was unsuccessful and led to serious complications

Table 3: Steps in Identifying 'Unmet Health Care Needs' for Acute Conditions

Domains	Categorization of domains for identifying the variable 'unmet health care needs' for acute conditions N (per cent)	
Sought health care (70)	YES	NO
Consulted health provider (52)	**52 (74.3)**	**18 (34.6)**
Started treatment (42)	42 (81)	10 (19.2)
Completed / On-going treatment (41)	41 (97.6)	1 (2.4)
Health problem resolved (37)	37 (90.2)	4 (9.8)
	18 (48.6)	19 (51.4)
	18 (25.7)	**52 (74.3)**
	Met need	**Unmet need**

Note: N (per cent) – Number (percentage).

Truncation of health care seeking before resolution of the health care need

Amongst the different categories of health conditions considered, unmet health care needs for acute conditions were noticeably higher. When we traversed through each step for identifying unmet health care needs for acute conditions, there seemed to be a sequential fall in met health care need with every step (see Figure 4). Truncation in health care seeking seems to be more drastic for acute conditions at the point of seeking care and while consulting a health provider. However, things are different for other types of health care needs. With chronic conditions and hospitalization, the reduction in met need seems to take place from completed or on-going treatment to the point of considering their health problem as resolved. For maternal and reproductive and child health, unmet health care needs were only noticeable in the last domains.

Unmet health care needs for acute morbidity conditions – a detailed examination

After identifying the extent of unmet need and the health conditions where these are most seen, this paper focuses only on one category to delve in-depth: acute health problems. The descriptive analysis illustrated in Table 3 gives evidence on why health care seeking gets truncated and important reasons that were reported as causing this. Among those who had acute conditions, 18 persons (34.6 per cent) did not seek health care due to single or multiple barriers. Among those who sought health care, 10 people (19.2 per cent) did not consult a physician; surprisingly all of them sought health care from medical shops and chose not to consult a physician. The conditions for which people sought health care from medical shops were mainly fever, body pain, knee and joint pain, and acute episodes of non-communicable diseases. One person could not start the treatment because of not being able to afford the laboratory tests prescribed by the consulting physician. Among those who started their treatment, four persons (9.8 per cent) did not complete their treatment for reasons such as distance to health facility, and difficulty in physically coping with drugs and treatment instructions particularly pertaining to diet restrictions. Lastly, 19 persons (51.4 per cent) considered their health problem as not resolved as their problem still persisted, or they suffered from related symptoms or as they could not seek higher referral care.

Within-group differentials in unmet need for acute morbidity conditions

The group differentials in unmet need for acute morbidity conditions are shown in Table 4. A larger proportion of females (76.3 per cent) reported an unmet need for health care when compared to males (63.6 per cent). Out of seven men who experienced an unmet need, the majority (57.1 per cent) reported an unresolved health condition. This means that they experienced unmet need at the last step after accessing health care. The case is entirely different for women - 37.8 per cent of women did not even seek health care, and their needs were unmet at the very first step of health care seeking.

A larger proportion (86.7 per cent) of those in the age group of 60 years and above, did not have their health care needs met. Of the 13 unemployed persons, the majority (41 per cent) did not even seek health care. Interestingly, being enrolled in state-sponsored insurance scheme for BPL population did not make a significant difference to whether or not a person's health care needs were unmet. This may be because the insurance schemes cover only inpatient care and not all health care needs. These intra- group differentials among those with an unmet health care need for acute conditions highlight how multiple inequities play their part in influencing care-seeking.

Table 4: Group Differentials in Unmet Need for Acute Morbidity Conditions

	Gender(N)		Age group(N)		Occupation status(N)		Insurance enrolment(N)	
	Male (11)	Female (59)	Less than 60 years (55)	60 years and above (15)	Unemployed (42)	Employed (28)	Enrolled (28)	Un-enrolled (42)
STEP-1: Did not seek health care	1	17	13	5	13	5	9	9
STEP-2: Did not consult a health provider	2	8	**9**	1	6	2	8	4
STEP-3: Did not start treatment	0	1	1	0	0	1	1	0
STEP-4: Not completed / nor undergoing treatment	0	4	4	0	2	2	3	1
STEP-5: Health problem unresolved	**4**	15	12	**11**	**8**	**7**	12	
Had unmet need for health care for acute morbidity N(per cent)	**7 (63.6 per cent)**	45 (76.3 per cent)	39 (71 per cent)	13 (86.7 per cent	**32 (76.2 per cent)**	**20 (71.4 per cent)**	21 (75 per cent)	31 (74 per cent)

Note: N (per cent) – Number (percentage).

The interplay of multiple disadvantages resulting in an unmet need for health care

The discussions has so far focused on unmet needs by a single axis of disadvantage. However, observations in the field showed that often, multiple disadvantages came together to deprive a person of needed health care. Based on observations and interactions, we depict selected case profiles that illustrate this.

Case profile – 1

A 62-year-old woman is the head of a household and a fish seller. She buys fish in bulk from the market and sells fish from house to house, carrying the heavy basket on her head and walking almost all day. Her alcoholic husband beat her brutally and left her when she was just 29 years old. She is single since and has raised her two boys by herself.

A year ago when she was selling fish seated on a roadside pavement, she was hit by a scooter, and *suffered a fracture on her left leg. She was not enrolled in any insurance scheme and underwent* *treatment in a private hospital. Her expenses were met by the scooter owner, and she did not incur any out-of-pocket expenditure. But this did not mean that there were no other problems. She could not get adequate rest and resumed fish-selling as soon as she could. Even after one year, she still suffers from frequent episodes of severe pain in her fractured leg. Selling fish is her only source of income and walking with a heavy load on her head aggravates the pain at the fractured site. She cannot take time off for seeking health care because that would mean loss of income.*

Case profile – 2

A 34-year-old woman divorcee, who is unemployed, lives with her parents who belong to the low-income group. She was divorced as her family was not able to give dowry as previously agreed. Three months ago, she developed frequent episodes of difficulty in micturition. Accompanied by her mother, she accessed care at the Taluk hospital, far from her house as she did not want her condition to be known by neighbours. The doctor advised her to go for laboratory tests from a private facility. Although she is enrolled in an insurance scheme, she could not undergo laboratory test as tests are not covered by her insurance scheme.

Case profile– 3

A 34-year-old man lives in a rented house with limited facilities, with his wife and two daughters. He is a heavy vehicle driver. His job takes him away from home for several days at a time, driving across different states. He suffers from frequent episodes of backaches, mainly owing to his occupation. He cannot afford to leave his job as he is paid adequately, and no other job will fetch him an equivalent income. During earlier episodes of backache, he went to government medical college and each time, took time off from work, resulting in loss of wages. He is therefore not able to seek proper care, and his problem remains unresolved.

These three case profiles depict how multiple axes intersect in the lives of the urban poor. In the first case profile, physical ailment affects the person's work life, and she is unable to take any time off from daily work. The second case profile illustrates difficulties faced by a female divorcee in accessing health care for gynaecological problems from nearby health facilities. Social and financial factors together influence her access to care, and enrolment in insurance did not help overcome these barriers. The third case profile reflects an apparent occupational health problem of the main income earner in an urban -poor household with a well-paying job, caught between a desire for a better life for his family, and the daily reality of a health issue aggravated by work. In all the three case profiles, the multiple disadvantages of one's social position, gender, occupation, and availability of appropriate health services play their part at one or many steps resulting in an unmet health care need that will need more than a doctor to overcome.

This detailed examination of unmet health care needs for acute morbidity conditions illustrates how equity in access to health care shapes one's health-seeking behaviour and determine whether or not a health care need is met.

Discussion

The study shows how the health care needs of an urban poor population in Thiruvananthapuram, Kerala, with well-distributed public and private health care institutions are still left 'unmet.' The aim of the paper was to examine the unmet health care needs of the urban poor population, by examining the major steps involved in having one's health care needs met.

Most studies on unmet need in India focus on family planning. One study examined the unmet need for public health services in Mumbai (Dilip & Duggal, 2004). In their study, a health care need was defined as 'met' if there was a public facility available in their neighbourhood, which could potentially meet their health need. A study by Shi and Stevens (2005) specifically looked at unmet health care needs owing to cost and examined the risk factors or 'vulnerabilities' associated with unmet needs owing to cost. They found out that people who are having low income, uninsured and havng no regular source of care are likely to delay the needed health care due to cost.

Many studies consider unmet health needs as an indicator of access to health care (Allin & Masseria, 2009). Apart from access, Chen and Hou (2002) claim that it is important to understand the availability, accessibility or acceptability barriers associated with unmet health care needs.

Our study is among the few that examine unmet need as consisting of five steps wherein multiple barriers may be encountered. It also considers five different categories of health needs rather than ask more generally about 'any health care need'. This method traces multiple types of health care needs and multiple points at which a health care need can become unmet. It shows that availability, accessibility, and acceptability alone do not guarantee met need. Taking resolution of the health problem as the indicator of 'met need' gives a truncated pattern of health care seeking, which allows us to visualize the point of disbandment from the care-seeking pathway.

We find that overall, for 52.1 per cent of those with any health care need, their need was unmet. This is higher as compared to other studies; a 2016 study assessed the unmet need for family planning in an urban area of south India to be at 20.5 per cent (Vasudevan & Soundarya, 2016). Our higher figures are a result of the definition which captures unmet need at various stages of health care seeking. An article on the importance of measuring unmet health care needs, states that unmet health care needs should be a core component of any health system assessment (Gauld, Raymont, Bagshaw, Nicholls & Frampton, 2014, p. 64). Gauld et al., (2014) further concluded that such assessment should be based on documenting unmet health care needs as perceived by representative segments of the population through formal interviews (p. 65). This study also adopted such an approach.

The proportion of our study population with any health care need was at 39.9 per cent which is significantly high when compared to 21.8 per cent of ailing persons during last 15 days in urban Kerala (Government of Kerala, 2016). This finding is also consistent with the well-known paradox of low levels of mortality coexisting with high morbidity in Kerala (Suryanarayana, 2008, p. 3).

The findings of the study clearly indicate that met health care needs for acute morbidity conditions were significantly low, creating a much larger proportion of unmet needs. This larger proportion of unmet health care needs were seen especially among women, the elderly and among the unemployed. This finding to some extent is consistent with findings from a study in the US where risk factors such as low income, no health insurance coverage and lack a regular source of care influenced the likelihood of having an unmet health need due to cost (Shi & Stevens, 2005).

Findings of our study indicate that both health system and patient factors influence unmet health care needs and urban health inequities. Chen and Hou (2002) reported health system factors such as long waiting time, non-availability when needed, and cost, as the main health system-related reasons for unmet health care need. In the present study as well, non-availability of appropriate services in the vicinity, costs and poor perceived quality of care were stated as reasons for unmet need.

Studies tend to look at a single axis of disadvantage in a vertical fashion as enhancing the risk of unmet health care need in a population. Our case profiles, although rudimentary, suggest the importance of considering multiple axes of disadvantages simultaneously. For example, the nature of one's health problem interacts with social position, gender, occupation and the availability of health services to render a health care need unmet. Single point interventions would not be adequate to change this situation.

Our study has some limitations. We measured unmet need from the respondent's subjective point of view. While this has its advantages in that subjective perceptions influence health care seeking patterns, there may be an over-estimation of unmet need especially in a highly medicalized society like Kerala.

Conclusion

Kerala reports high levels of health care availability and utilisation, with a population that is well aware of its health care needs. It appears that despite such an apparently good scenario, the unmet health care needs of marginalised populations are being overlooked. Documenting the unmet health care need is a way of moving towards more equitable health care provision and reducing urban health inequities in the long run.

Our study findings suggest the need for greater coverage by public sector health facilities and personnel, and by social health insurance schemes for low-income groups, in poor urban neighbourhoods in Kerala. This would prevent pushing poorer patients to seek care in the private sector, remove cost barriers to seeking care, and mitigate the bulk of unmet need. However, health sector action alone would not be sufficient. Many of the reasons why health care is not sought or treatment is not completed are related to the lack of social safety nets and social security that would prevent the sick from needing to work when unwell. Many illnesses are caused or aggravated by the poor living and working conditions of the majority of the urban poor. For Kerala to meet its Sustainable Development Goal (SDG) commitment to 'leave no one behind,' attention to urban health inequities is an urgent priority.

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Service Coverage and Financial Risk Protection Among Urban Poor Under Tamil Nadu's Voluntary Government-sponsored Health Insurance Scheme

Philip, NE[*]

Providing financial risk protection (FRP) to the poor and vulnerable population by preventing the incurrence of Catastrophic Health Expenditure (CHE) is critical to achieving Universal Health Coverage in any country. The World Health Organization has endorsed the ability of pre-payment financing mechanisms such as Social Health Insurance (SHI) to provide FRP and to improve access to healthcare for the poor. The state of Tamil Nadu in India introduced one of the early state- sponsored health insurance programmes in 2009, known since 2012 as the Chief Minister's Comprehensive Health Insurance scheme (CMCHIS). The scheme covers low-income households for hospitalizations. In this paper we examine the extent to which CMCHIS has enabled urban poor households to meet all their healthcare needs without the risk of incurring CHE.

We conducted a ten-month longitudinal study of 600 urban- poor households, selected using multi-stage random sampling, in the Kanyakumari district of Tamil Nadu. We categorized the poor households into four, based on their socioeconomic status: very poor, poor, marginal and vulnerable. Four waves of data were collected at zero, one, six and ten months, from six wards of two municipalities. Healthcare needs of the household were defined as any household member having chronic disease, seeking out-patient care (acute morbidity) or in-patient care (hospitalization).

Out of the 600 households 300 (50 per cent) households had one or more healthcare needs during the ten-month study period. Only 13 households out of the 138 (9.4 per cent) had all the hospitalizations in their households fully covered by CMCHIS, and a vast majority (113 or 81.9 per cent) had no member or episode of hospitalization covered. Households that were identified as Above Poverty Line (APL) by the government; and the marginal and vulnerable households with a relatively better economic status among the poor, were more likely to have service-coverage as compared to Below-Poverty-Line (BPL) households and very poor and poor households. Single episodes of hospitalizations with fewer days of admission in hospital were more likely to be covered by CMCHIS. Almost 64 per cent of the households with hospitalizations incurred catastrophic health expenditure, with a mean OOP of Rs 34,700, and the range was Rs 1560- Rs 7, 35,600). More than one-fourth of the households with CHE were APL card holders (28.8 per cent). Twenty-two households used CMCHIS and had hospitalizations and of these, 15 (68.2 per cent) had CHE. Only seven households enjoyed Financial Risk Protection by using CMCHIS. More than one third (33.7 per cent) of the households spent more than 100 per cent of their capacity to pay to take care of the health-related expenses. More than four-fifths (83 per cent) of the households with hospitalizations used distress financing mechanisms like sale of assets, un-secured loans, gold loans, mortgage of assets, mortgage of land or assistance / gift to meet the healthcare expenses.

This study indicates that even in a context of high availability of public and private sector health facilities and high literacy, the CMCHIS, which has a relatively higher utilization rate and one of the best benefit packages in the country, offered little service coverage with very poor financial risk protection to low income populations. This study suggests the need for careful reconsideration of the shift to a predominantly health-insurance- based healthcare system in the current Indian setting.

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Keywords : CMCHIS, Coverage, Health Insurance, Health Utilization, Financial Risk Protection, Out-of pocket Expenses, Service Coverage

Providing financial risk protection (FRP) to poor and vulnerable populations is critical to the achievement of Universal Health Coverage in any country. Data from around the world show that poor people have the greatest healthcare needs (Smith, 1999, p.145). There is a two-way relationship between poverty and health, with poverty leading to ill health and ill health further contributing to poverty (Wagstaff, 2002, p.97). While lack of financial resources or information can create barriers to accessing services, it has been found that the causal relationship between access to health services and poverty also runs in the other direction (World Bank, 2000). When healthcare is needed but is delayed or not obtained, people's health worsens, which in turn leads to lost income and higher healthcare expenditures, both of which contribute to poverty at the household as well as societal level (Marmot, 2006, p.2081, Narayan et al., 2000).

Considering the vulnerability to ill health of those living in poverty, there are healthcare programmes and schemes which target the poor the world over (World Health Organization [WHO], 2000). There are extensive debates about how to provide FRP to poor households in low and middle income countries (LMICs) (Meng et al., 2011, p.93, Mills, 2014, p.552). The World Health Organization has endorsed pre-payment financing mechanisms such as Social Health Insurance (SHI) to provide FRP and to improve access to healthcare to the poor (WHO, 2005). Many LMICs have introduced government -sponsored health insurance schemes for the poor and vulnerable groups, which are fully or partially subsidized by the government and have limited benefit packages (Meng, et al., 2011, p.95, Mills, 2014, p.554). This has also been the case in India. The Government of India launched a country-wide health insurance scheme named "Rashtriya Swasthya Bima Yojana" (RSBY) in 2008 targeting households living Below Poverty Line (BPL) (Narayana, 2010, p.13, Prinja, Chauhan, Karan, Kaur, & Kumar, 2017, p. e0170996).

Health insurance schemes for the poor and vulnerable in India

There are ten health insurance schemes[1] targeting poor and vulnerable households in India. Of these, RSBY is the only nation-wide scheme covering the costs of hospitalization of BPL households. The rest are state-run health insurance programmemes. In all these schemes, the poor are identified based on a poverty threshold used by the government of India or by the state government concerned, and all who fall below the threshold are classified as poor or BPL, regardless of the depth of their poverty and deprivation. More than 40 per cent of the Indian population lives under the global poverty line of $1.25 per day. Consequently, any expenditure other than essential food expenditure, such as significant out-of-pocket spending for healthcare is likely to push households just above the poverty line to below poverty line (Government of India [GOI], 2014).

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[1] These are the Comprehensive Health Insurance scheme-CHIS (2008) in Kerala, Rajiv Arogyasri in Andhra Pradesh (2007), Chief Minister's Comprehensive Health Insurance Scheme-CMCHIS (2012) in Tamil Nadu, Karnataka's Yeshasvini Co-operative Farmers Health Care Scheme (2003), Karnataka's Vajpayee Arogyashri Scheme (2009), Rajiv Gandhi Jeevandayee Arogya Yojana (RGJAY) in Maharashtra (2012), Mukhyamantri Swasthya Bima Yojana (MSBY) in Chhattisgarh (2017), Mukhyamantri Swasthya Bima Yojana (MSBY) in Uttarakhand (2015) and Himachal Pradesh's RSBY Plus Scheme (2012).

Chief Minister’s Comprehensive Health Insurance Scheme-CMCHIS

In place of RSBY, the state of Tamil Nadu chose to introduce in 2009, the Kalaigner Scheme, a state sponsored health insurance programme. In 2012, the state introduced the CMCHIS. Although both RSBY and CMCHIS cover only in-patient healthcare, the CMCHIS is very different from the classic RSBY scheme in terms of population coverage, service and financial coverage. While RSBY covers only five members of a household on a floater basis, CMCHIS covers all the household members. Not only BPL households, but those with an income of less than Rs 72,000 per year are eligible to benefit from the CMCHIS Scheme. While Smart Cards are issued, even those without a card but with a letter from the Tahsildar (official who preside over matters related to Land, Tax and Revenue at district level) certifying the household’s income status are eligible to benefit from the Scheme. CMCHIS covers 1016 procedures, inclusive of 23 diagnostic procedures and 113 follow-up packages. It provides a financial coverage of Rs 1,00,000 per family per year (up to Rs 150,000 for specified ailments) for medical and/or surgical procedures (Government of Tamil Nadu, 2017, Narayana, 2010, p.13, Prinja et al., 2017).

