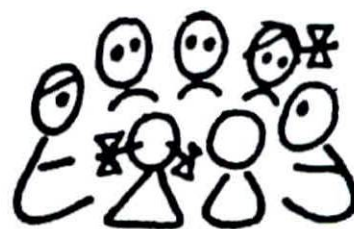
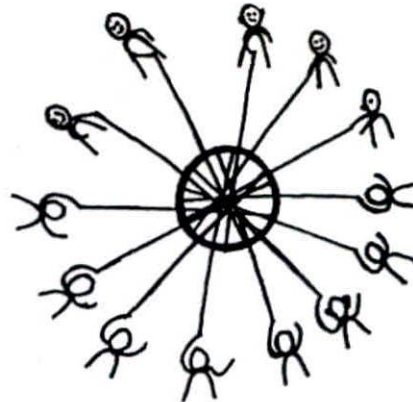


2014-15
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Community Health Learning Programme

*A Report on the Community Health Learning
Experience*

Anusha
Purushotham



School of Public Health Equity and Action
(SOPHEA)

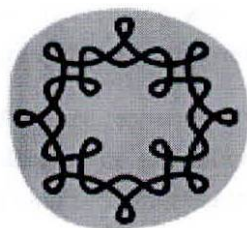


Society for Community Health Awareness Research and Action

My Community Health Learning Programme Journey

Anusha Purushotham

CHLP Fellow: January 2014 - July 2015



sochara

1. THE PATH THAT LEAD ME TO SOCHARA

Early in my childhood, I grew up with stories narrated by my grandmother from Hindu mythology about a world where everyone, including men and women, animals and humans lived harmoniously. Equality and peace was the basis of society. Upon entering the real world a few years later, I experienced the irony of the situation in the same country that was founded on the Vedic beliefs of equity and oneness. I witnessed the increasing level inequity that crept into all aspects of society, including access to food, shelter, health and education. This profoundly stirred my social consciousness and as a young student deeply passionate about biology, I made up my mind to pursue a career in biological sciences with a focus on improving the quality of health of all people.

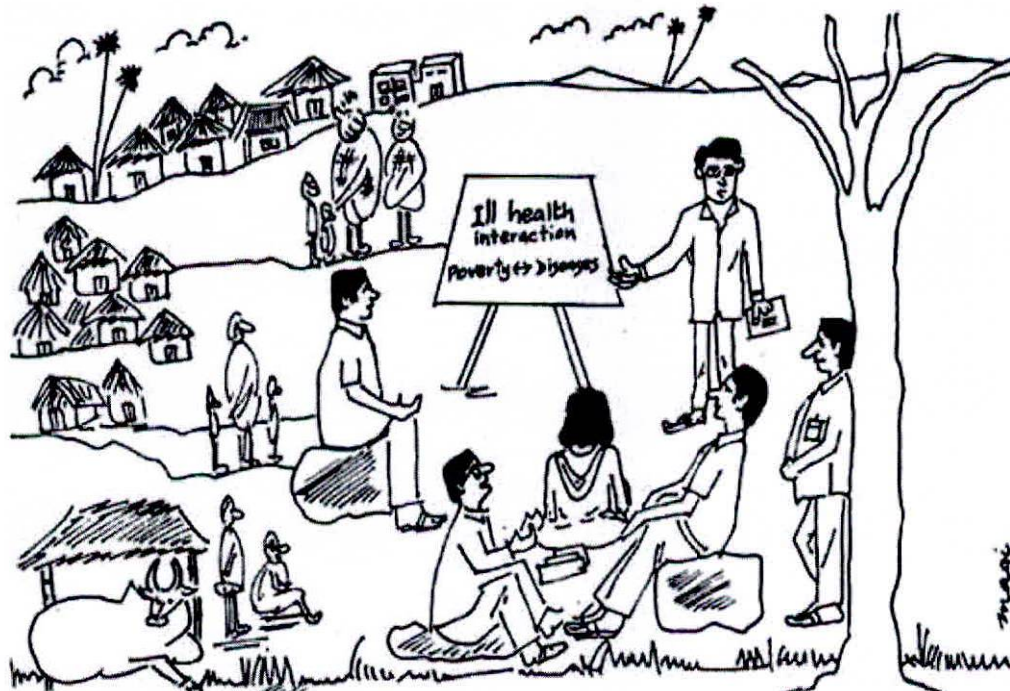
After completing my Bachelors degree in Molecular Biology at the University of Texas at Dallas and spending a year in biomedical research, I realized I yearned for something more than intellectual challenge that it offered. While the rigor of the research process was stimulating, I was disillusioned by the fact that most of research is published in journals and rarely gets translated into action or practical solutions. Unable to express my deep-rooted social sensitivity through this work, I decided to explore other options.