As per a report in 2017, CMCHIS covers more than 56 per cent of the population i.e., 1.5 crore households in the year 2017. But only 16.9 per cent households possessed a CMCHIS smart card. The claim ratio for the year 2015-16 was 107 (Total claim/Total premium) with a burn out ratio of 117 (Total expenditure/ Total premium). In the year 2015-16, the total expenditure on CMCHIS, the total premium paid, and the total claim amounts were Rs 887 crore, 755 crore and 811 crore respectively (Karan et al., 2017). In the year 2017, 178 government hospitals, 168 private hospitals and 52 diagnostic centres were empanelled under CMCHIS (Government of Tamil Nadu, 2017).

Rationale and objectives of the study

Currently, there is increasing support for a shift from a publicly financed and provisioned healthcare system to publicly-financed insurance with public and private-sector-based healthcare delivery. The National Health Policy 2017 of India explicitly stated its plan to continue with targeted government-sponsored health insurance schemes throughout the country. The government of Tamil Nadu allocates tax money of Rs 750 crore annually for CMCHIS (Government of Tamil Nadu, 2017, Prinja et al., 2017). In this context it is important to look at the extent of service coverage and FRP provided by CMCHIS in Tamil Nadu to gather evidence on the extent to which CMCHIS is on track with respect to achieving its objectives. However, there are very few published studies assessing the impact of CMCHIS and almost none examine issues from the perspective of the intended beneficiaries.

This paper examined the extent to which CMCHIS has enabled poor households to meet all their healthcare needs without incurring catastrophic health expenditure (CHE). It (a) identifies the healthcare needs and assesses the population coverage and service coverage by CMCHIS among poor households (b) examines the out-of-pocket expenses (OOPE) associated with healthcare needs and (c) calculates the percentage of poor households experiencing CHE.

Methodology

Study design and study setting

This paper uses data from a larger longitudinal study conducted in two states, Kerala and Tamil Nadu with 1200 poor households in two urban settings. In this paper we use data pertaining to

600 urban poor households from Kanyakumari district, Tamil Nadu. Kanyakumari district has a population of 1.87 million with a higher than state-average literacy rate of 91.8 per cent (2011) and a high Human Development Index (HDI) of 0.812 (as compared to 0.6663 for Tamil Nadu). More than 80 per cent of its population lived in urban areas (Registrar General of India [RGI], 2011). In 2017, five government hospitals (including one medical college hospital), three private hospitals, one cancer institute and one private diagnostic centre were empanelled under the CMCHIS in the district of Kanyakumari.

Working Definitions

a. Poor households: Since there were many limitations identified with the current 'Below-Poverty-Line' (BPL) list prepared by the government (GOI, 2014), for the purpose of the study 'poor household' was defined as a household with an income two times that of the Poverty line threshold set by the Rangarajan Committee i.e., Rs 2,707.36 per capita per month (GOI, 2014), with standard of living score <=21. We used a standard of living (SOL) screening questionnaire to identify poor households. The questionnaire included variables such as type of employment of the highest earning member, ownership of house with land, house type, flooring, source of lighting, location of toilet, source of water, fuel for cooking and ownership of durable goods. Poor households were again categorized into four SES categories namely: Very poor (<= 0.75 of poverty line income and SOL score <=12); poor (0.75-1 of poverty line income and SOL score 13-15); Marginal (1-1.25 of poverty line income and SOL score 16-17; and vulnerable households (>2 poverty line income and SOL score>=18) (Sengupta et al., 2008).[2]

b. Healthcare need: A household was counted as having a healthcare need if during the study period, any household member

   - was under treatment for a chronic disease
   - sufferred from any morbidity of sudden onset which affected the activities of daily living for more than 24 hours in the last 30 days or acute morbidity
   - suffered from any illness necessitating admission to a health facility of more than 24 hours during the past 30 days, or
   - used the health insurance card for obtaining healthcare.

c. Service coverage for hospitalization was defined as households with all episodes of hospitalization covered by CMCHIS as a proportion of the total number of households having one or more episodes of hospitalizations in the sample during the study period.

d. Financial Risk Protection (FRP): was defined as households who did not incur catastrophic health expenditure (CHE) with the use of CMCHIS as a proportion of the total number of households, which did not incur CHE for any health care need the in the sample.

e. Catastrophic health expenditure (CHE): Out-of-pocket expenses were considered to be catastrophic if it was greater than or equal to 40 per cent of the household's capacity to pay (CTP) (Xu et al., 2003).

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[2] Sengupta et al (2008) used the same 4 categories/terminologies in a series of papers on how to define the common people of India in terms of levels of consumption and socio-economic profile. We adopted the same terminologies for our study.

Sample size and Sampling procedure

Based on the utilization rate of insurance in Tamil Nadu, which was 7.8 per cent (Government of Tamil Nadu, 2017) the sample size was calculated with 95 per cent confidence intervals and 20 per cent precision. Adjusting for design effect and non-response, the final sample size was 600 poor households. Sample households were selected using three-stage random sampling: first, two municipalities were randomly chosen. Then three wards each were chosen from each of the municipalities and then, 100 households from each of the six wards, respectively.

Data collection

Data on healthcare needs, health-seeking behavior and OOPE of households was collected in four waves: at zero, one, six and ten months, with a view to capturing seasonality of morbidity and obtaining more accurate information on insurance-coverage and OOPE because recall errors could be minimized.

Data collection was done using a pre-tested interview schedule by the Principal investigator and trained field assistants in Nagercoil and Padmanabhapuram municipalities of Kanyakumari district.

Ethical considerations

Ethical clearance was obtained from the Institutional Ethical Committee of Sree Chitra Tirunal Institute for Medical Science and Technology, Thiruvananthapuram.Data was collected after obtaining written informed consent from the participants.

Results

The study population consisted of 600 poor households with 2154 family members. Out of these, only 69 per cent were identified as poor by the state government and the remaining 31 per cent had a ration card that identified then as Above Poverty Line or APL. According to our SES classification, 173 (28.8 per cent) of the 600 households were very poor, 115 (19.2 per cent) were poor, 179 (29.8 per cent) were marginal and 133 (22.2 per cent) were vulnerable. The mean household size was 3.57 with a standard deviation of 1.34. A majority of the households had 3-4 members (57.5 per cent) and the heads of the households were mainly manual labours (53.0 per cent). Most of the households used LPG as cooking fuel (given free by the government) but almost 8 per cent of the houses did not have toilets.

At the individual level, more than two-thirds of the sample population (68 per cent) belonged to the productive age group (age 19-60 years), 7.8 per cent were elderly (age >60 years) and 6.3 per cent were children under five years of age. The male to female ratio was 1:0.0967. Almost two-thirds of the sample population was married (65.9 per cent) and 9.9 per cent were widowed/separated. Almost one-sixth of the sample population were illiterate (16.9 per cent) and most of the others had schooling up to 10th standard (58.9 per cent). Only 4.8 per cent had education up to post-graduation-level or more.

Table 1: Sample Characteristics: Household and individual

Variables	Total (per cent) N=600
Household size (members)	
<=2	127(21.2)
3-4	345(57.5)
>=5	128(21.3)
Categories of SES	
Very poor	173 (28.8 per cent)
Poor	115 (19.2 per cent)
Marginal	179 (29.8 per cent)
Vulnerable	133 (22.2 per cent)
Occupation of head of household	
Un-employed / on pension	130(21.7)
Un-skilled elabour	318(53.0)
Private job/ self employed	107(17.8)
Professional	45(7.5)
Job of the highest earning member	
Un-employed / on pension	39(6.5)
Un-skilled labour	361(60.2)
Private job/self employed	144(24.0)
Professional(only one gulf employed)	56(9.3)
Categories based on Poverty Line	
Rice only card	252(42.0)
Sugar only card	162(27.0)
Others	186(31.0)
Religion	
Hindu	389(64.8)
Christian	183(30.5)
Muslim	28(4.7)
Caste	
SC*	104(17.3)
OBC	421(70.2)
Others	75(12.5)
Type of house	
Kutcha	53(8.8)
Semi-pucca	199(33.2)
Mixed	123(20.5)
Pucca	225(37.5)

Ownership of Land	
Yes	51(8.5)
No	549(91.5)
Location of toilet	
no toilet	50(8.3)
Shared toilet	63(10.5)
Outside house	149(24.8)
Inside house	338(56.3)
Cooking fuel	
Wood/ kerosene	72(12.0)
LPG or electricity	528(88.0)
Monthly per-capita Household expenditure (median with range) RS	
Food expenditure	1000(2416.67)
Non-food expenditure	845(2656)
Total expenditure	1720(4395)
INDIVIDUAL CHARACTERISTICS	**N=2154**
Age	
0-5	136(6.3)
6-18	385(17.9)
18-60	1464(68.0)
>60	169(7.8)
Sex	
Male	1095(50.8)
Female	1059(49.2)
Marital status (excluding males<21 years and females <18years)	
Un-married	386 (24.2)
Married	1055(65.9)
Widow/separated	159(9.9)
Educational status(excluding <5 year children)	
Illiterate	347(16.9)
4 years of schooling	253(12.4)
5-7 years of schooling	328(16.0)
8-10 years of schooling	624(30.5)
11-12 years of schooling	168(8.2)
Undergraduate	229(11.2)
Post graduate/professional	99(4.8)

Healthcare needs

Of the 600 households, 300 (50 per cent) households reported having at least one individual with a healthcare need (chronic disease/acute morbidity/ hospitalization) during the ten-month-study-period. Two hundred and forty (40 per cent) households had at least one member having one or more chronic diseases, 90 (15.0 per cent) had at least one member who had experienced acute morbidity and 138 (23 per cent) had at least one member hospitalized. Healthcare needs varied across the poor, marginal and vulnerable groups. The very poor category had the highest proportion of households with healthcare need (59.5 per cent) as compared to the other poverty-categories. The difference was statistically significant (p=.018). They also had the highest proportion of persons suffering from chronic diseases (45.7 per cent) and had the highest proportion of hospitalizations (27.7 per cent) compared to other groups

Table 2 Household-level Health Care Needs During Study Period

Variables	**Chronic diseases** **N=240**		p value
	Yes (per cent)	**No (per cent)**	
Categories of SES			
Very poor	79(45.7)	94(54.3)	.127
Poor	37(32.2)	78(67.8)	
Marginal	74(41.3)	105(58.7)	
Vulnerable	50(37.6)	83(62.4)	
	Acute morbidity **N=90**		
Very poor	28(16.2)	145(83.8)	.113
Poor	10(8.7)	105(91.3)	
Marginal	26(14.5)	153(85.5)	
Vulnerable	26(19.5)	107(80.5)	
	Hospitalizations **n =138**		
Very poor	48(27.7)	125(72.3)	.342
Poor	26(22.6)	89(77.4)	
Marginal	36(20.1)	143(79.9)	
Vulnerable	28(21.1)	105(78.9)	
	Overall healthcare need **N=300**		
Very poor	103(59.5)	70(40.5)	.018
Poor	49(42.6)	66(57.4)	
Marginal	82(45.8)	97(54.2)	
Vulnerable	66(49.6)	67(50.4)	

Turning now to healthcare needs at the individual level, out of the 2,154 individuals, 447 (20.8 per cent) had a healthcare need during the study period, out of which 295 (13.7 per cent) had chronic diseases, 106 (4.9 per cent) had acute morbidities and 180 (8.4 per cent) had hospitalizations during the study period. Elderly (>60 years) had the highest proportion of persons with overall healthcare needs (53.8 per cent), chronic diseases (50.9 per cent) and hospitalizations (9.5 per cent) as compared to other age groups. Children under-five had the highest proportion of acute morbidities (14.7 per cent). Males reported slightly higher overall healthcare needs, hospitalizations and acute morbidity compared to females. But the prevalence of chronic disease was higher among females (14.1 per cent). Widowed and separated individuals had the highest proportion of healthcare needs (43.4 per cent). Persons with no schooling and unemployed persons were more likely to have had a healthcare need as compared to other groups. At the individual level, those from the poorest groups had the highest proportion with healthcare needs (28.1 per cent)

Table 3 Individual-level Healthcare Needs During Study Period

Variables	**Chronic diseases N=295 Yes (per cent)**	**Acute morbidity N=106 Yes (per cent)**	**Hospitalizations n =180 Yes (per cent)**	**Overall healthcare need N=447 Yes (per cent)**
Individual level data				
Age Group				
0-5	1(0.7)	20(14.7)	9(6.6)	29(21.3)
6-18	7(1.8)	18(4.7)	22(5.7)	39(10.1)
19-60	201(13.7)	52(3.6)	133(9.1)	288(19.7)
>60	86(50.9)	16(9.5)	16(9.5)	91(53.8)
Sex				
Male	146(13.3)	56(5.1)	106(9.7)	219(20.0)
Female	149(14.1)	50(4.7)	74(7.0)	208(19.6)
Marital status				
Un-married	30(3.2)	28(2.9)	60(6.4)	98(10.4)
Married	199(18.9)	64(6.1)	103(9.8)	260(24.6)
Widow/separated	66(41.5)	14(8.8)	17(10.7)	69(43.4)
Education				
Illiterate	109(31.4)	37(10.7)	37(10.7)	126(36.3)
Primary education	28(11.1)	16(6.3)	24(9.5)	48(18.9)
Upper primary education	51(15.5)	17(5.2)	20(6.1)	69(21.0)
High school education	79(12.7)	27(4.3)	56(8.9)	124(19.9)
>10years of schooling	29(5.8)	9(1.8)	43(8.7)	60(12.1)

Occupation				
Un-employed /on pension	79(31.5)	12(4.9)	24(9.6)	85(33.9)
Un-skilled labour	93(19.2)	34(7.0)	48(9.9)	124(25.6)
House-wife	67(13.3)	21(4.2)	31(6.2)	94(18.7)
Privately employed/ gulf/self employed	49(20.2)	19(7.8)	36(14.8)	64(26.3)
students/children	7(1.0)	20(2.9)	41(6.1)	60(8.9)
Category SES				
Very poor	89(17.5)	29(5.7)	65(12.8)	143(28.1)
Poor	52(11.4)	12(2.6)	33(7.2)	76(16.6)
Marginal	91(13.2)	34(4.9)	44(6.4)	117(17.0)
Vulnerable	63(12.5)	31(6.2)	38(7.6)	91(18.1)

Health- seeking behavior

There were 161 episodes of acute morbidities requiring out-patient-care among 106 individuals. Most of them (64.2 per cent) had a single episode of acute morbidity. Only 19.8 per cent had two episodes of acute morbidities and 16 per cent had three episodes. Eleven episodes of acute morbidities were untreated. We found that 65.9 per cent sought care for acute morbidities from private hospitals, and only 29.9 per cent sought care from public hospitals.

In the case of events of hospitalization, about 70 per cent of the individuals had only one episode of hospitalization and about 21 per cent had two episodes of hospitalization. The majority (78.3 per cent) obtained care from private hospitals and only 15.6 per cent obtained care from public hospitals.

Table 4 Details of Health Seeking Behavior for Acute Morbidities and Hospitalizations

Variables	Individuals (per cent)	Episodes (per cent)
Acute morbidities		
Yes	106 (4.9)	161
No	2048 (95.1)	
Details of episodes		
Single episode	68 (64.2)	68 (42.2)
Two episodes	21 (19.8)	42 (26.1)
Three episodes	17 (16.0)	51 (31.7)
Treatment		
Yes	97	150 (93.2)
Private hospitals/clinics	64 (65.9)	113 (75.3)
Public hospitals	29 (29.9)	32 (21.3)
Homeopathic clinics	2 (2.1)	3 (2.0)
Ayurvedic clinics	2 (2.1)	2 (1.3)
Untreated morbidity	11	11 (6.8)
Self-medication	9 (81.8)	9 (81.8)
No	2 (18.2)	2 (18.2)
Insurance covered		
Yes	0	0
No	106 (100)	161(100)
Hospitalization		
Yes		
	180 (8.4)	217
No	1974 (91.6)	
Details of episodes		
Single episode	151 (69.7)	151(69.6)
Two episodes	23 (21.2)	46(21.2)
Three episodes	4 (5.5)	12(5.5)
Four episodes	2(3.7)	8(3.7)
Treatment (episodes)		
Public hospitals	28(15.6)	42(19.4)
Private hospitals	141(78.3)	160(73.7)
Empanelled private	10(5.6)	14(6.5)
Alternate medicine	1(.5)	1(0.4)

Population coverage

We defined population coverage as the proportion of the households in the sample with CMCHIS card/ who has letter from Tahasildar for the year 2015-16. Out of the 600 sample households only

97 households (16.2 per cent) possessed a CMCHIS smart card during the study period, and 56 households (9.3 per cent) had renewed their card or used CMCHIS scheme. This may be because there was no active enrolment for CMCHIS for the year 2015-16.

Service coverage

Since the CMCHIS Scheme covers only hospitalization, more than half of the households with healthcare needs (162/300 or 54 per cent) are out of its purview. For service coverage we only examined the 138 households, which had one or more members hospitalized during our study period. For better understanding of the service coverage offered by CMCHIS we defined: "fully-covered households" as households with all episodes of hospitalization covered under CMCHIS, "partially- covered households" as households with not all, but only some episodes of hospitalization covered by CMCHIS and "not- covered households" as households with none of the episodes of hospitalization covered by CMCHIS.

Only 13 households out of the 138 (9.4 per cent) had all the hospitalizations in the households "fully- covered" by CMCHIS. Twelve (8.7 per cent) households had some episodes covered for one or more members of the household. A vast majority of the households (113 or 81.9 per cent) were "not-covered" i.e. none of the episodes of hospitalizations for any of its members was covered by CMCHIS. Thus, four-fifths of the households were totally unprotected by CMCHIS.

Households with single hospitalized member with only one episode of hospitalization were more likely to be "fully-covered" under CMCHIS. In terms of individual level service coverage, only 13 (7.2 per cent) individuals had all episodes covered by CMCHIS out of the total of 180 individuals who were hospitalized during the study period.

Determinants of service coverage: While looking at the services coverage among the four SES groups it can be seen that very poor and poor households had the least percentage of "fully-covered" hospitalizations compared to the marginal and vulnerable households. Households that were identified as APL by the government; the marginal and vulnerable households with a relatively better economic status among the poor households were more likely to have service coverage as compared to BPL households and very poor and poor households

Table 5 Household-level by CMCHIS

Variables	Fully/partially covered	Not-covered	p-value
Categories based on Poverty Line			
Below Poverty Line (BPL)	6 (15.4)	33(84.6)	.05
Above Poverty Line (APL)	19(19.2)	80(80.8)	
Category SES			
Very poor	5(10.4)	43(89.6)	.04
Poor	5(19.2)	21(80.8)	
Marginal	8(22.2)	28 (77.8)	
Vulnerable	7(25.0)	21(75.0)	
Household size			
<=2 members	4(16.7)	20(83.3)	.523
2-4 members	16(21.3)	59(78.7)	
>=5members	5(12.8)	34(87.2)	
Chronic disease present			
Yes	17(18.3)	76(81.7)	.572
No	8(17.8)	37(82.2)	

As for factors affecting service coverage, the only factor that emerged as statistically significant at the individual level was the presence of chronic disease. Individuals who had chronic diseases were more likely to be covered by CMCHIS as compared to others. Widowed or separated individuals also had a higher chance of being covered by CMCHIS as compared to those who were currently married or never married. There were no significant differences in coverage across other social and demographic characteristics. It is worth noting, however, that the economically productive age group had the maximum proportion of individuals who were "fully-covered" by CMCHIS for all episodes of hospitalizations (11 out of 13 fully covered individuals, 84.6 per cent) and children under 5 years of age and adolescent age groups had none who were "fully-covered".