During this time, I got an opportunity to volunteer at Parkland Hospital, the busiest public hospital in Dallas. Here, I was re-introduced to the hospital setting after five years, but this time I was in urban United States and not India. Despite the technological advancements, I observed that health disparity in the US was similar to what was present back in India. Closely interacting with "frequent fliers" in the emergency room, newborns with drug withdrawals and teenage mothers in the obstetrics clinic, I came to understand that poor health was only the tip of the iceberg and factors like race, education and socioeconomic status played a major role in their quality of life.

I then worked for a year as a medical scribe in another emergency care unit and this gave me an insight into the gaping holes in the system that were beyond the scope of medical science. Numerous honest discussions with emergency room personnel about the health crisis in America influenced a critical shift in my perspective and introduced me to the concept of public health. Until that time, I was only aware of a biomedical model, looking to improve quality of life either through scientific discovery or the treatment of illnesses. What I had failed to consciously realize was that in addition to studying the underlying biological causative factors of a particular disease, I had always been curious about the lives of patients in the context of their communities. These experiences and realizations came together to create a strong interest in health promotion and disease prevention of whole populations as an effective alternative to treating diseases on an individual basis.

At this critical juncture, I moved back to India and through a friend's recommendation visited SOCHARA. My first meeting with Dr. Thelma Narayan and Dr. Adithya Pradyumna, instantly sealed my interest in learning more about community health and public health, and thus, the wonderful CHLP journey began!

2. ORIENTATION TO COMMUNITY HEALTH AND OTHER LEARNINGS FROM THE COLLECTIVE SESSIONS



Source: Community Health Cell

Community health is:
"enabling and empowering people
to take care of their own health
which includes conscientisation and
political action"

"it increases individual, family and community
autonomy over health and over organizations,
means, opportunities, knowledge
and supportive structures
that make health possible"

Reflections from the collective sessions:

- **Community and community health**

Community, to me, meant people who all live together and share common goals. Hence, I thought a community health professional would go into the community and solve their problems. However, from this session with Dr. Ravi, I learned the true meaning of community health. Communities have both similarities and differences and the first thing a community health professional does is become a part of the community. By understanding their cultures and beliefs, building on their similarities and reconciling their differences, the community health professional helps strengthen the sense of 'belonging' among community members. Once this is established, the community will be able to identify their own problems and create solutions. The community health professional only facilitates this process while the actual ownership belongs to the community themselves.

Furthermore, the 10 community health axioms in the "Red Book" given to us as a guide was extremely helpful during my fieldwork as I could reflect whether I was truly engaged in community health work or merely health work.

This poem by a Chinese poet Lao Tsu, introduced to us by Dr. Ravi, really captures the essence of community health.

"Go to the people
Live among them
Love them
Learn from them
Start from where they are
Work with them
Build on what they have
But with the best leaders
When the task accomplished
The work is completed
The people all remark:
'We have done this ourselves'"

- **Social Determinants of Health and SEPCE Analysis**

WHO defined health in 1948 as “a complete state of physical, mental and social well-being, and not merely the absence of disease or infirmity.” Understanding that health is not just limited to diagnoses and medication, but rather depends on social, economic, political, cultural and environmental (SEPCE) determinants is the key learning of this fellowship. Analyzing health problems or situations using SEPCE analysis adds depth to the solutions that can be formulated. Social determinants refer to religion, caste, gender, family, domicile, age. Economic determinants include income, education, transportation, employment. Political determinants refer to power, position, policies while cultural determinants refer to customs, dress, entertainment, attitude, values, food, language etc. Environmental determinants comprise of the built environment (housing) and natural environment (rivers, hills, plains etc)

One of the most powerful messages to me was the realization that tuberculosis is caused by poverty just as much as it is caused by the biological factor: mycobacterium tuberculosis. Social determinants of health are the reasons for the vast health inequities in our country and around the world. People are more vulnerable to diseases due to their social conditions and to further complicate problems, the same people have less access to care because of the same social conditions. If health is only looked at under the biomedical lens, as it is presently done, we will be denying the right to health to a vast majority of the population and perpetuating inequity.

- **Equity vs. Equality**

Like most people, I thought that equity and equality meant the same. However, it was during the many collective sessions that the crucial difference between the two became all the more clear. Equality is providing the equal opportunities to everyone regardless of their background while equity is providing more opportunities for those who have less by virtue of structural inequalities. Equity means reaching the unreached. Therefore, by equity measures, everyone is on a level playing field. Health equity is defined as the absence of unfair and avoidable or remediable differences in health. This principle of equity is most critical in public health systems so that healthcare and other public services reach the most marginalized sections of society.

- **Health Pluralism/Alternative medicine**

Allopathy is the most dominant form of medical system in the world. However, due to this, other traditional forms of medicine like Ayurveda, Yoga, Unani, Siddha/Sow-Rig-Pa, Homeopathy (AYUSH) and other Local Health Traditions (LHTs) have taken a back-seat. The Indian Government and other South Asian countries recognize formal degrees in Ayurveda (BAMS), Yoga (BYMS), Unani (BUMS), Siddha (BSMS) and Homeopathy (BHMS). AYUSH doctors are even practicing in the Primary Health Centers of the National Health Mission. Yet, many people do not have either the choice or trust in these alternative forms of medicine because of

the dominance of allopathy and western science. Dr. Ravi's session and a visit to FRLHT (Foundation for Revitalization of Local Health Traditions) helped me understand that every medical system has its own benefits at different stages of illness and therefore, integrating these systems will be beneficial to everyone. Local healers like Visha Vaidyas, bone-setters and Dayis (Traditional Birth Attendants) are still present in some communities and are greatly trusted by since generations. However, these informal health systems (systems other than AYUSH) are slowly dying and there is a need to revive and preserve them. One way to do this is to formally recognize these local healers and certify them. Therefore, IGNOU and Institute of Ayurveda and Integrated Medicine are working towards a certification of these Local Health Traditions by the year 2018.

- **Health Systems**

Health system as defined by WHO is "any activity performed towards health is part of the health system." I had a very brief idea about the public health system in India and this session opened my eyes to the realities of the privatization of healthcare in India. I was surprised to know that out of the 5.8% of GDP on health expenditure only 1.1% goes to public health spending while 4.7% of GDP comes from out-of pocket expenses of the citizens. Nearly 70% of healthcare in India is private. Since health is a state subject with the centre providing only minor technical/financial support, 17% of public health expenditure comes from central tax and 83% of health expenditure comes from state tax. The public health system is overlooked by the central and state governments, municipals and panchayats. The public health system includes sub-centers, primary health centers, community health centers, taluk hospitals, district hospitals, tertiary hospitals and teaching hospitals.

- **National Rural Health Mission (NRHM) and Communitization (Community Action For Health)**

Launched in 2005, by the UPA government, it was fascinating to know that the NRHM (now called the National Health Mission) serves 750 million people and is the largest public health initiative in the world. Described in the previous section on health systems is the structure of the public health system under NRHM. Despite the various challenges, it was interesting to know that NRHM has made great strides in improving the health status in rural areas.

Another fascinating aspect of NRHM is the focus on involving people in the decision-making process through 'communitization.' This is a significant step forward for community health since communitization allows communities to actively partner with the government and not merely be passive participants. The selection of Accredited Social Health Activist (ASHAs), a woman selected per 1000 population from the community who acts as an interface between the community and the health system is one of the biggest the strengths of the NRHM. The other mechanism of decentralization is through the formation of Village Health Sanitation and Nutrition Committees (VHSNC) who make village health plans as well as supervise the Village Health Sanitation and Nutrition Day (VHND). VHSNC comprises of Panchayat leaders, ASHAs,

SHG members, youth groups, community groups who work in health and other community representatives. Another important component of NRHM, Community monitoring/Community Action for Health (CAH) involves training VHSNC members and Planning and Monitoring Committees (PMCs) who monitor the public health system. By involving the community and not the health systems in monitoring, accountability and utilization should increase. However, community monitoring has not been widely accepted by the medical community and this needs to be changed.