There was no significant difference between males and females in service coverage. As education increased the proportion with "fully-covered" decreased. Unskilled labourers had the highest proportion (5 out of 13 fully covered individuals, 38.5 per cent) of "fully-covered" episodes. Those with single episode of hospitalizations had more chance of being "fully-covered" under CMCHIS as compared to those with more than one episode of hospitalizations. Among individuals with four episodes of hospitalizations none were covered by CMCHIS.

For testing whether there is any statistical difference in the duration of hospital stay (number of days) between those covered and those not covered by CMCHIS, we first checked the normality of the distribution (test of normality). On finding that it was not a normal distribution, we used non-parametric test (Mann-Whitney U test) to compare the differences in duration of hospital stay by coverage status of CMCHIS. We found that episodes with fewer days of hospital stay were covered by CMCHIS, p=.003.

Table 6 Individual- level Factors Affecting Service Coverage by CMCHIS

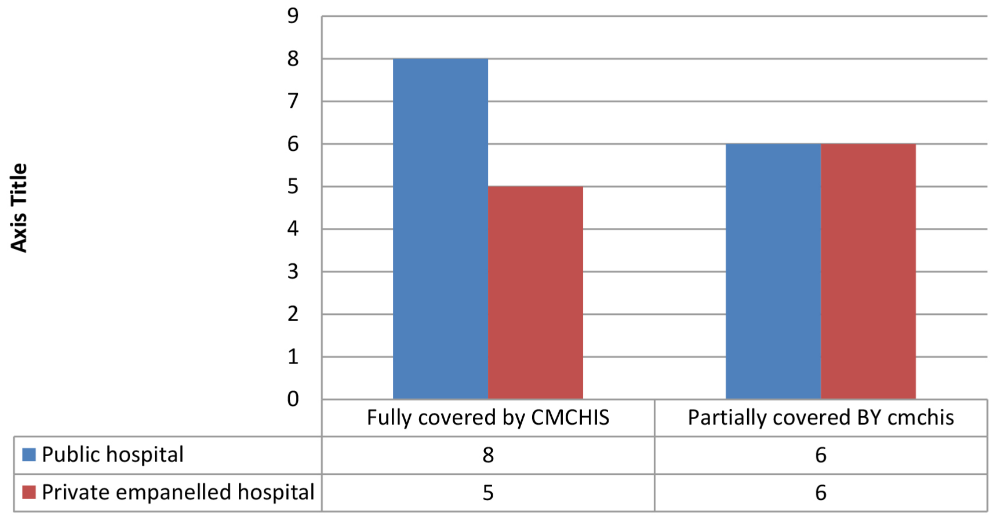
Variables	Fully-covered	Not-covered	p-value
Age Group			
0-5	0	9(100)	.348
6-18	0	22(100)	
18-60	11(8.3)	122(91.7)	
>60	2(12.5)	14(87.5)	
Sex			
Male	6(5.7)	100(94.3)	.248
Female	7(9.5)	67(90.5)	
Marital status			
Un-married	1(7.8)	59(98.3)	.008
Married	8(7.8)	95(92.2)	
Widow/separated	4(23.5)	13(76.5)	
Education			
Illiterate	4(10.8)	33(89.2)	.771
Primary education	2(8.3)	22(91.7)	
Upper primary education	2(10.0)	18(90.0)	
Secondary education	3(5.4)	53(94.6)	
>10years of schooling	2(4.6)	41(95.4)	
Occupation			
Un-employed /on pension	3(12.5)	21(87.5)	.414
Un-skilled labour	5(10.4)	43(89.6)	
House-wife	3(8.3)	33(91.7)	
Privately employed/students/children	2(2.8)	70(97.2)	
Chronic Disease			
Yes	11(8.7)	116(91.3)	.001
No	2(3.8)	51(96.2)	
Median Days of hospital stay(Range)			
	14(3-30days)	30(12-17days)	.003

Out of the 13 "fully-covered" hospitalizations by CMCHIS majority (8) were in government hospitals (61.5 per cent) and five were in private empanelled hospitals. Out of the 12 partially covered hospitalizations by CMCHIS half were in government hospitals

Out-of-pocket expenses and financial risk protection (FRP)

For computing the total healthcare- related expenses, we added drug related expenses for chronic diseases, direct and in-direct out-of-pocket expenditure related to acute morbidities and hospitalizations during our study period. We excluded the 300 households which had no healthcare need during the study period.

Figure 1: Service Coverage by Type of Hospitals



It was found that the mean (range) OOP expenses related to monthly drug expenses at household level was Rs. 1,094.1 (0-5040) . The mean (range) OOP expenses related to acute morbidity was Rs 3,871 (0-24000) . The mean (range) OOP expenses for all hospitalizations was 34,700 (1560-7,35,600) . The mean (range) direct OOP expenses was Rs 16,989.18 (0- 4,90,000) and mean (range) indirect OOP expenses was Rs 4,902.12 (1150-2,65,000) . For hospitalization- related expenses we compared the direct, indirect and total out-of-pocket expenses among the two groups (those episodes which were covered by CMCHIS and not covered by CMCHIS) using Mann-Whitney test after checking for normality of the distribution. We found that the mean total OOP were higher among those not covered Rs 46,400, with a range of Rs 6,743 to 7, 35,600. But the mean direct expenses were highest among the episodes covered by CMCHIS: Rs 22636.4, range (0-4,09,000). The mean indirect and total OOP expenses were highest among the episodes which were not covered by CMCHIS, with mean as Rs 4,927.0, and range from Rs 1150 - 2, 65,000))

Table 7: Household level Out-of-pocket Expenses for Various Health Care Needs

Out-of-pocket expenses	
Chronic disease related monthly drug expenses	**(mean with range)RS**
Total OOP	1094.1 (0-5040)
Acute morbidity related expenses	
Direct OOP	2628 (0-18000)
Indirect OOP	1243.6 (40-8100)
Total OOP	3871 (0-24000)
Hospitalization related expenses	
Direct OOP	16,989.18 (0-4,09,000)
Indirect OOP	4902.12 (1150-2,65,000)
Total OOP	34,700(1560-7,35,600)
Hospitalization related expenses	
OOP among those who used CMCHIS	
Direct OOP	22636.3636(0-409000)
Indirect OOP	4877.2727 (2400-74000)
Total OOP	23000 (1100-541400)
OOP among those who did not use CMCHIS	
Direct OOP	11341.9741 (0-3,14,000)
Indirect OOP	4926.9741 (1150-2,65,000)
Total OOP	46400 (6743-7,35,600)

Catastrophic Health Expenditure: Hospitalization related out-of-pocket expenses were considered to be catastrophic if they were greater than or equal to 40 per cent of the household's capacity to pay (CTP) (Xu et al., 2003). For assessing the extent of FRP offered by CMCHIS among the insured we computed the percentage of households which had no catastrophic health expenditure. CTP of a household was total household expenditure minus subsistence expenditure or food expenditure, whichever among the two was less. Food Expenditure (FE) corresponds to money spent by the household on food items and non-alcoholic beverages. Subsistence Expenditure (SE) refers to the average food expenditure of the household in the 45th to 55th percentile adjusted for household size.

We found that 177 (59 per cent) of the households with any healthcare need (drug expenses for chronic diseases, acute morbidity- related- expenses or hospitalization- related- expenses) experienced catastrophic healthcare spending. Of the 240 households that had members with chronic diseases, 86 (35.8 per cent) had CHE. Of the 90 households with acute morbidity 8 (8.9 per cent) had CHE. If hospitalizations alone were taken into account, 64 per cent of the households had catastrophic healthcare expenditure (CHE).

We then examined catastrophic health expenditure among households covered by CMCHIS. We found that out of the 22 households which had the CMCHIS-Smart Card and had hospitalizations 15 (68.2 per cent) had CHE. More than one-fourth of the households with CHE were APL card holders (28.8 per cent).

Only seven of the 123 households without CHE during the study period enjoyed financial risk protection by using CMCHIS (5.7 per cent). Of the 300 households that had a healthcare need, 101 households (33.7 per cent) had spent more than 100 per cent of their capacity to pay to take care of the health- related expenses. More than four-fifth (83 per cent) of the households with hospitalizations used distress financing mechanisms like sale of assets, un-secured loans, gold loans, mortgage of assets, mortgage of land or assistance / gift to meet the healthcare expenses.

Discussion

This is among the few studies as per our knowledge carried out in Tamil Nadu, looking at healthcare needs, service coverage and financial risk protection offered by the state sponsored health insurance schemes among the urban poor. We used prospective data on healthcare needs and out-of-pocket expenses, at different points of time during a 10-month period to capture seasonal variations and to minimize recall bias.

When we examined the socio-demographic and economic characteristics of urban poor in Kanyakumari district of Tamil Nadu, we found that even in the state with one of the least percentages of urban poor (6.2 per cent) as per the World Bank data, the living conditions were abysmal. Almost 8 per cent had no toilets and one-fifth of them were living in mud houses with thatched roofs. The study population consisted mainly of productive age group and had only 7.8 per cent elderly population. This was because many of the urban poor households had settled in urban areas for employment, while their elderly parents remained in the villages.

Half of the households had some healthcare need during a ten-month period. The healthcare needs among the poorest households were the highest as compared to the other three groups of the slightly better of households which is very much sync with the literature on healthcare needs of the poorest (Smith, 1999, p.145).

Population coverage

Although CMCHIS is meant to cover all households with an annual income of less than Rs 72,000, less than 10 per cent of the households in our sample had a Smart Card in their possession. All our sample households would come under the income category eligible to be CMCHIS beneficiaries. So in practice the population coverage by CMCHIS is minuscule even though the government documents claims that it covers 50 per cent of the whole population (Government of Tamil Nadu, 2017). This result is very similar to findings from other studies on RSBY and CHIS in Kerala, which also find that population coverage for voluntary SHI schemes are very low compared to mandatory SHI schemes (Philip, Kannan, & Sarma, 2015, Prinja et al., 2017).

Service coverage

A majority of healthcare needs of the urban-poor were not a part of the benefits package because CMCHIS covers only hospitalization. Service coverage was only 9.4 per cent. It was surprising to find that even in the district of Kanyakumari with a high literacy rate and with more than 49 empanelled hospitals (Government of Tamil Nadu, 2017) mainly concentrated in the urban areas, only 6 per cent of the episodes of hospitalizations were covered even after 7 years since the beginning of the insurance scheme. We also found that the very poor and the poor households had the least service coverage by CMCHIS. Thus, the most socially and economically vulnerable households were not covered. The existing literature on government- sponsored health insurance schemes for poor also reports that the neediest in the target population are excluded in most of the cases (Spaan et al., 2012, Jowett, Contoyannis, Vinh, 2003, Gakidou et al., 2006). As CMCHIS is a voluntary scheme and as there was no active enrolment, people were totally unaware of the scheme and its benefits.

In terms of service coverage, there is limited evidence that government-sponsored-health insurance schemes have increased access to healthcare services. This is especially true if there is no public investment to create any new point of service provision, but the insurance tries only to remove the financial barrier in accessing care (Acharya et al., 2012). The narrow benefits- package is another reason for the low service coverage. The schemes are mainly focused on secondary care and exclude the most impoverishing, high cost treatments due to the principles of social health insurance i.e., exclusion of the low frequency high cost interventions (Scheil-Adlung et al., 2006, Normand & Weber, 1996).

Financial risk protection

We next examined whether the insured incurred out-of-pocket spending, given that CMCHIS was introduced with the specific aim of reducing OOPE. Since CMCHIS only covered 13 episodes of hospitalizations, the households incurred both direct and indirect OOP expenses for healthcare needs not involving hospitalization. We also found that instead of reducing the out-of-pocket spending during hospitalization, those who used CMCHIS had higher direct OOPE compared to those who did not use it. This finding was contrary to findings from Vietnam and a systematic review by Ernst Spann et al from Asia and Africa. These studies found that insurance reduced OOP expenses (Spaan et al., 2012, Jowett, Contoyannis, Vinh, 2003).

However, studies from India have similar findings to ours. They have found that there was either no impact or an increase in OOP expenditures among the insured (Philip, Kannan, & Sarma, 2015, Prinja et al., 2017). This finding can be attributed to the non-translation of population coverage into service coverage which provides a false assurance of coverage among insured. They go to empanelled private hospitals expecting all their healthcare expenses to be covered, but are left with a huge bill to pay because the total expenditure exceeds the maximum amount to be covered. The rampant corruption in hospitals, which are empanelled under CMCHIS could also result in insured persons being deliberately not given the benefits due to them and many beneficiaries stated that they had to pay bribe in the hospital (Karan et al., 2017). The financial burden borne by the households were immense. The mean OOP per episode of hospitalization is almost nine times the mean per capita expenditure (MPCE) of an urban household in Tamil Nadu (Rs 2,534.32) and 31 times the MPCE of the lowest quintile (Rs 725). The mean drug expenditure per month was more than the total expenditure of the lowest quintile in Tamil Nadu (GOI-NSSO, 2015). So the households are financing their healthcare by distress finance mechanisms and this is not a one-time event as these poor households have people who are prone to hospitalizations and drug expenses for chronic diseases are life-long. This finding calls an immediate attention of the policy makers to develop a service package which also covers acute morbidities and chronic disease care which constitutes more than 70 per cent of the total OOPE in India (GOI, 2005), otherwise more and more households will be pushed below poverty due to the huge OOP spending.

Catastrophic health expenditure

A majority of the hospitalized households incurred catastrophic health expenditure, which was supposed to be covered by insurance, by spending more than 100 per cent of their capacity to pay to take care of the health-related expenses. Moreover, CHE was incurred during treatment for acute morbidities, and for expenses on drugs for chronic diseases, both of which are not covered by CMCHIS. This finding is consistent with findings from other studies, showing that between 3.5 per cent and 6.2 per cent of the India's population is pushed below the poverty line every year due to out-of-pocket (OOP) expenses (Gupta, 2009, GOI, 2005, Van Doorslaer et al., 2006, Garg & Karan, 2009, Berman, Ahuja, & Bhandari, 2010). These findings suggest that voluntary government-sponsored health insurance schemes may not contribute towards reducing poverty by providing financial risk protection to poor households.

Conclusion

There is an ongoing debate on the breadth of the service and financial coverage provided by the government sponsored targeted health insurance schemes and whether it will promote equitable healthcare access and financial access. This study indicates that even in a context of high availability of public and private sector health facilities and high literacy, the CMCHIS, which has a relatively higher utilization rate and one of the best benefit packages in the country, offered little service coverage for less than 10 per cent of hospitalizations and financial risk protection to less than 6 per cent of low income populations. This was the experience of an urban-poor population, which constituted the target population of CMCHIS and lived in an area with a high concentration of empaneled hospitals. This study suggests the need for careful reconsideration of the shift to a predominantly health- insurance- based healthcare system in the current Indian setting.

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Conflict of interest: none

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Social Exclusion and Health of Muslim Communities in Maharashtra

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The relationship between social exclusion and health is a complex one. Social exclusion predisposes affected communities to a variety of social and economic vulnerabilities with the potential to jeopardize their health. These result in the community being 'left out' deliberately, discouraging social participation or even actively denying them services. The institutional structures that perpetuate social exclusion differ by gender, class, sexual orientation, race, ethnicity and other similar structures. In India, religious identity is one such structure, and Muslims (a religious minority) is one such socially excluded group.

This paper examines the health status of Muslims in the State of Maharashtra. It describes the socioeconomic context of Muslims and explores how this influences the health of the community. Using secondary data, it also seeks to compare how Muslims fare on key health indicators versus other socio-religious groups in India.

This paper is based on analysis of the National Family Health Surveys, District Level Household Surveys, and the National Sample Survey Organizations data sets. It also draws upon published literature, particularly primary studies commissioned by the Maharashtra State Minority Commission in 2013.

Maharashtra is home to about 12 million Muslims, who constitute nearly 12 per cent of its population (Census, 2011) and their location is largely urban. We found relative disadvantage among Muslim communities in terms of socioeconomic status, education and their work profile. Studies provided evidence of poor access to clean drinking water and sanitation, and poor availability of public health facilities in Muslim ghettoes. In the absence of public health facilities, many communities are forced to access private healthcare providers. Childhood mortality has improved little over the years, and recent data shows child mortality indicators for Muslim children are worse than for other religious communities. While utilization of maternal health services by Muslim women are more or less at par with other communities, there are concerns around respectful care. The data also calls into question myths related to Muslim fertility, arguing for the provision of appropriate methods of contraception to Muslim women. There is evidence of deep-rooted biases amongst health providers resulting in discriminatory behaviour towards Muslim women, which affects access to services.

This paper has examined the socioeconomic context of Muslims in Maharashtra, which conveys marginalization and isolation, and illustrates how this affects the health and well-being of this community. The findings throw up important questions and hypotheses that need to be studied in greater detail if we seek to better understand and address the needs of the minority population in a context-specific manner. We need to uncover and document mechanisms of social exclusion and structural obstructions, with a view to eliminating these.

Keywords : social exclusion, Maharashtra, Muslim communities, marginalisation, isolation

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Inequities between and within countries are among the most pressing concerns of our times. These include not only economic inequities, but also developmental inequities. The Sustainable Development Goals (United Nations [UN], 2015) recognize this reality and call for "leaving no one behind." Health inequities are being recognized as a significant barrier to the achievement of Universal Health Coverage and several other targets within Goal 3 on ensuring healthy lives and promoting the well-being. Goal 10 of the SDGs explicitly calls for reducing inequalities between and within countries. The framework of social exclusion allows us to examine these inequities in some depth. Rather than viewing inequities as absolute differences among groups, social exclusion provides a framework to understand inequities as the consequence of various social processes and linked to other forms of exclusion including economic, political and cultural.

Social exclusion has been defined as "the process through which individuals or groups are wholly or partially excluded from full participation in the society within which they live" (European Foundation for the Improvement of Living and Working Conditions, 1995, cited in deHaan 1998). According to WHO's Social Exclusion Knowledge Network, social exclusion operates in four critical dimensions – economic, political, social and cultural – and at different levels, individual, household, group, community, country and global. Social exclusion is relevant while discussing health inequities because it results in unequal access to resources, and reduced capabilities and rights, based on social status (World Health Organization [WHO], 2008). When specific groups of people are pushed to the margins of society, there is a power imbalance resulting in 'discrimination' against these groups.

The relationship between social exclusion and health is a complex one. On the one hand, social exclusion predisposes affected communities to a variety of social and economic vulnerabilities that have the potential to jeopardize their health. On the other, the status of such communities serves as a significant barrier to accessing services, resulting in 'leaving them out' deliberately, discouraging their participation or even denying services. Factors that perpetuate social exclusion differ across contexts. In India, the grounds and sources of social exclusion and discrimination are many – caste, class, religion, gender, and so on. The India Exclusion Report 2013–14 which explores exclusion in four "public goods" – education, urban housing, decent work in labour markets and legal justice concerning anti-terror legislation—finds that Dalits, Adivasis, Muslims and persons with disabilities in India are most consistently excluded from all. The report finds that members of these groups tend to be "excluded on unequal and discriminatory terms compared to other sections of society" (p.8). The present report looks at one such group, the Muslims.

Muslims,A Socially Excluded Community in India

Muslims constitute 14 per cent of India's population, making them the largest minority group in the country. The exclusion of Muslims however, does not merely come from being a minority. Rather, it is rooted in decades of unrest between them and the majority Hindu community, which has given rise to many communal riots, dating back to pre-independence. In fact, the movement to partition India has, by some, been said to be rooted in this sense of exclusion faced primarily by the Muslim elite who feared further exclusion in a united independent India (Engineer, 2007). Post-independence, two government reports – the Gopal Singh Panel report of 1983 and a report prepared by a committee chaired by S.Vardarajan, a member of the National Commission for Minorities in 1996 - examined the issue of exclusion of Muslims. They reviewed the exclusion of Muslims especially from representation in public services, judiciary, the private sector and banking services, and found it to be abysmally low compared to the share of the community in the general population. The Gopal Singh Panel Report noted that "there was a "sense of discrimination prevailing among the minorities" and that it "must be eliminated, root and branch if we want the minorities to form an effective part of the mainstream." (Venkitesh, 2006).This report, however, was never tabled in Parliament and was released only in 1989. Most recently, a high-level panel set up in 2005, by the Manmohan Singh Government headed by Justice Rajinder Sachar (or the Sachar Committee as it is known) to study the social, economic and educational conditions of Muslims in India, provides perhaps the most comprehensive picture of the exclusion of the community in India. The report of the committee, released in 2006, notes that Muslims find themselves facing a "dual burden" – of being labeled anti-national and at the same time, of being appeased. As if countering the misconception that Muslim "appeasement" has led to any positive developments for the community, the report finds high levels of poverty and precarious employment among the community. It also highlights their lack of representation in public and law enforcement services (Government of India [GoI], 2006). Yet, the official discourse on developmental exclusion in India has not, as Hasan argues, always taken religious minorities into account (Hasan, 2009).

As a follow up to the Sachar Committee report, in 2008, the Maharashtra State Minority Commission (MSMC) set up a commission (the Mahmoodur Rahman Committee) to document the conditions of Muslims in the state (Government of Maharashtra, 2013). Various studies were commissioned drawing on primary and secondary data, especially from four Muslim dominated areas including Malegaon, Bhiwandi, Behrampada, and Mumbra. The purpose of doing these studies was to inform a multi-sectoral development plan which would guide efforts towards the development of Muslims in the State. The Center for Enquiry into Health and Allied Themes (CEHAT) was commissioned to carry out a study to synthesize emerging findings related to health from the various reports. This study was published as a chapter of the final report (Contractor & Barai-Jaitly, 2014).[3] The present paper explores the social and economic conditions of Muslims in the state one state of India – Maharashtra – that has relatively good development indicators and links them to the prevalence of health inequities and discrimination towards the community.

Based on this analysis, we hope to draw attention to the need for health research to recognize the presence of inequities and exclusion-based on religion, as well as adopt a more nuanced approach to understanding the processes that affect the health of this socially excluded group in India.

Methods

This paper is based on a previous report commissioned by the Maharashtra State Minority Commission, as part of the Mahmoodur Rehman Committee Report. The data used here is primary and secondary data from various sources. First, we look at key indicators from the published state reports of the National Family Health Surveys (NFHS), District Level Household Surveys (DLHS) and the National Sample Survey Organizations (NSSO), to understand emerging patterns and trends related to the health of Muslims. Second, we draw upon primary studies commissioned by the Maharashtra State Minority Commission and others in Muslim dominated ghettoes in Maharashtra. (Nirmala Niketan, 2011, Poonacha et al., 2011, Shaban, 2011a & Jain, 2014). These studies used a mix of qualitative and quantitative methodologies including sample surveys in the four areas

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[3] For a more extended version of the report, please see Contractor S and Barai-Jaitly T (2014) *Health of Muslims in Maharashtra,* CEHAT Mumbai. http://www.cehat.org/publications/1491288467

and qualitative methods such as focus groups, in-depth interviews and key informant interviews to study different aspects of development in these communities such as employment, education, infrastructure, women's issues and health. For the purpose of this paper we have drawn on the findings related to health from these reports. We refer to these studies hereafter as the study from Bhiwandi/Behrampada/Malegaon/Mumbra, respectively. Finally, the report also brings together existing published literature on the health of Muslims in Maharashtra, to add to the analysis emerging from the secondary data and primary studies.

Findings

Socioeconomic Context of Muslims in Maharashtra

Maharashtra is home to about 12 million Muslims, who constitute nearly 12 per cent of its population (Registrar General of India [RGI], 2011), making them the most numerous religious minority in the state. The state stands fourth as far as absolute size of the Muslim population is concerned (after Uttar Pradesh, West Bengal, and Bihar) and 12th in terms of percentage of total population in the State. Muslims are concentrated in the central belt of Maharashtra. Specific blocks of the districts of Akola, Parbhani, Nashik, Aurangabad, Nanded, and Raigarh, as well as the highly urbanized areas of Mumbai, Mumbai (Suburban) and Thane, have a significant Muslim population (Government of Maharashtra, 2013). Muslim communities in Maharashtra are not homogenous – they include various sects and castes, in addition to wide variations in class. A few communities such as the Bohras and Khojas are relatively wealthy, but these do not represent the average. While there is a range of social determinants affecting health, in this paper, we present three critical areas for which data are available. These are economic conditions (including poverty and unemployment), education, and neighbourhoods (ghettoization of Muslims), which in turn demonstrate a link to social exclusion of the community.

Economic conditions

About 70 per cent of Muslims in Maharashtra reside in urban areas, and 60 per cent of these in slums (Shaban, 2011b). The Muslim community in Maharashtra has among the lowest monthly per capita expenditure (MPCE). Muslims residing in the urban areas of Maharashtra have a dismally low MPCE of Rs. 68.14 (derived from the table in John & Mututkar, 2005). Muslims also face higher unemployment than Hindus, and their work participation ratio (WPR)[4] is lower than Hindus both in Maharashtra as well as at the national level. (See Table 1) The proportion of Muslims employed in the unorganized sector is more than any other socio-religious group. The most significant share of the Muslim workers in Maharashtra is in 'other works,' particularly in urban areas. Included in 'other works' are occupations such as carpentry, masonry, fabrication, mechanics, hawking, pulling rickshaws, etc. (Shaban 2011b).

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[4] Worker population ratio is defined as the number of persons employed per thousand persons. WPR= No. of employed persons x 1000. /Total population. Worker Population Ratio is an indicator used for analyzing the employment situation in the country.

Table 1: All India Worker Population Ratio (WPR)*, NSSO 66th Round (2009 – 10)

Region	Hindu	Muslim	All religions
Maharashtra	608	496	593
India	568	497	599

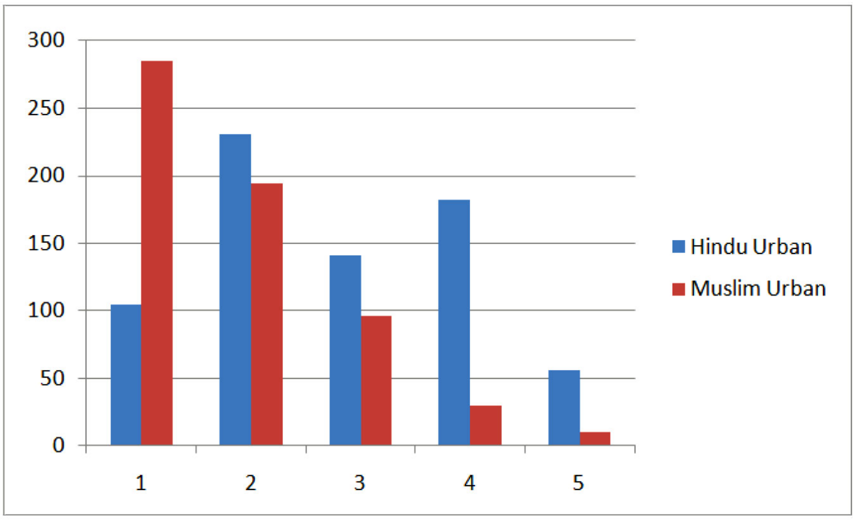
* According to Usual Status (ps+ss) Among Persons of Different Categories of the Major Religious Groups (Urban and rural, male and female, 15 years and above)

Source: Ministry of Statistics Planning and Implementation [MOSPI], 2013

Education

Census data shows that the literacy rate among Muslims was more than 80 per cent in Maharashtra. In this regard, Muslims fare better than Hindus in the state and better than their counterparts in India as a whole as well (Directorate of Economic and Statistics, 2015-16). However, concerning actual educational attainment, the picture is somewhat bleak. The NSSO 66th Round (2009 – 10) indicates a high enrolment ratio of Muslims, but this is followed by sudden dropouts, even in urban areas where access to of higher education institutions is expected to be better (see Figure 1).

Figure 1: Distribution of Level of Education Across Religions in Urban Maharashtra,
NSSO 66th Round (2009 – 2010)



X-Axis: Literate up to Pre-primary (1), Secondary (2), Higher Secondary(3), Graduate (4) and Post Graduate(5).

Y-Axis: Per 1000 distribution of persons of age 15 years and above.

A state-wide survey (Shaban, 2012) showed that only 2.2 per cent of Muslims were graduates or more, and among women, this rate was even lower. Evidence shows that reasons for drop out range from monetary problems and the imperative to start earning, poor quality of schools, and discrimination in the labour market. (Jain & Shaban, 2009). Further, lack of availability of higher educational institutions is a concern. Maharashtra is amongst the top eight states in the country with the highest number of colleges and has a high college- density of more than 25 (number of colleges per lakh eligible population in the age-group 18-23 years) (National Sample Survey Organization [NSSO], 2009 -10). However, Bhiwandi, an area where Muslims constitute 56 per cent of the population has only three colleges for a population of more than seven lakhs. Discrimination has also been reported in schools. During the focus group discussions in the primary study in Behrampada, parents talked about the biases of teachers against their community. One parent said that when her son went to school after an absence of a day, the teacher snidely remarked that he must have gone to attend his father's second marriage, and hence he did not come to school.

Neighbourhoods

The socioeconomic context of Muslims in Maharashtra appears to belinked in many ways to ghettoization. A disproportionately large number of Muslims live in slums; 70 per cent of the Muslims in the state of Maharashtra live in urban areas, and about 60 per cent of these stay in slums and another 30 per cent in lower income areas (See Table 2). The Mahmoodur Rehman committee report notes that 90 per cent of Muslims live in Muslim-majority areas, eight percent live in mixed neighbourhoods and just two percent live in areas where there are very few Muslims (Government of Maharashtra, 2013).

Table 2: Distribution of Muslim Households by type of Neighbourhood in Urban Areas in Maharashtra

Type of neighbourhood	**Slum**	**Low-Income Area**	**Middle Income Area**	**High-Income Area**	**Mixed**
Proportion of households	57.7 per cent	31.3 per cent	9.1 per cent	1.6 per cent	0.3 per cent

Source: Shaban 2011b.

Shaban (2012) notes that the segregation of settlements in Mumbai along religious lines is not new. 'Enclaves' of communities such as that of Parsis in Wadala, Bohris in Dongri, Maharashtrians in Dadar, Gujaratis in Johri Bazar, and so on existed from earlier. However, these established a 'horizontal social order' of communities and were not considered better or worse than the other. However, this changed in recent times with increasing fear and insecurity. Maharashtra has witnessed a number of Hindu-Muslim riots post-independence, and this contributed to the ghettoization. The first communal riot dates back to 1893. In 1967 riots broke out in Malegaon; in 1970, there were riots in Bhiwandi, Jalgaon and Mahad, and in 1984 in Bhiwandi again and in parts of Mumbai. In recent years, (particularly 1992-93) Mumbai, Malegaon, Aurangabad, Bhiwandi, Pune, Nagpur and Dhule are some of the areas of the state that saw a large number of riots that caused displacement of people on an unprecedented scale, affecting Muslims largely. Large numbers of families were forced to leave the places where they had lived all their lives. Increased polarization, failure of the state to control riots and its possible participation in riots (see, for instance Sabrang Communication 1998), led to a feeling of insecurity that resulted in a situation where people choose to live among those of their own community, i.e. ghettoization. Asghar Ali Engineer describes the process as follows:

> Many people are unable to return to their homes even now not just for imaginary fear. When they returned to get the panchnamas made, or just to survey their lost homes, they found their neighbours uncommunicative. In some cases, walls had been erected and boards put up saying, 'Minorities not wanted'. All of them want to sell their rooms and 'live with members of their community if possible', even if it means, as Shahabuddin of Pratiksha Nagar said, 'Living in third class surroundings compared with my A-class area'. Shahabuddin is not alone in his sentiments. There has been distress sale of properties on both sides, i.e., Muslims selling off properties in the Hindu area and vice versa. Thus, in a way, communal divide is complete. (Samiti, 1993)

This led to formation of areas with high concentration of Muslims, and discrimination in the housing market forces led even those who were not victims of riots, to live in 'Muslim areas'.

Living Conditions and Health in Muslim Dominated Areas

Housing, Water, and Sanitation in Muslim Ghettos

The living conditions in Muslim-dominated areas appear to be poor in terms of access to basic amenities including housing, water, and sanitation. In Bhiwandi for instance (where 25 per cent of the population resides in slums), 25 out of 27 slum pockets were Muslim dominated. Nearly 50 per cent of the residents lived in *kuccha* houses. The houses of 44 per cent of the respondents measured 100 square feet or less; almost 90 per cent did not have separate kitchens. Some Muslim dominated slums were also located on forest land and therefore remained neglected by the Municipal Corporation. Because they were considered to be 'illegal,' they were not provided with basic amenities (Nirmala Niketan, 2011). In Malegaon too, Muslim localities consisted mostly of *kuccha* houses (Shaban, 2011a). In Behrampada, the housing consisted of several huts with one storey perched precariously on the other – sometimes as high as four storeys – a safety hazard (Poonacha et al., 2011).

As for drinking water, Shaban (2011b) found that a substantial percentage (12-13 per cent) of households in Mumbai, Thane, and Nashik relied on purchased water for their daily need (Shaban, 2011b). In Bhiwandi city, the survey which covered 14 slums, found that none of the communities had a municipal water connection and had to make do with private connections or tankers for water, the portability of which was questionable particularly in the monsoons. Another common feature of the areas studied was the lack of adequate sanitation (Nirmala Niketan, 2011). In Bhiwandi and Behrampada, there was a shortage of toilets and children as well as adults often had to defecate in the open or in the gutters. In Behrampada, only 21 per cent of the households had private toilets attached to their houses, 77 per cent used public toilets, and two percent use paid public toilets. The number of toilets was inadequate, particularly for women, who had to leave early in the morning and wait in long queues. Fights over the use of the toilets were reported to be common, and the condition of toilets was said to be filthy due to the clogging of drains. Further, residents used the same area for washing utensils (Poonacha et al., 2011).

The picture emerging from the studies mentioned above shows that the condition of Muslim-dominated ghettoes in Maharashtra vis-à-vis water, sanitation, and housing facilities is extremely poor. The residential segregation of Muslims is evident, which directly and indirectly impacts their health.

Morbidity Related to Living Conditions

The living environment and lack of water and sanitation described above were bound to result in the spread of communicable diseases. In places like Malegaon, 45.4 per cent of recorded deaths among Muslims are in the age group below five years and are primarily due to pneumonia and diarrhea (Shaban, 2011a). In the primary studies from Malegaon, Bhiwandi, Behrampada, and Sion-Koliwada, 60 to 90 per cent of the respondents reported having suffered from a minor illness in the year preceding the study. Common minor illnesses included viral fever, cough, cold and stomach problems. The most commonly- occurring serious illnesses in all four studies were malaria and tuberculosis, the prevalence of which varied across the regions (Poonacha et al., 2011). In certain some areas like Bhiwandi, 30 per cent of the families reported the presence of a member who suffered from malaria in the year preceding the study while one in ten reported a case of tuberculosis in the family (Nirmala Niketan, 2011). In Behrampada, malaria was reported by about 10 per cent of families and tuberculosis by less than 5 per cent. Other serious illnesses included jaundice, typhoid and non-communicable diseases like diabetes, asthma and cardiac problems. The high prevalence of infectious diseases like malaria and tuberculosis was attributed to the congested living environment, a feature of most slums in which urban Muslims reside (Poonacha et al., 2011).

Reproductive Health

Fertility and Contraception: The fertility rate of the Muslim population in India, in general, is an intensely politicized issue, and has been used by politicians to stoke majoritarian fear. (See for instance, Outlook Web Bureau 2018). A look at the data, however, shows a very different picture. Foremost, various rounds of the NFHS provide a view of the declining fertility rate among Muslims. The Total Fertility Rate (TFR) of Muslims in Maharashtra steadily reduced from 4.11 in 1992-93 (NFHS 1) to 3.3 in 1995-96 (NFHS 2), to 2.8 in 2005-06 (NFHS 3), and to an almost replacement level fertility rate of 2.33 in 2015-16 (NFHS 4). This drop in TFR was better for Muslims than for the whole state (International Institute for Population Studies [IIPS] & ORC Macro, 2001, IIPS & Macro International, 2008, IIPS & ICF, 2017).

Table 3: Demand for Contraception by Selected Socio-religious groups, NFHS -4, Maharashtra 2015-16

Religion	**Any modern method**	**Unmet need for family planning**		**Met need for family planning (currently using)**		**Percentage of demand satisfied**
		For spacing	**For limiting**	**For spacing**	**For limiting**	
Hindu	63.1 per cent	4.2 per cent	5.1 per cent	4.9 per cent	60.2 per cent	87.5 per cent
Muslim	55.9 per cent	4.7 per cent	6.6 per cent	6.5 per cent	52.0 per cent	83.8 per cent
Schedule Caste	26.1 per cent	4.6 per cent	6.1 per cent	4.6 per cent	59.7 per cent	85.7 per cent
Schedule tribe	15.5 per cent	4.7 per cent	4.6 per cent	4.4 per cent	58.5 per cent	87.1 per cent

Source: IIPS and ICF, 2017

Contraceptive use among Muslims in Maharashtra was also found to have increased over the years but dropped slightly in the last decade from 57.4 per cent in NFHS 3 (2005-06) to 55.9 per cent in NFHS 4 (2015-16). Data from NFHS 4 also suggests that Muslims prefer the use of spacing methods such as pills and condoms. The use of condoms among Muslims is 16.8 per cent as compared to 11 per cent for the state, and oral contraceptive pills is 3.7 per cent as compared to 1.4 for the state. (IIPS & ICF, 2017) Similarly, in the primary study in Behrampada, community health workers reported that women were not averse to using contraception, but preferred spacing methods rather than sterilization (Poonacha et al., 2011). Since the family planning programme in India is focused mainly on permanent methods of contraception, it is possible that the low utilization of contraception among Muslim may be the result of this skewed focus and the poor availability of spacing methods in the public health system. Other studies have reported that non-availability of the preferred method of contraception as one of the barriers to accessibility of family planning services among Muslim women. (Hussain, 2008, Jeffrey & Jeffrey, 2000, Chacko, 2001). As a result, Muslim women have a high unmet need for family planning, and the lowest percentage of demand satisfied, while the total demand for contraception is more or less within the range of the rest of the groups (see Table 3).