- **Health Economics**

Health economics was a fairly new concept to me and the sessions on health economics and globalization were very eye-opening. Health economics provides tools to manage and prioritize resources to aid decision making. The reason we need to prioritize is because there are two scarcities – the desire to remain healthy is unending and material resources are limited.

Understanding why health is a market failure was crucial for me in order to understand why health cannot be privatized. Health is a market failure because there is information asymmetry and hidden externalities that are not accounted for. We have to go beyond the efficiency argument and focus on equity because if only efficiency is considered, marginalized sections of society who cannot afford to pay will be excluded. There are three principles of health financing – Risk Pooling, Cross Subsidy and Solidarity and five types of health financing – Tax-based, External funders/loans, Out of Pocket Expenditure, Insurance (Social, Public, Private, Community-based) and User fees. Tax-based system of health financing is the most equitable followed by social health insurance.

The sessions on globalization and political economy of health highlighted the strong ties between money and political will. Nations like the US, who have more power and capital dictate the direction of global health priorities. Globalization, although has brought many advancements in science and technology has left the world more divided and iniquitous than before. Therefore, health is a very political subject and each one of us, who is interested in achieving 'Health For All' must be aware and also actively engage with the political mechanisms.

- **Health Policy**

Policy is a systematic process to achieving goals. However, society is not systematic and human behaviour is not systematic. Therefore, these need to be considered while framing policies. Policies are guiding documents that give direction to achieve the target and goals, what to prioritize and how to formulate action plans. The action plans need to be context-specific. Most importantly, policies need to be equity-oriented such that the marginalized sections of society are benefited. Since health is an issue that is related to all aspects, be it education, water and sanitation, finance and other departments of the government, there is a strong need for 'Health in All Policies'.

However, after reading the National Health Policy of 2002 and the draft National Health Policy of 2015, I was critical of the policy process because despite the many well-thought out and well-written policies in our country, very few have been actually implemented effectively. This is not to say that I disregard the need for good policies. They are indeed very important. However, what is equally, if not more important is the implementation of these good policies into action.

- **Research methodologies**

The session on qualitative methodologies was especially informative, for someone like me who had previous experience only in quantitative research. I appreciated Adithya's session on the differences between the two types of research and the guidelines to use the appropriate methodology based on the type of research questions. What was most important was the session on research ethics by Dr. Thelma. It became very clear that research for community health is done with the intention of creating social change that benefits the community and not for mere knowledge generation. This value-base greatly helped me while conducting my own research study during my second field placement.

- **Environmental Health**

The session on climate change was particularly interesting because most people do not associate climate change with immediate health impacts and hence, environmental health is largely neglected in policies and health discourse. To understand the extent of devastating long-term health impacts of climate change, in addition to the environmental changes that affect more than one species was startling. Mitigation (reduce drivers that cause climate change) and adaptation (methods to adapt to the effects of climate change) are the two ways to tackle the effects of climate change presently. What is interesting to know is the countries that are contributing to climate change are the larger/more industrialized/rich countries while the countries that are most vulnerable to the ill-effects of climate change are the poor/small/less developed countries. Therefore, mitigation measures must be adopted by the rich countries while the poorer countries have resort to adaptation measures which are resource-intensive. It was not surprising to know that inequity is present even in environmental health. Hopefully, the Paris Agreement of 2015 which focuses on "common but differentiated responsibility" will be able to bridge this gap as it requires developed nations to raise funds to assist developing nations in their climate resilience efforts.

- **Occupational Health**

Occupation health should aim at maintenance of the highest degree of physical, mental and social wellbeing of workers in all occupations. It is the adaptation of people to their work and work to the people. This session helped me understand the need for amicable working conditions, not just for those who work in industry but also in the unorganized sector. Majority

of the Indian population works in the unorganized labour force and hence, they have little or no job security let alone worker safety/insurance schemes. Employers try to cut costs and maximize profits by denying workers, even in risky professions like coal mining, glass factories and asbestos factories, the right to compensation for any injuries or illnesses that occur at work. Empowerment of employees through unions and other strategies are required to demand for their rights to a safe work environment.

- **Sanitation and Waste Management**

The session on sanitation was particularly interesting because it made me realize that the problem was not the lack of toilets but rather social and cultural reasons that prevents people from using them. The national “Swacch Bharat Campaign” like previous such governmental schemes to construct toilets misses this critical issue: the need to bring about behavioral and attitudinal changes. I was delighted to know that Prahlad and other SOCHARA partners had constructed low-cost toilets with the communities using locally appropriate technology and worked with these communities for a long time to create a sense of acceptance for using indoor toilets.