Therefore, there is a clear mismatch in what Muslim women need and what is provided by public health services, thereby resulting in their potential exclusion from services, or pushing them to access these services from the private sector.

Maternal health

With regard to maternal health, no disaggregated data by religion is available in recent times. However, the utilization of services by different socio-religious groups provides some indication of maternal health in the Muslim community. As per NFHS 4, Muslim women are as likely to utilize maternal health services as women from other communities (IIPS & ICF 2017). In the previous round, i.e., NFHS 3 (IIPS & Macro International, 2008), the proportion of Muslim women who had institutional deliveries and went for antenatal checkups was greater than other communities, but this gap has reduced with an overall improvement in these indicators for all communities over the last ten years. However, despite utilization being almost the same as the majority community, concerns over the quality of care exist. For instance, as per NFHS 4, about as many Muslim women (70 per cent) as Hindu women (72 per cent) are likely to go for 4 or more antenatal checkups. However, only 28 percent of Muslim women received all components of antenatal care, as compared to 32 per cent of Hindu women (IIPS & ICF 2017). The reasons for this warrant exploration as they may reflect systematic unavailability of services in Muslim dominated areas or may be related to untrained providers. Similarly, almost an equal proportion of Hindu and Muslim women deliver in health facilities. However primary studies show that, despite residing in the urban areas with proximity to health facilities, some women do have their child delivery at home. Instances of home births were seen in Bhiwandi as well as in Behrampada, which is located not more than 7kms from a health facility (Nirmala Niketan, 2011 & Poonacha et al., 2011). The Behrampada study also reported that not all of these home deliveries were assisted, indicating high risk to lives of the mother and child. The study reported that one of the reasons for not approaching the health facility was that as per prevailing government rules, only first two deliveries were conducted free of charge. Further, women reported bad behavior of staff towards them, discrimination and higher expenses, as reasons for not going to the hospital (Poonacha et al., 2011).

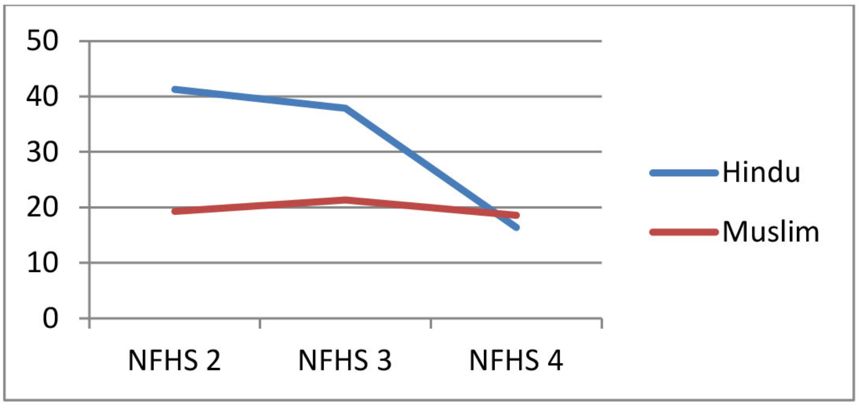
Child Health

Child Mortality: NFHS 2 and NFHS 3 suggested that the neonatal mortality rate, infant mortality rate, child mortality rate and the under-5 mortality rate of Muslim children were better than for Hindu children (Contractor & Barai-Jaitly, 2013). The relatively better childhood mortality rates among Muslims in India, despite their poorer education and wealth status, are a subject of much debate. Better sanitation (Geruso & Spears, 2014) and urban location of Muslims (Contractor & Barai-Jaitly, 2013) are some of the hypotheses proposed to explain this relative advantage. However, NFHS 4 shows a very different picture. It appears that while childhood mortality rates dropped overall in Maharashtra, for Muslims, they remained constant. As per NFHS 4, childhood mortality for Muslims in Maharashtra was higher than that for Hindus and the state as a whole (See Figures 2, 3 and 4).

It is pertinent to note that as per NFHS 4 (2005-06) Infant Mortality Rate, Neonatal Mortality Rate and Under-5 Mortality Rate are all lower in urban areas than rural areas in Maharashtra (IIPS & ICF, 2017). Muslims being located in urban areas should, therefore, be at an advantage but this does not appear to be the case. The reasons for this must be explored. Infant mortality rates are reflective of a large number of contextual factors such as literacy, socioeconomic status, nutrition (of the pregnant woman and children), and importantly availability and utilization of health facilities. The reasons why childhood mortality rates did not improve for Muslims as compared to Hindus in Maharashtra, may perhaps be related to these factors, especially the poor living conditions of Muslims, which overshadow the urban advantage.

Figure2: Neonatal Mortality Rate Trends for Muslim & Hindu children, Maharashtra,

NFHS 2, 1999; NFHS 3, 2005 – 06; NFHS 4, 2015 – 16



*Y-axis indicates the neonatal mortality rate

Source: IIPS & ORC Macro, 2001, IIPS & Macro International, 2008 & IIPS & ICF, 2017

Immunization: Along with changing trends in child mortality indicators, it is also important to point out the changing trends in immunization. At the time of NFHS 2 (1998-99), there were wide gaps in immunization coverage with 35 per cent of Hindu children receiving all vaccinations as compared to 26.3 per cent of Muslim children. At the time of NFHS 3, the gap decreased to 59.8 per cent of Hindu children receiving all immunizations against 54.8 per cent of Muslim children. However, at the time of NFHS 4, the gap appears to be widening again with 59.3 per cent of Hindu children receiving all vaccinations as compared to only 45.6 per cent of Muslim children. While there has been a general trend on reduction in coverage in the last decade, it seems to have had a significant negative impact on Muslim children, and the gap is wider than that of NFHS 2 (1998-99) in terms of complete vaccinations (IIPS & ORC Macro, 2001, IIPS & Macro International, 2008 & IIPS & ICF, 2017).

Availability of Public and Private Healthcare

The paucity of health facilities in Muslim-majority ghettoes emerges from the data in the four primary studies. (Nirmala Niketan, 2011, Poonacha et al., 2011, Shaban, 2011a & Jain, 2014) As per the standards proposed in the National Urban Health Mission, one Urban Health Post is required to cater to a population of 25,000-50,000 persons. In stark contrast to this, the findings from the studies are as follows:

- Bhiwandi has ten urban health posts and only one public hospital catering to a population of about 7 lakh residents. Residents mentioned that the hospital is unable to provide any specialized care. Only normal deliveries are performed and no C-sections. They also mentioned that the hospital does not have emergency facilities, ambulances or blood banks. There are no multi-specialty or tertiary care facilities and people travel to Mumbai or Thane for any surgery.
- In Mumbra, there are three urban health posts and one maternity home that caters to a

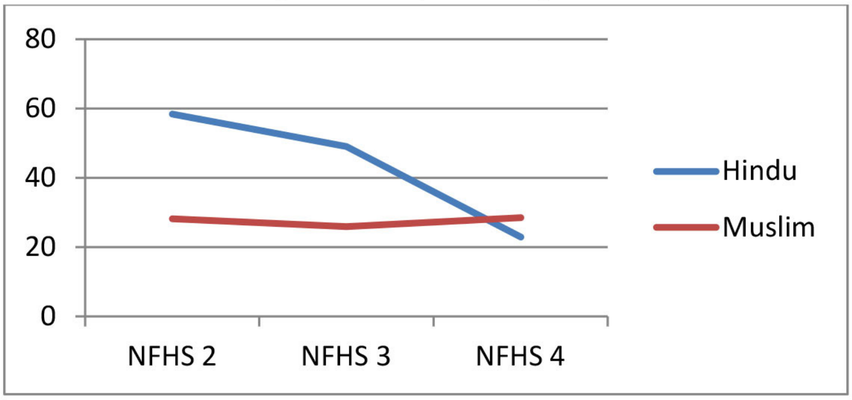
population of 8 lakh people. Further, the few urban health posts are only open for two hours, six days in a week at a time that is inconvenient for people, which makes access extremely difficult. The only hospital is located in Kalwa, and for conditions that cannot be addressed there, residents travel to Mumbai or Thane

- Malegaon with a population of 4.7 lakh has four municipal dispensaries, three maternity homes, and two municipal hospitals, along with a district hospital. However, the study mentioned that municipal hospitals largely cater to paediatric and child needs, whereas the district hospital provided limited services.
- The study from Behrampada showed that the area had no health post for a population of 49,829 and residents accessed health post located in Kherwadi for their needs.

This further exemplifies the lack of public health facilities available in these densely populated areas, which has a bearing on the health of the community.

Figure 3: Infant Mortality Rate Trends for Muslim & Hindu children, NFHS 2, 1999;

NFHS 3, 2005 – 06; NFHS 4, 2015 – 16



**Y-axis indicates infant mortality rate*

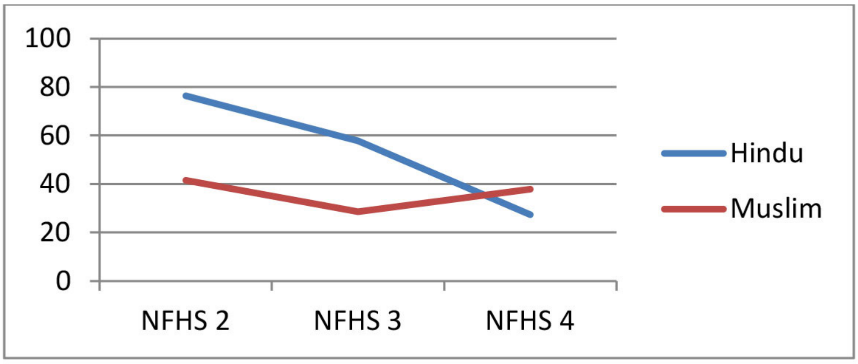
Source: IIPS & ORC Macro, 2001, IIPS & Macro International, 2008 & IIPS & ICF, 2017.

Flourishing Private Health Facilities

The non-availability of public health facilities in Muslim ghettoes may have led to the flourishing of private health facilities. In Bhiwandi, for instance, there were 75 private hospitals/nursing homes as compared to one municipal hospital and ten health posts. According to a survey report of private medical practitioners in Bhiwandi, (As cited in Chief Minister's Study Group Government of Maharashtra, 2013) over a third of private medical practitioners were Unani doctors, followed by Homeopathy and Ayurveda, while about a tenth were allopathy doctors with a bachelor's degree (Nirmala Niketan, 2011). Similarly, in Behrampada, there were 16 private practitioners in the field area of the study, most of them with an Unani or Homeopathy degree. There were no specialists or super-specialist facilities available (Poonacha et al., 2011).

Figure 4: Under - 5 Mortality Rate Trends for Muslim & Hindu children,

NFHS 2, 1999; NFHS 3, 2005 – 06; NFHS 4, 2015 – 16



**Y-axis indicates the under-5 mortality rate*

Source: IIPS & ORC Macro, 2001, IIPS & Macro International, 2008 & IIPS &ICF, 2017.

Prejudice among Health Care Providers

The prejudiced behaviour of health care providers was reported in the primary studies conducted particularly in Bhiwandi and Behrampada, where women specifically said that they did not like going to health facilities because they felt discriminated against by the hospital staff (Poonacha et al., 2011 & Nirmala Niketan, 2011). This finding is supported by the Sachar Committee report which found that Muslim women are deterred from accessing public health institutions because of the "unacceptable behaviour" that they encounter, and further states that due to this discrimination, they prefer going to providers from their own community, even if they are not suitably qualified, and end up receiving substandard treatment. It also points out that Muslim women wearing the burqa feel that they are not treated well in public facilities such as hospitals, schools, public transport, etc (Government of India, 2006). Another study in Mumbai (Khanday & Tanwar, 2013), found that Muslim women felt that they were treated differently from women of the majority community. Muslim women reported that the manner in which health care providers spoke to them at the health facility was different from how health care providers spoke to people of their 'own' community. This feeling of 'otherness' was perpetuated by the fact that providers would refuse to pronounce or spell Muslim names correctly. Muslim women also reported that they were called derogatory names, such as *'landiyabai'* (wife of circumcised man) at health facilities. They were referred to as *'ladaku log'* (people who tend to fight) if they refused to remove the burqa. Moreover, women have expressed that it is the wearing of the burqa that brings about a change in the attitude of the hospital staff (Khanday &Tanwar, 2013).

> "They look at the veil, and they make a face; feel irritated. They feel that we are dirty underneath the veil. They ask us to remove it the minute we enter the hospital. Nowadays in certain hospitals, they do not allow women with veils. They say that women in veils steal children. Someone may have done it, but is it right to label the entire community because of one act?"(Khanday & Tanwar, 2013).

Table 4: Available Health Facilities in Four Areas of Primary Studies

Area	Population	Health post/ dispensaries	Maternity Home	Public/ municipal Hospital	Private
Bhiwandi	7,11,329*	10 health posts		1	75 hospitals/nursing homes.
Malegaon	4,71,006*	4 dispensaries	3	1 District + 3 Municipal	
Behrampada (H/E Ward)	6,63,742 (ward)				
49,829 (Behrampada)	6 dispensaries & 8 health posts	6 dispensaries & 8 health posts	1	1	38 nursing homes/ 254 practitioners

**Data from Census 2011.*

Source: Nirmala Niketan, 2011, Shaban, 2011a & Poonacha et al., 2011

The prevalence of stereotypes and myths among health care providers is also evident. The study by Khanday and Tanwar highlighted various stereotypes that health care providers harbor about Muslim women– that Muslims have too many children, they are dirty and uneducated. Other subtle forms of stereotypes were also evident in the primary studies. For instance, in the Behrampada study, one health worker while speaking about the high prevalence of tuberculosis in the community, remarked that Muslims tend to have more TB because they eat beef leading to the transmission and spread of Bovine TB (Poonacha et al., 2011). Similarly, in Bhiwandi, according to the Chief Medical Officer, immunization of children was a "big challenge" because a majority of the Muslims refuse to administer their children the vaccinations including polio drops since they believe that the vaccine contains the genes of pigs. This, despite the fact that 94 per cent of the children under 5 in the area were immunized, as per the primary survey (Nirmala Niketan, 2011). These perceptions cast Muslim communities as backward, stringent followers of religious *diktats* no matter how harmful, and resistant to change. They also reinforce the "otherness" of communities (see Table 5).

Table 5: Experiences of Women while Accessing Public Health Facilities

Faced by	Description of Behaviour
	• Rude language • Corruption to jump the queue • Abuse in labour ward – made to clean floors, physical and verbal abuse, no privacy • Behaving badly towards accompanying persons • Health care providers use English which is not understood by the patient population
	• Use of derogatory remarks about women married to circumcised men, "Landiyabaika." • Being singled out as "Musalmanaurat" creating a negative impression • Refusal to understand and comprehend Muslim names • Asked to remove veil even before the turn for examination • Taunted as "dramatic" women because of inhibitions to remove burqa • Biases that Burqa-clad women steal children. • Stereotypical remarks o Muslim women have many children o Muslim people are uneducated o Muslim women refuse to use contraception o Muslim people are dirty

Source: Khanday & Tanwar, 2013

Despite this poor behavior and discrimination encountered at public health facilities, Muslim women continued to access them. Given that dignified treatment is a core component of quality of care and a human right, this aspect of provider behavior needs more attention.

Discussion

The literature on religion-based inequalities, discrimination, and exclusion of Muslims vis-à-vis health, in India, is scarce. For instance, a recent comprehensive review on inequities in maternal and reproductive health in India found only one article specifically about the Muslim population and pointed out that while some studies included data on religion, they did not explore the linkage between health status and being part of the Muslim community (Sanneving et al., 2013). Nevertheless, over the past decade, some studies and reports have attempted to highlight the health conditions of Muslims and their relative disadvantage. The Sachar Committee report (GoI, 2006), released in 2006, showed that of all the villages without medical facilities, 16 percent were located in Muslim concentrated areas. The availability of health facilities in the village declined with a rise in the proportion of Muslims in the population, particularly in larger villages. Similarly, concerning access to basic amenities, Menon and Hasan (2004) state,

> Clearly, there are disparities in access to services and programmemes along rural and urban lines and possibly along socio-economic status and community lines, reflecting discrimination in their provision by caste and religion.

Where inequalities around the religious community are reported, the studies are largely around maternal and reproductive health. A study reported that Muslim women (among slum populations) were less likely to have a birth attended by a trained birth attendant (Hazarika 2010). One study found that Muslims (along with other disadvantaged communities like SCs and STs) were more likely to report poor self-rated health (Bora & Saikia, 2015). The greater likelihood of receiving antenatal care (in Madhya Pradesh) and accessing post-natal care (in West Bengal) by Muslim women was reported (Jat, Ng & Sebastian, 2011, Tuddenham et al., 2010).

The present paper attempts to look beyond religion as an individual characteristic which determines health status and instead seeks to establish the disadvantaged socioeconomic conditions of Muslims in Maharashtra, drawing linkages to discrimination against the community and the historical impact of violence that pushed them into ghettoes. Located largely in urban areas, Muslims should have had an advantage, but indicators reveal a mixed picture. In case of childhood mortality rates, it appears that despite being located in urban areas, Muslims have not benefitted from the fall in mortality rates in the state over the past decade. Similarly, although utilization of maternal health services among Muslim communities is at par with the majority community, there are concerns around discrimination in accessing care. The findings of this paper are in no way conclusive, but rather indicate the need for exploring in greater detail, the mechanisms that explain differences in indicators as well as uncover the experiences of Muslims in the state.

That said, it is also important to note that considering Muslims as one group is not always helpful, as there are huge class, caste, gender and geographic differences between them. Intersectional analysis seeks to uncover the unique experiences of these different sub-groups and is therefore essential. The experiences of Muslim women or Dalit Muslims are likely to be quite different owing to additional layers of marginalization to which they are subjected. To be able to understand this, both qualitative and quantitative studies are required. These differences are insufficiently explored in the literature and, the paucity of large datasets further makes it difficult to conduct a detailed examination of these differences.

In this context, evidence from some western countries suggests that lifetime exposure to discrimination is associated with poor health outcomes as well as poor health-seeking behaviour (increased delays in seeking health care and poor adherence to treatment regimens) and poor utilization (Casagrande et al., 2007). The trust deficit between the State and the Muslim community is bound to play out also in its interactions with the health system, as has been reported in an ethnographic study from rural Uttar Pradesh which explores how widespread lack of trust in the public health system affects women's access to institutional delivery care. This warrants more context-specific, qualitative studies which can uncover these experiences, especially since we know from other contexts that such discrimination affects health. The impact that behaviour of providers, reported in this paper and other studies, has on people's health-seeking behaviour and health status needs to be considered more seriously and remedied. Similarly, the stark context of residential segregation of Muslims in the state and its impact on the health of the population also requires more serious investigation. Residential segregation has been identified as a fundamental cause of health inequities among racial and ethnic minority groups in the United States (Williams & Collins, 2001). Even the availability of health facilities and pharmacies in segregated areas is likely to be poorer than in other places (Williams & Collins, 2001). We see these characteristics in Muslim ghettos as well.

Finally, this paper only examined certain health issues for which literature and data were available. The general condition of Muslims, the stresses they face in everyday life also warrants more research into the impact of everyday micro aggressions faced by Muslims on their mental health. Similarly, the evidence on the Muslim community's precarious employment in the unorganized sector also warrants more research on occupational health hazards that the community faces.

Conclusion

The findings reported in this paper indicate that a large proportion of Muslims in Maharashtra live in relative isolation and are subject to relative disadvantages vis-à-vis poverty, employment, education and living conditions. These conditions affect their health and well-being, as explored in this paper. The findings throw up important questions and hypotheses that need to be studied in greater detail if we seek to better understand and address the needs of the minority population in a context-specific manner. It is, therefore, important that the mechanisms of social exclusion and structural obstructions are uncovered and documented so that they may be eliminated.

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(Un) popular Traditional Medicine
Community Perceptions, Changing Practices, and State Policy in Nepal

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Traditional medicine refers to different forms of medicines and therapeutic practices, both popular and scholarly. This paper draws on the field data collected from two villages of Nepal to reflect on whether popular traditional medicine is becoming unpopular among the rural communities. The article looks into community perceptions, changing practices and therapeutic choices among the local people. Inequalities and differences were observed in the use of popular traditional medicine (PTM) and scholarly traditional medicine (STM). We found that the overall popularity of PTM has declined over the past few decades. Field narratives and treatment- seeking data show the falling use of PTM. It appears that the present trajectory of healthcare development has had a damaging effect on PTM.

STM, which has been recognized as part of national health care system, gets some support for its growth and development but PTM, on which still a large number of people rely, lacks such support. We argue that the damages to PTM will have a serious implication from a health equity perspective. Rising inequities in health cannot be addressed without taking PTM on board. Furthermore, the damages to PTM will have a damaging effect on the growth and development of STM as well. We question the policy rhetoric of "promoting Ayurveda and other alternative systems" and "making health care services accessible to all." We conclude that promotion of positive aspects of PTM can contribute to the advancement of STM. Making healthcare services more accessible and affordable lies not in the growth of an unregulated private sector and pushing towards biomedicine- based- government- healthcare provisioning. It depends on the promotion and strengthening of the public sector with a balanced role for traditional medicine, both popular and scholarly.

Keywords : Traditional medicines, traditional practices, health policy, Nepal

Traditional medicine[2] is an umbrella term that includes all the systems of medicine and therapeutic practices which do not fall under the domain of biomedicine. Traditional medicine consists of different strands, different forms, different therapeutics, and of different systems. It includes codified and non-codified, formal and informal, elite and subaltern, professional and popular medicine. Dunn (1976, p. 139), divides traditional medicine into two groups: (1) Popular traditional medicine (PTM),

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[2] WHO defines traditional medicine as 'the sum total of the knowledge, skill, and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness"(WHO, 2013, p. 15).

[3] The local health tradition is a broad concept which "represent the practices and knowledge of the common people and folk practitioners who follow an oral tradition of learning and passing on of the knowledge through practice" (Priya & Shweta, 2010).

and (2) Scholarly traditional medicine (STM). PTM is rooted in local health traditions[3] which play a significant role in the rural communities, and includes small-scale local systems of medicine. STM includes regional medical systems which are distributed over a relatively large area such as Ayurveda, Unani and traditional Chinese medicine.

Medical Systems in Nepal

Many medical systems and therapeutic practices co-exist in Nepal. Biomedicine (or allopathy) has a robust presence especially in the urban areas in the public sector and the private sector. As the mainstream medical system, biomedicine gets by far the most significant share of public resources. State policies and programs emphasize the expansion of biomedicine -based health care system. As a part of Nepal's planned development efforts, many central, regional, zonal and district level hospitals, primary health centers, health posts and sub-health posts have been established. Doctors, nurses, health assistant, village health workers, maternal and child health workers, and female community health volunteers provide biomedical healthcare services. There are parallel hospitals, specialty centers, nursing homes, pharmacies, dispensaries and clinics in the private sector.

Among STM, Ayurveda has a lead status and constitutes an integral part of the national healthcare system in Nepal. There are Ayurvedic hospitals and health centres and Ayurveda dispensaries at the central, regional, zonal, district and *ilaka* level. There are also private Ayurvedic clinics providing Ayurvedic services in the urban centers. Homeopathy, Unani, Tibetan system (Amchi), yoga and naturopathy do poorly in terms of public provisioning. There is only one homeopathy hospital and an Unani dispensary in the public sector. There are homeopathy, Unani, Amchi, naturopathy clinics and yoga centers across the country in the private sector. However, biomedicine-based health facilities greatly outnumber STM facilities.

PTM is one of the most accessible healthcare options for the rural, poor and indigenous ethnic communities in Nepal, as is the case in many parts of South Asia ((J. Subedi, 1989; M.S.Subedi, 2003). PTM in Nepal mainly consists of three types of practices: shamanic or faith healing practices, herbal practices, and massage and midwifery practices. There are a number of PTPs who are known as *dhami-jhankri* (shaman), *jhar-phuke* (sweeper or blower of the spirit), *pundits, lama, gubhaju, pujaris* (priests), *janne manchhe* (the person who knows about healing), *jyotish, yogi-baba* (astrologers), *vaidya* (herbal practitioners), *sudeni* (traditional midwife) and *malis-garne-wala* (massagers). These practitioners use healing mantras, a variety of herbs, plants, animal and mineral resources, massage and body manipulation techniques and midwifery services.

There are a considerable number of practitioners of PTM in Nepal as compared to the formal practitioners of both biomedicine and STM. There is hardly a village where one cannot find PTPs. Despite the expansion of formal medical care, traditional practices remain highly popular, and in many remote areas, they are the only source of treatment (Shrestha & Bhattarai, 2003, p. 155). Official reports also affirm the significant role played by traditional practitioners in the healthcare sector of Nepal (Ministry of Health and Population [MoHP], 2012, p. 1). However, official support is tilted in favour of biomedicine. STM such as Ayurveda, homeopathy, and Unani receive "minuscule" state support and "PTM gets almost no financial support, though there were efforts at linking them with the public health system. (Nepal South Asia Centre [NESAC], 1998, p. 60).

With the recent socio-economic and political changes in favour of biomedicine, PTM is at a crossroad. In recent times, biomedicine is being expanded throughout Nepal, and this has altered the existing medical pluralism making biomedicine a dominant one followed by STM along with the Complementary and Alternative Medicine variants, with PTM at the bottom of the pile.

In Nepal, the urban few have access to formal government-funded medical care, whereas the rural mass is still deprived of government healthcare services. They have access to the PTM, but many of the popular traditional practices are often tagged as primitive, unscientific and irrational (Pigg, 1992). The advocates of formal biomedicine also raise the question of safety and efficacy when it comes to PTM, and they reduce popular traditional practices to the superstitious beliefs or shaman's tricks. The modern educational system that takes anything 'traditional' as 'unscientific' has a role in shaping the community's perceptions.

These changes have posed a threat to the very existence of PTM. Some studies claim that if the current trend continues many of the traditional practices will be a thing of past (Payyappallimana & Hariramamurthi, 2012, Raut & Khanal, 2011) as the process of making the popular into unpopular has already begun. In this context, this paper seeks to understand community perceptions, changing practices, and therapeutic choices among different sections of the people. The specific research questions are:

Has the use of PTM been declining over the last few decades?

How does the community view popular traditional practices and the use of PTPs in the present context? More specifically, this study attempts to understand whether PTM is becoming unpopular in the changing context.

Methods

Study setting

This paper draws on qualitative data collected from two villages of Terai region of Nepal: one from Dang and another from Kailali district. Socio-economically these two villages do not differ much. There is some difference in terms of the educational status, location of health facilities and availability of PTPs. Village A of Dang district has 124 households consisting of six different caste and ethnic communities. There are a dozen PTPs including shamanic or faith healers, herbal healers and traditional midwives. The people from neighbouring villages also consult these practitioners. The people from this village also go to other neighbouring and distant villages to consult some of the reputed PTPs for the treatment of snake bites, dog bites, and navel dislocation, problems related to nose, and children's illness. In the middle of the village, there is a medical shop privately run by a paramedic who sells drugs (mostly biomedical and a few Ayurvedic) and provides primary care services such as giving injections, measuring temperature, weight and blood pressure and carrying out minor surgery for small cuts and injuries. A public health post is located approximately at a distance of five km and provides primary health care services. Instead of going to the health post people prefer to go to Ghorahi, the district headquarters located eight km away. Ghorahi is preferred because there is transport facility to get there, they could visit a wide range of practitioners, both public and private, and they could avail urban facilities. There is another medical shop on the way to Ghorahi.

Village B of Kailali district has 86 households from five different caste/ethnic groups. There are half a dozen traditional practitioners in the village, and a majority of them are guruwa (faith healers). There is no medical shop in the village, but there is a sub-health post and a medical clinic in the adjoining village. The villagers go to the neighbouring village to visit one of the famous herbal practitioners. If needed, they also go to distant villages to consult traditional practitioners treating specific conditions. They go to Dhangadhi, the district headquarters,16 km away, which has hospitals and different types of clinics (eye, dental, biomedical, Ayurvedic, etc.). In both the villages, Tharu are in the majority followed by Chhetri, Brahmin, Kami, and Damai. A majority of the people in both villages is involved in agriculture, but the number of people with 10th grade education and above, and private and public job holders is relatively high in the village A. The people of village A are in a better socio-economic condition with an urban influence than people of village B.

Sample selection and conduct of interviews and Focus-Group Discussions

This was a cross-sectional study using qualitative methods of data collection. The respondents were household heads, traditional practitioners, medical persons, the staff of government health- posts, local leaders, and school teachers. Fifteen such persons were selected purposively and interviewed about the use of PTM. Special attention was given to select respondents who were the residents of the sample village and were knowledgeable about the use of different medical traditions as users or practitioners. Besides the interviews, we conducted three focus group discussions (FGDs) among the school teachers, cooperative members, and female community health volunteers. Questions posed were on availability and use of the PTPs, and whether they had seen any changes in the choice of medical system by community members. The discussions were also intended to know whether the PTM is as popular as in the past (two or three decades). The responses were audio recorded, transcribed in Nepali and translated into English. The field data and information were analyzed manually and presented in narrative forms.

Ethical clearance was obtained from the Institutional Review Board of Jawaharlal Nehru University, Delhi.

Results

Healthcare seeking patterns

There are mainly three types of PTPs: shaman or faith healers, herbal practitioners, traditional midwife and massagers in both the study villages. The villagers also go to the neighbouring or distant villages to consult the practitioners who have a reputation as the bone setter, herbal practitioners, jaundice vaidya, snake bite healers, shaman, priests, and astrologers.

The local people have an understanding of the causation of illness, which guides them to choose a practitioner for a particular health problem. Shamanic and faith healers are considered the only options available for illnesses which are of unknown origin, deemed to be supernatural in nature or ascribed to evil spirits. These healers mostly use healing mantras (chants), and some of them know about the merits of locally available medicinal herbs, plants, and animal products.

A participant who had recently visited a faith healer said

> “I visited the healer because I was having a bad dream (nightmare). It was of bloody fighting and death of my

> husband. When I had such bad dream, again and again, I suspected the role of bad spirits, and for this, I visited the guruwa (a faith healer among the Tharu community). Where to go, I had no other option. People will laugh at you when you go to the hospital with such a problem."

For physical illnesses, they prefer to visit an Ayurvedic vaidya or may want to go to a medical shop, health post or hospitals. If the treatment fails, then they go back to the PTPs or seek services from another hospital located in one of the big cities of Nepal or neighbouring India. More often such big hospitals are visited by well-off sections and in cases of serious illness conditions.

For assistance in childbirth and postpartum care and massage services, they seek help from traditional midwives *(sudeni, dai)*. There are other traditional massagers who are consulted at times of bodily pain, sprain and muscle dislocation. The socio-economically weaker sections of society resort more to these traditional practitioners whereas well-off sections resort more to the health facilities or the practitioners of biomedicine.

However, in many instances patients move across allopathic practitioners, practitioners of STM and PTM. A common perception is that one should not solely rely on PTPs, one should also visit hospitals or other practitioners of formal medicine.

The following quotation illustrates the pattern of care-seeking in case of a health problem of unknown origin:

> "My husband was suffering from weakness. He used to look tired and preferred to take rest lying in bed and used to complain about a headache and pain in the body. It was in the month of mid-June, and we thought that that was because of hot weather. So we gave him cold things… watery porridge, watermelon, papaya, sugarcane juice and the like. We visited two or three clinics and bought drugs as prescribed by the doctors but instead of decreasing his weakness increased further. Then we visited a guruwa (a faith healer) two times. The guruwa suggested that we perform the pati-baithna (a healing ritual) suspecting the problem to be one of lagu-bhagu (evil spirit). We did the offerings and waited or the first few days hoping that the weakness will disappear soon. But nothing improved even after that. Then we went to the hospital of Nepalgunj [a city at a distance of 200 km], and we did blood and urine test, and the doctor said that was because of jaundice. We were surprised because he did not look like yellowish like other jaundiced patients. It was black jaundice. A person who had a similar type of jaundice suggested us to visit a vaidya who was known for jaundice treatment. We went to the vaidya, and the vaidya gave herbal decoction of some plants and roots. My husband drank a lot of decoction for almost two weeks, and he gradually improved, and at last, the vaidya gave a coarse herbal powder, and that cured him." (A woman aged 54)

Many people consult the local PTPs first and then move to formal health facilities. When treatment fails, they move back and forth between various therapeutic options. In the above case, the doctor's medicine might have worked, but the credit went to a Vaidya. But in many cases, credit often goes to the biomedical practitioner because of the treatment success. People have strong faith in biomedicine because of its amazing success in the treatment of complicated and severe disease conditions with the discovery of newer and potent drugs; and its success in difficult surgeries such as open heart surgeries, transplant of livers and kidneys and other such landmarks (Subedi, 2016).

Perspectives on popular traditional medicine (PTM)

We interviewed a wide cross-section of community members about their perspectives on popular traditional medicine and changes in its popularity in recent times.

We found that many of those who were educated and considered themselves to be modern, were skeptical about PTM. According to a college student,

> "Diseases cannot be cured just by eating jhar-paat (grass of no medicinal value). Why do we need all these big hospitals and modern drugs and injections if we get cured by having jhar-paat or by listening dhyangro (a drum played by shamanic healers in a healing session) because this does not work and there is no such thing as lagu-bhagu (attack by dead spirit)."

A school teacher viewed shamanic and faith healing practices as irrational and unscientific:

> "The faith healers first say 'I will treat you. Don't worry; your condition will be improved soon' because they want to be served with home-brewed rice liquor along with rooster's meat for few more days. The treatment by faith healer is more like throwing an arrow in the dark. There is very less chance that it hits where it aims to hit. The condition might improve if there is no such real problem or of an emotional thing. If there is a real problem and when the condition worsens they ask them to go to the hospital."

Belief in PTM was also considered to be a thing of the past, bound to disappear as educational levels increased and society modernized:

> "Awareness level has increased, medical shops have increased, hospitals have increased; no one believes in superstitious and unscientific things anymore...I do not believe in the reading of rice grain (a common diagnostic practice of traditional faith healer) and jhar-phuk (an act of shaman or faith healer in which a hand broom is used to sweep down or blow out evil spirits by reciting healing mantras)."
>
> "Certainly, people are educated and feel it necessary to go to medicals [private medical shops run by paramedics] and hospitals, rather than to such (popular traditional) practitioners."

A practitioner of modern medicine not only thought PTM to be obsolete and irrelevant but believed it to be bad and harmful:

> "Bad things cannot sustain long, they vanish, and they must vanish. What good can the dhami-jhankri (shaman) offer, and who believes in his way of treatment in these modern times? No educated person believes that a boksi (a witch) can cause illness."

However, elderly members of the community support PTM and are unhappy with its rejection by young people:

> "If you believe in lagu-bhagu then there exist an unknown power, and we need the service of faith healers for an illness caused by such power. If you do not believe, then there is no such thing. These young people don't understand the importance of medicinal herbs; they can't distinguish between jhar-paat (grass of no use) and jadi-buti (roots and plants having medicinal value), they can't distinguish between gu (human feces) and gobar (cow dung).
>
> It (PTM) hasn't vanished yet, and I do not think it will vanish soon. Some things are important, and they can't vanish. People visit popular traditional healers because there is something in their treatment. If there is nothing, people will not visit them repeatedly."

There are others who make a distinction between shamans and other popular traditional practitioners, as was the case with an NGO worker:

> "All the popular traditional practices cannot be considered to be the same. I believe in the works of sudeni and vaidya, but I do not believe in dhami-jhankri. For normal delivery, if you have an experienced sudeni in your village, you do not have to go to a distant hospital. And there is no substitute of sudeni for postpartum care. I understand the importance of medicinal herbs, and I believe in those dhami-jhankri who use traditional herbs but not in those who only use the mantra. I believe in the power of medicine than the power of mantra."

Our discussions with PTMs revealed that although they still served a reasonably large clientele, the growth and dominance of modern medicine has made them defensive.

They routinely refer patients to biomedical health facilities, just to be on the safe side.

A snake bite healer, for example, said:

> "Till now I have disappointed no one. I try my best, but there is no guarantee that all the people will be cured. Sometimes, treatment does not work because sometimes they call me very late and if poison spreads throughout the body the risk increases. This is one reason why I suggest them to go to the hospital for treatment. If one dies, they will accuse me of the death, but doctors in hospitals are not accused when their patients die."

This shows that they are afraid of taking a risk and want no trouble arising from treatment failure. A faith healer also shared similar concerns:

> "When people come to me, I must do whatever I know. Because they come with hope. After my treatment, I tell them that I did whatever I knew, but it would be better if you visit a hospital too. Because if there is lagu-bhagu (illness caused by spirits) my jhar-phuk will show its effect but if they wait long and something happens to the sick person who will be responsible?"

A community elder remarked on these changes, as follows:

> "It is the demand of time, education and awareness demand new things, and it neglects traditional things or leaves it to vanish. But the traditional practitioners, even the dhami- jhankris are also coming up with new ways of treatments. They are adopting new ways. You see, now they are providing attractive amulets casting their healing mantra into it, and they are providing manufactured herbal medicines. They know the importance of hospitals and they are sending their patient to the hospital when they feel that they cannot treat the case at hand."

Changes in the popularity of PTM

The community had varied perceptions of the changes in PTM. Most of the FGD participants agreed that popular traditional practices were declining. They said that earlier there were not so many medical shops, clinics, and hospitals and they had to depend upon the PTPs. The situation had since changed. Various health institutions had been established; transportation facilities had improved; awareness and education levels had increased; superstitions had subsided, the supremacy of science had been established.

Most villages were undergoing a change because of various socio-economic factors and were at the crossroad of tradition and modernity. They had not abandoned their tradition but were also not unaffected by modernization. At the same time, they were not comfortable with modern health care services. Even today, for many villages, hospitals were at a distance and it took a whole day or two to avail services. Public hospitals meant long queues, the absence of doctors, costs of diagnostic tests and costly medicines. Private hospitals or clinics charged exorbitantly and sold unnecessary medicines, ordered them to do unnecessary tests repeatedly. Highlighting the importance of PTPs a participant said:

> "They [the PTPs] are doing their best whether they do jhar-phuk (brush down or blow out evil spirit using healing mantras) or give us jadi-buti (medicinal herbs)…this is for us, not for them. They are not looting us like the doctors. You go to the hospital, and you will know how they treat you."

Another reason for the decline of PTM was the reluctance of the younger generation to engage in the popular traditional medical practice. Most of the popular traditional practitioners were elderly and experienced, and only a few of them were below 40 years of age. The young were not ready to follow the profession as a family tradition. There was little money in practicing traditional medicine, and people expected voluntary services from the PTP. The younger generation is unwilling to be satisfied with a bowl of rice liquor and stick of cigarette or a cup of tea like their elders. Though some of the PTPs charge for services and sell medicines that they prepare, they cannot charge as much as the allopathic practitioners for fear of losing their clients to formal practitioners.

Despite these changes, those from low-income groups in rural areas were dependent on PTM for their common healthcare needs. The extent and use of PTM varied among the socio-economic groups. The well-off section resorted more to allopathic medicine. The poorer sections went to PTPs at the local level to treat minor ailments without wasting time, energy and money. For them, popular traditional practitioners are a great help for meeting primary healthcare needs. In cases of chronic ailments and severe health problems, people went o to allopathic medicine practitioners or formal health facilities.

Discussion

Early studies have documented that a large majority of the people in rural areas relied on popular traditional medical practices and recognized that faith healing is the most prevalent one (Streefland, 1985). It has also been well documented that the PTPs have been playing an important role in providing primary health care to rural villagers (Nichter, 1978). Later, some studies claimed that "when modern development appears, folk system disappears" (Anyinam, 1995), the indigenous or folk healing practices are "vanishing" or they are "at the verge of extinction" and they will "vanish slowly but surely" (Bajracharya, 2006, Paudyal & Ghimire, 2006, Raut & Khanal, 2011). However, some studies also observed the continued use of PTM in specific contexts (Sujatha, 2014). Many studies which observed the continued use of such practices, contested the assumption that "biomedicine would replace the traditional medical practices" or "traditional medical practices would soon die out" (Lock & Nguyen, 2010, p. 61, Najunda, Annapurna, Midatala, & Laxmi, 2009, p. 706).

However, the use of the terms such as 'revitalization of local health tradition', 'revival of folk or indigenous medicines', 'pluralization of health care services' (Cant & Sharma, 1999; Shankar, 2007) signal that the PTM are experiencing or at least experienced in the immediate past a great loss and has not recovered yet. Nonetheless, these studies also point to the dynamic nature of the medical pluralism and changes in the level and extent of use of the co-existing systems of medicine, including the PTM.

The co-existence of biomedicine and traditional medicine is not a new phenomenon. What is new is that the volume of biomedical facilities and practitioners has increased significantly in the last few decades. Biomedicine, as a mainstream system, has greatly developed over time and it is likely to expand further. The dependency on formal allopathic medicine increased remarkably in the recent years while the dependency on PTM is falling. PTM is steadily losing its space to the power and influence of modern medicine. PTM is being neglected and may disappear in due course if not given importance and incentives to revive (Cameron, 2008).

Making health care system more inclusive and ensuring better-qualified practitioners, better medicines and better services are necessary. The only way to ensure better health care options is to improve the existing situation by ensuring safe and effective therapeutic options for all. Allopathic medicine cannot cater all the health care needs of all the people. The acceptance of the PTPs as contributors to primary health care, and their due recognition and accreditation would be important in the present times. PTM on which a large number of people especially the tribal, rural, and poor communities rely, is deprived of state's support and is becoming unpopular because of state's differential treatment. A strong and efficient PTM can serve as a source of healthcare to the rural and poor population who have less access to the formal medicine and who feel that allopathic medicine is not enough for some of their health problems. The irony is that on the one hand, the PTPs have been contributing and are well recognized by the communities, and on the other, they are deprived of state's support and official recognition of their contribution.

The process of making PTM unpopular has begun with the state's policies towards the adoption and expansion of biomedicine as state responsibility, which was much influenced by neoliberalism. The 1990s movement restored parliamentary democracy in Nepal, and the then government adopted neoliberal policies, privatized many public institutions, promoted the private sector and laid emphasis on biomedical education and biomedical health care system. The primary objective of the National Health Policy (1991) was to extend basic primary health care services up to the village level to increase the access of modern medical facilities (Ministry of Health, 1991). On traditional medicine, the policy was to develop the Ayurvedic system and encourage other alternative traditional health systems (such as Unani, Homeopathy, and Naturopathy). The policy remained silent on PTM or traditional practitioners in the healthcare service. Modern medical facilities expanded up to the village with the establishment of health posts in each village development committee and female community health volunteer in each ward. However, the policy on traditional medicine remained only on paper. Neither the STM nor the PTM experienced encouragement and development. The recent National Health Policy 2014 intends to "Develop Ayurvedic medical systems by managing and utilizing the herbs available in the country as well as protect and do systematic development of other complementary medicine systems (MoHP, 2014)." The planning documents (National Planning Commission [NPC], 2010, 2016) have repeated such policy statements. While STM has been getting some space at least in the policy and planning document, they do not make any mention of PTM. Policy support is necessary for the recognition, revitalization, and professionalization of the PTPs. This calls for an intervention by the state to prevent PTM from further damages.

Classical Ayurvedic texts such as Caraka Samhita and Susruta Samhita refer to the complementary relationship between scholarly knowledge and popular knowledge. These texts acknowledge the knowledge of forest dwellers and the importance of learning from shepherds, cowherds, hunters and gatherers and the people who live in the forests or close to nature (Payyappallimana & Hariramamurthi, 2012, Priya & Shweta, 2010). This suggests that popular traditional medicine can play a complementary role to contribute to STM. The loss of popular traditional knowledge is likely to indirectly impact the growth and development of scholarly traditional knowledge. Hence, the trend of making popular traditional medicine unpopular must be reviewed and reflected upon.

Conclusion

Popular Traditional Medicine (PTM) comprises vast healthcare knowledge, and its practitioners have been contributing to the physical, mental, emotional and spiritual health of the community. However, with the changing socio-economic and political context, popular traditional medicine is on the decline. The decline has resulted mainly because of the present policy, which favors biomedicine and discourages PTM. PTM is deprived of state's support, and practitioners have no incentives to practice. The younger generation seems to be not interested in learning and practicing PTM because of the many disincentives involved. This is likely to lead to the further erosion of popular knowledge.

The irony is that on the one hand, the popularity of PTM is declining, and the people are losing their traditional healthcare resource; and on the other, they do not have viable alternatives. To be indifferent to the erosion of popular traditional knowledge and let the PTPs continue their practice without enhancing their knowledge also implies providing the poor with poor quality services. The damages to PTM is likely to disempower the local communities, and it will also have a serious implication from a health equity perspective.

The rising health inequality in Nepal cannot be addressed without taking PTM on board. Furthermore, the damages to PTM will have a damaging effect on their growth and development of STM. Hence, "promoting Ayurveda and other alternative systems" will not be possible by demoting PTM. And "making health care services accessible to all" will not be achieved without supporting the provision of traditional health care services. To conclude, making health care services more accessible and affordable lies not in the growth of the unregulated private sector and pushing towards biomedicalized health care system but in the promotion and strengthening of the public sector with a balanced development of modern and traditional medicines, both popular and scholarly.

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Recognizing Maternal Health as a Community Issue

Using a Survey Tool to Develop Social Accountability Interventions Amongst Community Leaders in Three Districts of Gujarat

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SAHAJ (Society for Health Alternatives), a non-government organization (NGO) and two other partner NGOs have been working since 2012 with tribal and marginalized communities in three districts of Gujarat to strengthen social accountability for maternal health. This paper discusses the results of an evaluation conducted during April 2016-March 2017 to assess the changes in community leaders' knowledge, attitudes and understanding towards maternal health.

The evaluation was conducted in 45 control and 43 project villages. This evaluation assessed the effectiveness of the NGOs' interventions (from a gender and rights perspective) wherein the organizations' staff disseminated focused messages about maternal health, government entitlements, and strategies for improving accountability among community members. The evaluation consisted of three components: a baseline quantitative survey (April 2016), longitudinal qualitative research consisting of participant observation of periodic review meetings and field activities (April 2016-March 2017), and an end-line survey (March 2017).

Significant improvements were seen in knowledge levels of antenatal care (ANC) services available, high-risk symptoms, handling emergency obstetric situations, maternal-health entitlements, and maternal death reviews. Significant improvements were also seen in views and understanding towards maternal health as a Gram Sabha (village council) issue and on the responsibilities of the Panchayat (village government) towards maternal health. There was also an increase in the number and variety of maternal health issues discussed in Gram Sabha meetings and increased participation of community members and local health system-actors.

In a setting with community organizations and strong NGO support, systematic multi-method dissemination of key maternal health messages, along with discussions and actions through the Panchayat, can succeed in making maternal health a community issue.

Keywords : Maternal health, community action, social accountability, Panchayat, Gram Sabha, Gujarat

In 2015, the world was transitioning from the Millennium Developmental Goals (MDGs) ending in December 2015 to the Sustainable Developmental Goals 2030 (SDGs) adopted in September 2015 by the United Nations General Assembly. Around this time, India hosted the 'Global Call to Action Summit-Ending Preventable Child and Maternal Death' in August 2015 demonstrating

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India's commitment to SDGs, specifically improving maternal health and achieving the SDG target of reducing maternal mortality ratio (MMR) to less than 70 per 100,000 (PTI, 2015).

India's MMR declined from 560 per 100,000 live births in 1990 to 167 in 2011-13 (RGI-SRS)[2] (Press Information Bureau [PIB], 2015). However, India accounts for 17 per cent of global maternal deaths, and shows a wide disparity in maternal mortality ratios across states and income groups (El-Saharty & Ohno, 2015). In the state of Gujarat in Western India, MMR decreased from 122 in 2010-12 to 112 in 2011-13. In terms of the percentage of reduction of maternal mortality ratio, Gujarat ranked 11th with 30 per cent reduction amongst the 15 larger states of India (Comptroller and Auditor General of India, [CAG], 2016).

Several initiatives and programmes have been started by the government of India to achieve the Maternal Health targets of SDGs. These include programmes such as the Village Health and Nutrition Days (Government of India [GoI], 2007), and the Pradhan Mantri Surakshit Matritva Abhiyan (PMSMA) launched in 2016 which mandates antenatal clinics by a Medical Officer and private Obstetricians and Gynecologists, on the 9th of every month (GoI, 2017). In 2011, the Government of India launched the Janani Shishu Suraksha Karyakram (JSSK) (GoI, 2013) which assures cashless antenatal care, deliveries, and neonatal care in public health facilities up to 30 days after birth.

It is therefore surprising that recent data from the National Sample Survey Organization (NSSO 71st Round) indicates that families were incurring 'Out of Pocket Expenditure' to the extent of around Rs. 2750 (average of rural and urban OOPE)[3] for childbirths in the public sector facilities (NSSO 71ST Round, January-June 2014). Other studies have also confirmed the poor quality of maternal health services in government health facilities, out of pocket expenditures in spite of JSSK, lack of awareness on various maternal health entitlements and poor functioning of village health and sanitation committees (Neil, Naeve, & Ved, 2017, Chattopadhyay, Mishra, & Jacob, 2017, Jan Swasthya Abhiyan [JSA], 2017).

Government programmes such as the JSSK are stated to have built-in grievance redressal mechanisms. However, they often fail to be accountable to the users and to the local communities. The government's monitoring system does not pick up the ground realities. This is why social accountability through 'health literacy' becomes important especially for community leaders who can play an active role in demanding quality services.

Social accountability is an approach towards building accountability that relies on civic engagement. In social accountability it is the ordinary citizens and/or civil society organizations who participate directly or indirectly in demanding accountability (World Bank, 2004). Health literacy as developed by Ratzan and Parker (2000) is, "the degree to which individuals can obtain, process, and understand basic health information and services to make appropriate health decisions" (as cited in Flaherty, 2011). An essential prerequisite for citizens to engage in demanding accountability is for them to be aware of their rights and entitlements through various government schemes and programmes.

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[2] The sole source of data for fertility and mortality in India.

[3] An average of Rs. 5544 was spent per childbirth in rural areas, and Rs. 11685 in urban areas. The average amount spent per childbirth as an in-patient of a private hospital (almost Rs. 17,000 in rural and Rs. 22,000, in urban) was more than nine times of that spent in the public hospital (Rs. 2600 in rural and Rs. 3100 in urban) in both rural and urban area.

Successful community participation and mobilization strategies have been observed earlier with women's groups in states like Odisha and Jharkhand in India. In these states, Ekjut, a non-governmental organization, used participatory approaches to develop knowledge, skills and 'critical consciousness' of women's groups for better maternal and neonatal health outcomes (Rath et al., 2010). A four-country study by Prost et al., (2013) that included India concluded that 'with the participation of at least a third of pregnant women and adequate population coverage, women's groups practicing participatory learning and action are a cost-effective strategy to improve maternal and neonatal survival in low-resource settings.' Recent studies have recommended working with women's groups as a way of reducing maternal mortality and achieving better maternal health outcomes (Global Health Vision, 2015, Perry et al., 2015, Lunze et al., 2015, Mangham-Jefferies et al., 2014, Azad et al., 2010). A rights-based approach to maternal health interventions in recent years has been mostly about strengthening community voices (Dasgupta et al., 2015, Bayley et al., 2015).

Learning from such efforts and with the intention of making maternal health into a community issue and responsibility, SAHAJ, an NGO based in Vadodara, Gujarat, with her partner organizations implemented during 2016-18, the second-phase of an ongoing maternal health accountability project.

About the project

'Ensuring better maternal healthcare outcomes through community action and social accountability mechanisms' was a partnership of SAHAJ, Vadodara with two other organizations, ANANDI (Area Networking and Development Initiatives) working in Dahod and Panchmahals districts (two of the most deprived districts of Gujarat) and KSSS (Kaira Social Service Society) working in Anand district. Both ANANDI and KSSS work with poor and marginalized communities. The project involved marginalized groups in the study areas and adopted a gender, equity and rights perspective. During the first-phase of the project from 2012- February 2016, the project raised the consciousness of service users on their entitlements to quality antenatal, delivery and postpartum care. The first phase produced five report cards on the quality of maternal health care as reported by pregnant and lactating women. The report cards documented an overall poor quality health care services and facilities (George, Sri, & Ved, 2016).

During Phase two of the project, we aimed at involving community leaders to further the cause of maternal health issues in the community. Community leaders for our intervention study were defined as: leaders from the village self-help groups (SHGs), leaders of women's collectives (Sangathan)[4] and Panchayat members (with a preference for women Panchayat members). What did these leaders think was their responsibility towards pregnant women in their village? Did they as leaders feel that they had any role to play in ensuring maternal health?

We designed a formative evaluation of knowledge, attitudes, and practices of community leaders to help us to plan the project activities, and the key messages to increase their 'maternal health literacy' and motivate the leaders towards their responsibilities. The baseline evaluation became a guide for deciding the focus areas and developing the intervention plans and visual materials. Following this, there were intensive inputs for nine months (June 2016 to February 2017), wherein

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[4] SHGs are women's Self-Help Groups who do savings and credits through their monthly meetings. Sangathan is a federation comprising of two leaders from each SHG, and representatives of the Village Development Committee. The Sangathan also meets every month to discuss different issues brought up by the members. For the intervention, these monthly meetings were an important forum for discussing messages related to maternal health and for promoting community action.

key messages were disseminated through different methods like discussions through innovative learning games, distribution of pamphlets, campaigns, wall paintings and other visual materials along with meetings and focus group discussions. Also, ongoing support and hand-holding were provided to the community leaders before the Panchayat and Gram Sabha meetings.

Phase Two of the project thus became an intervention study with the objectives of a) formative evaluation of the community leaders' knowledge, attitudes, and practices related to maternal health, b) a series of field level activities to enhance these, and c) an end-line survey to assess the changes. Table 1 gives details of the interventions involved in the two phases and Table 2 gives a brief description of the study areas.

Table 1: Interventions in Phases One and Two

Project period	Stakeholders	Project activities
Phase 1: 2012-2016	-Pregnant and lactating women -Women from self-help groups and collectives -Village Development Committees -Health system providers	-Community meetings for maternal health awareness -Educational materials developed like birth preparedness poster, Toran (banner type) on antenatal services, a documentary film on traditional birth attendants (Hoyani) -Community monitoring of maternal health services through 'healthy mother' tool, VHND monitoring checklists of services provided -Community participation in maternal death reviews -Community Dialogues and Meetings with field level health workers and officials
Phase 2: 2016-2018	In addition to the above, -Panchayat and Gram Sabha members	In addition to the above: -Conducting surveys -Raising maternal health issues in Panchayat and Gram Sabha meeting through women and community leaders -More educational material developed like posters on high risk symptoms, women's views on safe delivery, antenatal services; pamphlets on maternal health entitlements; board games; wall paintings -Strengthening community action and accountability -Improving relations with field level health workers -Dissemination of project outcomes

Table 2: District Wise Study Design and Sample Selection

S. No	Dahod and Panchmahals Districts (under ANANDI) (poorer districts)	Project activities	Project
1.	Area context: This is a poor, rural and tribal belt, amongst the poorest districts of India with challenging socio-economic context. Many villages are situated far off from roads, and they have poor transport facilities.		
2.	Selection of villages	Villages where the maternal health project is not directly implemented in Phase 2, but some villages may have been part of Phase 1	Villages where ANANDI was working on the maternal health project in Phase 1
3.	Number of villages	25	23
4.	Number of respondents at	Baseline- 123 Endline- 117 Total- 240	Baseline- 120 Endline- 114 Total- 234
5.	Taluka/Blocks chosen	Baria (Dahod) and Goghamba (Panchmahals)	
6.	No. of PHCs, Sub-centers and population covered in the project area	Four PHCs and 14 Sub-centres. Population covered 33,602	
7	Category of respondents	Around 24-32 per cent Panchayat members (percentages varied at baseline and end-line and also between control and project villages) Rest SHG/Sangathan women leaders	
8.	Gender of respondents	Around 80-90 per cent were women (percentages varied at baseline and end-line and also between control and project villages)	
S.No.	**Anand District (under KSSS)** ***(better off district)***	**Control**	**Project**
1.	Area context: This is a more urbanized district and socio-economically a better-off district. The district has very good road connectivity and transport facilities. The government health infrastructure is adequate, and there is a flourishing private sector.		
2.	Selection of villages	Villages where KSSS never worked and no other NGO worked on maternal health	Villages where KSSS was working in Phase 1. These villages were selected for Phase 2.
3.	Number of villages	20	20
4.	Number of respondents at	Baseline- 97 Endline- 103 Total- 200	Baseline- 96 Endline- 99 Total- 195
5.	Taluka/Blocks chosen	Anand and Umreth	
6.	No. of PHCs, Sub-centers and population covered in the project area	Four PHCs and 11 Sub-centres. Population covered 73,819	
7.	Category of respondents	Around 38-43 per cent Panchayat members (percentages varied at baseline and end-line and also between control and project villages) Rest SHG/Sangathan women leaders	
8.	Gender of respondents	Around 78-80 per cent were women (percentages varied at baseline and end-line and also between control and project villages)	

Methodology

Study design

The study adopted a quasi-experimental before-after design in selected areas of three districts of Gujarat, as shown in Table 2. The quantitative data from the surveys were triangulated with observations during ongoing field activities and supervision visits by the SAHAJ team. Monthly reports of the partners' teams, as well as quarterly review meetings, also provided rich qualitative information.

Sampling

Project and control villages were selected after discussions with the field teams based on logistics and outreach. The project villages selected were the villages where KSSS and ANANDI were currently working on the maternal health project, while the control villages included villages where the maternal health project had not been implemented.

Respondents - women leaders from SHGs and women's Sangathan (collectives) and Panchayat members (especially women members) - were selected purposively based on their availability and willingness to participate in the survey. Only verbal consent was taken by the teams.

As far as possible, vocal leaders were chosen as respondents. This is because many women Panchayat leaders are elected against the women's reservation quota (33 per cent of total seats) and do not have the competence to be leaders. So male family members often run the show.

Five respondents were selected from each village: two from Panchayat and three from at least two SHGs/ Sangathan. If a Panchayat member could not be contacted after some visits, they were replaced with an SHG/ Sangathan member. Further details related to the study design and sample selection are given in Table 2.

In the end-line survey, attempts were made to interview the same respondents, but because of non-availability of all the original respondents, some new members exposed to the maternal health activities had to be taken. Also, Panchayat elections took place after the baseline survey and some new Panchayat members had to be included in the end-line survey.

Baseline data collection was done in March-April 2016 and end-line in April 2017 in 45 control villages (N=220 at baseline and end-line) and 43 project villages (N= 216 at baseline and 213 at end-line) across three districts.

Study team

The ANANDI and KSSS field staff – local women familiar with the dialect, with minimum 12 years of schooling and considerable community organizing experience - were oriented to the survey tool and trained to ask questions and fill in the forms. Training sessions were held at their offices and in the field by the SAHAJ team. During actual data collection, the SAHAJ team accompanied them to provide on-the-job support and suggestions for improvement. Coordinators from the two partner organizations also closely monitored their teams.

Research tools and data analysis

The survey form included questions on knowledge and attitudes or perceptions based on topics or issues where we wanted to bring about changes. The form was finalized after several revisions and pre-testing in the field. The final version covered a range of issues the following issues:

- knowledge of antenatal and postnatal services
- indications of high-risk pregnancies
- symptoms of obstetric complications
- maternal health entitlements/schemes
- the nearest primary health centre
- perspectives on the responsibility of self and of Panchayat members towards maternal health
- importance of Gram Sabha meetings on maternal health issues
- maternal death reviews.
- functioning of and funds allocated to Village Health and Sanitation Committees.

The survey tool had mostly close-ended questions with one open-ended question.

Calculating knowledge levels: The number of correct/incorrect responses were converted to scores and coded as poor and good levels of knowledge.

Statistical analysis: Frequencies (Mean±SD) were calculated with independent t-tests to see the mean differences in knowledge levels using Statistical Package for Social Sciences (SPSS). Significance (P value) was taken at $\leq .05$. (Table 2 about here)

The findings based on the baseline and end-line comparisons were discussed in a review workshop with the three partner teams. The teams referred back to their monthly reports and their field notes to incorporate qualitative information and explanations.

Limitations

One limitation of the formative study was that the NGOs are not research organizations and thus lack the confidence to carry out a 'research study'. The analysis was initially done in terms of simple frequencies based on which interventions could be initiated. Later towards the end of the project period, further analysis was done, and tests of significance applied.

Another limitation is that while the partner organizations follow highest standards of respect, participation and informed decision making in their community-based work, and the same standards were applied to this intervention study, a formal ethical review was not done because of unavailability of a research ethics review committee.

Findings

The following thematic sections present some of the main survey findings, supported by qualitative analysis of documentation of outcomes based on monthly reports, field visit reports and periodic review meetings of partners.

Knowledge and attitude related to maternal health care

Improvements were seen more in the project groups about knowledge related to ANC services, symptoms of high risk during pregnancy, and handling emergencies during deliveries. (Table 3 about here)

The poor knowledge levels reflected in the baseline survey exposed the need to make community leaders aware of the free ANC services and importance of the Village Health and Nutrition Day (VHND). The issue was addressed through dialogues, meetings using games and visual media like posters and wall paintings to inform them of their rights. This eventually made the community leaders and the pregnant and lactating women demand the services including diagnostic tests and medicines, and facilities (including infrastructure and better roads, water facilities and electricity) and also demand improvement in the quality of care.

Lack of knowledge of high-risk symptoms during pregnancy at baseline also emerged as another important issue. With the inputs mentioned above, the knowledge levels improved significantly in all the project villages as seen. The reports of the field staff showed that women and their families were better prepared to deal with emergencies and if necessary, the Female Health Workers were informed to provide extra care.

A majority of the respondents had poor knowledge levels at baseline about handling complications during delivery. As a result of the interventions to create community awareness about emergency situations and how they could help, lists of villagers who were ready to donate blood and to provide emergency transport, were made in many villages and displayed in the Panchayat office. The community leaders became aware that they could help the women merely by accompanying them to health facilities. Community leaders, especially the Panchayat members, revealed that they had never considered this as a part of their responsibility, or imagined that they could be of help in such situations.

In all the districts, respondents in the intervention villages felt that Maternal Death Reviews (MDR) should be carried out. They had improved knowledge levels and knew at least one of the following: that MDR helps to reduce maternal deaths; increase accountability; improve quality of health services. They also understood that it should be done by both, government officials and the community.

Table 3: Knowledge and Attitude Related to Maternal Health Care

Knowledge & Perceptions	**Per cent scoring**	**Poorer districts**				**Better-off districts**			
Where can you get each of the ANC services?		**Control**		**Project**		**Control**		**Project**	
		Baseline	**Endline**	**Baseline**	**Endline**	**Baseline**	**Endline**	**Baseline**	**Endline**
	Poor	89.4	71.7	80.3	29.8	19.6	21.9	72.8	34.3
	Good	10.6	28.3	19.7	70.2	80.4	78.1	27.2	65.7
	P –value	0.000*		0.000*		0.697		0.000*	
Can you name the various high risk symptoms?	Poor	80.5	65.0	70.1	15.8	95.9	90.6	90.3	10.1
	Good	19.5	35.0	29.9	84.2	4.1	9.4	9.7	89.9
	P –value	0.007*		0.000*		0.147		0.000*	
Do you know what all can be done to handle emergency situations?	**Poor**	82.9	75.8	77.8	57.0	99.0	92.7	86.4	8.1
	Good	17.1	24.2	22.2	43.0	1.0	7.3	13.6	91.9
	P –value	0.173		0.001*		0.029		0.000*	
Can you tell us why you think MDR should be done?	**Poor**	91.9	85.8	78.6	58.8	99.0	93.8	93.2	44.4
	Good	8.1	14.2	21.4	41.2	0.0	6.2	6.8	55.6
	P –value	0.136		0.001*		0.053		0.000*	

*$p<0.05$

Knowledge related to government schemes and entitlements

By the time of the end-line study, respondents from project villages in all districts could name the various maternal health entitlements. The flyers and board games on entitlements specially created to spread awareness were highly appreciated in these villages.

Table 4: Can You Tell Us About the Benefits Under Each Maternal Health Schemes, and Who Can Get These Benefits? Per Cent Responses

Poorer districts	Janani Shishu Surksha Karykram (JSSK)							
	WHOM				WHAT BENEFITS			
	Control		Project		Control		Project	
	Baseline	Endline	Baseline	Endline	Baseline	Endline	Baseline	Endline
Correct answer	**0.9**	4.3	4.1	2.7	0.9	0.0	4.1	1.8
Incorrect answer^	99.1	95.7	95.9	97.3	99.1	100	95.9	98.2
P Value	0.227		0.000*		0.000*		0.000*	
	Janani Surksha Yojna (JSY)[10]							
	WHOM				WHAT BENEFITS			
	Control		Project		Control		Project	
	Baseline	Endline	Baseline	Endline	Baseline	Endline	Baseline	Endline
Correct answer	50.5	23.9	46.9	32.4	45.7	29.3	39.8	53.2
Incorrect answer^	49.5	76.1	53.1	67.6	54.3	70.7	60.2	46.8
P Value	0.000*		0.000*		0.001*		0.000*	
Better off district	Janani Shishu Surksha Karykram (JSSK)							
	WHOM				WHAT BENEFITS			
	Control		Project		Control		Project	
	Baseline	Endline	Baseline	Endline	Baseline	Endline	Baseline	Endline
Correct answer	**5.5**	0.0	18.0	6.2	5.5	0.0	14.0	5.2
Incorrect answer^	94.5	100	82.0	93.8	94.5	100	86.0	94.8
P Value	0.001*		0.000*		0.022*		0.003*	
Better off district	Janani Shishu Surksha Karykram (JSSK)							
	WHOM				WHAT BENEFITS			
	Control		Project		Control		Project	
	Baseline	Endline	Baseline	Endline	Baseline	Endline	Baseline	Endline
Correct answer	18.2	16.0	22.0	69.1	25.5	33.9	26.0	76.3
Incorrect answer^	81.8	84.0	78.0	30.9	74.5	66.1	74.0	23.7
P Value	0.282		0.015*		0.436		0.005*	

^ Including Don't know responses

*$p<0.05$

Regarding the Janani Shishu Suraksha Karykram (JSSK)[5] scheme – an important programme to prevent any out of pocket expenditure on pregnancy, childbirth and newborn-related health care through public sector facilities - in all three districts most did not know the details/components or eligibility or answered incorrectly, even at the end-line.

For Janani Suraksha Yojna (JSY)[6] , respondents in all three districts had better knowledge (compared to JSSK) in both control and project villages at baseline. However, the better- off district had better scores by end-line compared to the poorer districts.

Attitudes and perceptions related to maternal health

Responsibility of self towards maternal health

When asked what the respondents thought about their responsibility towards maternal health, by end-line, besides the general answer that they would ‘help in emergencies,’ a higher proportion of respondents in the project villages mentioned that they would donate blood, (not mentioned at baseline). In the project villages, the end-line answers included: blood donation, helping by giving/arranging for money, accompanying the pregnant women, calling 108[7] /ANM, providing information on schemes and making blood donors’ lists. None of the respondents mentioned ‘Don’t Know’ during the end-line - they were able to think of some responsibility towards maternal health.

Table 5: What Do You Think Is Your Responsibility Towards Maternal Health? Per Cent Responses

Poorer districts	Control		Project	
	Baseline	Endline	Baseline	Endline
Donate blood	1.6	6.7	0.8	10.5
Will help during emergency	69.9	47.5	75.2	61.4
Awareness regarding health	22.8	31.7	11.1	21.9
Others*	25.2	27.5	22.2	44.7
Don’t know	8.1	17.5	12.0	0.9
Poorer districts	**Control**		**Project**	
	Baseline	**Endline**	**Baseline**	**Endline**
Donate blood	3.1	1.0	2.9	34.3
Will help during emergency	57.7	32.3	56.3	82.8
Awareness regarding health	15.5	24.0	23.3	48.5
Others*	22.7	53.1	31.1	74.7
Don’t know	12.4	15.6	13.6	-

As multiple answers, simple frequency percentages calculated
Others*: Would accompany/send someone, take her to hospital, call 108, call doctor, give own vehicle, money etc.

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[5] Janani Shishu Suraksha Karyakaram (JSSK) scheme includes free and cashless delivery (including C-section, free medicines, diagnostics, food, blood provision, and transportation

[6] Under the JSY, eligible pregnant women are entitled to cash assistance irrespective of the age of mother and number of children for giving birth in a government or accredited private health facility.

[7] Emergency Government ambulance service

Role of Panchayat members in maternal health

Regarding what could be the Panchayat's responsibility for maternal health, some district wise variations can be seen. The project villages had better scores by end-line compared to control villages; the change is more marked in the better off district. During the review meeting to discuss the findings of the end-line survey, the field teams attributed this to the intensive community discussions and use of materials such as the board game developed to facilitate such discussions. The field reports also revealed that the Panchayat members admitted that they were increasingly clearer about their roles to safeguard maternal health in the community.

Table 6: Attitudes and Perceptions Related to Maternal Health

Knowledge & Perceptions	**per cent scoring**	**Poorer districts**				**Better-off districts**			
What do you think can be the Panchayat's responsibility towards maternal health?		**Control**		**Project**		**Control**		**Project**	
		Baseline	**Endline**	**Baseline**	**Endline**	**Baseline**	**Endline**	**Baseline**	**Endline**
	Poor	96.8	93.3	100.0	80.7	100.0	100.0	95.1	53.6
	Good	3.2	6.7	0.0	19.3	0.0	0.0	4.9	46.4
	P –value	0.221		0.000*		-		0.000*	
In the Gram Sabha that you attended was there any discussion on maternal health?	**Poor**	27.1	26.3	28.9	62.5	6.3	17.1	4.9	36.5
	Good	72.9	73.7	71.1	31.3	93.7	63.4	95.1	63.5
	P -value	0.554		0.164		0.190		0.000*	

$^*p<0.05$

Maternal health in Gram Sabha meetings

Making maternal health a wider community issue was one of the main objectives of this project, and this could be achieved to a great extent. Table 6 shows that in the baseline, more than 93 per cent in Anand, the better off district, said that maternal health was not included in the Gram Sabha agenda. By end-line survey, there was more discussion in both groups, but it was significantly higher in the project villages, while in the control villages there was hardly any change.

The most important aspect of maternal health issues being discussed in the Gram Sabha meetings is how the quality of discussions changed from the baseline to the end-line. The baseline responses, in both project and control villages, indicated general discussion around nonspecific issues like general health, vaccination, malnutrition, the importance of institutional delivery and maternal health schemes of the government.

In the end-line survey, newer subjects of discussion were included, for example: high risk conditions in pregnancy, the negative consequences of tobacco-use in pregnancy, the consequences of anaemia in pregnancy, maternal death reviews, pregnancy detection, early registration, ANC services, importance of regular ANC check-ups, diet and nutrition during pregnancy, women's health and diseases, blood availability in emergencies, services provided on Village Health and Nutrition Days (VHNDs), opening of bank accounts for pregnant women to enable cash transfers related to health schemes, irregular visits by village nurses, infrastructure issues related to PHCs and sub centres such as toilet, light and water facilities for pregnant women and demand for more sub centres.

So in sum, there were significant improvements in the knowledge, attitudes, and perceptions related to maternal health issues, in the respondents from the intervention villages. However, it is worth noting that such changes in knowledge and attitudes were also found in the control villages in all three districts. The influence on control villages was more pronounced in ANANDI's field area because the control villages had the presence of the Mahila Sangathan. The internalization of issues by the team members and the Sangathan's monthly meetings, and the annual Livelihoods and Food Security Campaign led to the diffusion of the messages to the non-project villages. The KSSS members also reported that the staff of the entire organization had so internalized the maternal health issue that team members working in control areas were also spreading maternal-health-related messages.

Discussion

Maternal health care is a women's human right. How can communities be mobilized to recognize this right and respond to it? How can maternal health be made a public issue beyond the boundaries of the family and the household? These were the concerns that motivated the present intervention.

The baseline survey tool helped to identify gaps in knowledge and perceptions of community leaders regarding maternal health and related services. The findings of the baseline survey constituted the basis for developing the interventions, specific activities and key messages for the changes that were envisaged. The baseline tool also succeeded in raising the curiosity of the respondents and provoked them to begin thinking about some of the issues.

Participatory learning activities to address the gaps were developed and successfully implemented with a rights-based approach. The overall results were improvements in the knowledge, attitudes, and perceptions related to maternal health issues, especially amongst the community leaders from the project villages. The enhanced knowledge through the project activities led to demands for better services through social accountability mechanisms of community monitoring and dialogues with health care providers. Papp et al., (2013) report similar results from efforts focusing on the role of local women, intermediary groups, health providers and elected politicians (Papp, Gogoi, & Cambell, 2013). Flores's study also discusses how methods drawing on community participation and collective action were most effective in influencing responsiveness from authorities. (Flores, 2018). By involving the community and its leaders in all aspects of maternal health - pregnancy registration, accessing antenatal services, safe delivery, and social autopsies of maternal deaths if they occurred - helped to make it a community issue and also improved the quality of services and institutional deliveries.

Some lessons that can be learned from this project include designing interventions that enable local government institutions to put maternal health on their agenda and to respond to women's claims as rights holders. Diffusion of the information on entitlements through the community-based organizations (women's collectives and federation of village development committees) helped promote awareness of rights and a culture of accountability. Social accountability as demonstrated through this project was not limited to demanding answerability of the health care providers but was extended by the action of women's collectives to demanding accountability from the village institutions the Gram Sabha, Panchayat, Village Health, Nutrition, Sanitation Committees. This exemplifies Yamin's proposition, "adopting a rights-based approach requires demanding and opening of spaces for women to exercise choices and subverting the social - and power relations - that deny them their full humanity" (Yamin, 2010).

Our experience has shown that with some hand-holding to build capacities of the local women leaders to speak up and raise questions, women begin to draw upon the strength of their collectives and occupy mandated spaces and also create new spaces to articulate their issues. Preparatory meetings with the women Panchayat members and with leaders of women's collectives resulted in them attending the Panchayat meetings and the Gram Sabhas with greater confidence and articulating their issues as rights claimants. A big challenge was to gain access to and make the Panchayat leaders aware and pro-active on maternal health issues. During the duration of the project, as elections were held, new members were elected, and the cycle of awareness generation had to be repeated. We realized the importance of an ongoing and institutionalized system of Panchayat members' education of their responsibilities towards maternal health. Another related learning was that overall the Panchayat system is fraught with many fundamental problems – the larger political system does not appear to want local self-governance and decentralization to work. The devolution of powers has not happened to ensure true democracy to function. In this larger context, our project was too ambitious in its aspiration to make it work for women in the short time that we had. As an outcome of our learnings one partner, in fact, decided to work more intensively to enable grassroots democracy with Panchayat members.

Another insight gained was that while monitoring of the implementation of schemes by communities is a critical feature of social accountability, reflecting the participation and voice of users, this cannot be a substitute for internal accountability within the health system. The responsiveness of frontline health providers is possible if internal monitoring, supervision and demanding corrective action systems are in place. The Medical Officer and the Female Health Worker will attend the Gram Sabha meetings if the Taluka Health Officer also deems that these are important. As Fox points out (Fox, 2016), social accountability, and community monitoring will help solve short-term, simpler and local level health system problems. Higher level policy changes to do with human resources and budgetary issues may not be amenable to community demands unless these acquire the shape of a larger mass-based political movement for 'health for all.'

The limitation of the study was that the project period was too short to ascertain how much of the momentum would be sustained and what would be required to sustain it.

Conclusions

This project showed that key focused health promotion interventions with a limited range of key community actors even in a short time frame can be successful in bringing about the desired results. Through the baseline and end-line evaluations of an 18-month field-based project in tribal and rural districts of Gujarat, we saw that Panchayat leaders and Gram Sabhas could be made to respond to maternal health issues of local women in project areas. Scaling up this successful model would require government commitment at a policy level, and this is a challenge that needs to be addressed.

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