The session on waste management completely change the way I viewed waste. Waste, in reality, is not something that is deemed useless and needs to be discarded. Waste can be converted to useful resources – for example biological waste can be used as manure after proper storage and processing. It also opened my eyes to the problem of waste mismanagement in our country and how that can complicate problems, especially during times of calamities like floods.

- **Systems Thinking**

This 3-day session with Mr. Sam Joseph was very unique and exciting as it helped us apply the tools taught (social mapping, ADICO, CATWOE, Purposeful Activity Model, Preferential Scoring) directly in the field since we were allowed to go to the community after 1.5 days of lecture and present our learnings on the third day. The most important takeaways were how to view the community as a system with boundaries, identifying the parts of the system and how they relate to each other, finding the actors and then helping the community prioritize their needs. Another critical learning was that systems are sustainable while projects or programs have a shelf-life. This really made me understand the need to focus on creating sustainable systems that communities can manage themselves.

- **Health For All and Paradigm Shift**

‘Health For All,’ the overarching theme of our fellowship and was formally introduced to us by Dr. Ravi in his session about the Alma Ata Declaration of 1978. The principles of Alma Ata are -

1. Equity
2. Community Participation

3. Intersectoral Collaboration
4. Appropriate Technology
5. Primary Health Care
6. Right to Health

Looking back, when I was first heard these terms, I only had a theoretical understanding. However, after the various collective sessions, field visits and field placements, I now truly understand and appreciate the need for these principles. Additionally, the concepts of social vaccines and people's movements became clearer especially through Dr. Ravi's anecdotes and my readings.

All my learnings from the collective sessions can be summed up in two words: "paradigm shift." Similar to the external paradigm shift from a medical to a social model of health, the fellowship caused an internal paradigm shift in me too by enabling me to change my lens and view the world in a different way. I strongly believe that health is a social process of empowering people to lead productive fulfilling lives and everyone, from all walks of life, is an integral part of this process.

3. THE HEADSTREAMS CHAPTER: MY FIRST FIELD EXPERIENCE IN COMMUNITY HEALTH

I came to Headstreams (Bangalore) from SOCHARA after one month of orientation to community health with a very “fixed” mindset of understanding the “health status” of the urban poor. Although in the collective sessions at SOCHARA I was introduced to the social model of health, I realized through this field experience how challenging it was to unlearn my deeply ingrained biomedical model of health, layer after layer.

Headstreams is an organization that was founded in 2008 by a group of professionals from diverse educational backgrounds with a vision “A world where every person has an opportunity to realize their inherent potential to **live a positive, confident, intentional and socially productive life.**” The target population of the organization is primarily **women and children** from low-income neighbourhoods and urban slums.

Madhavi, a co-fellow from SOCHARA, and I were placed in the ‘Aalamba’ (help and support) programme, a livelihood initiative of Headstreams that works towards empowerment of women through Self-Help Groups (SHGs). It is a programme that provides a platform for sharing livelihood needs, identification of interests and a centre for training the members for various livelihood units. The programme also tackles the problem of financial needs through the practice of micro-savings, internal lending and educational schemes for their children.

The very first day of my internship, I was introduced to the women from all the Self-Help Groups (SHGs) at a large gathering of SHG Representatives at the Bruhat Bengaluru Mahanagara Palike (Bangalore Municipal Corporation) Tailoring Center in KR Puram (a locality in Bangalore). The first thing that struck me was how welcoming all the women were towards me and Madhavi. This openness and acceptance was a constant theme that I experienced in all the SHGs during the entire two month period of the field placement.

The first month of my field placement involved accompanying Cecilia and Lokesh (Headstream staff members) to the SHG bimonthly meetings across Bangalore City. During these visits, I got an opportunity to observe and interact closely with the women. The first few field visits were quite challenging because I had to test my own understanding of health. Aalaamba program did not work on physical health issues and I had to reflect on how financial empowerment through livelihood creation was related to health. I had to refrain from asking the women pointed questions about their physical health since this made them slightly uncomfortable as I had inadvertently introduced a distance between us – I became the provider and they became the recipients. Once I changed my approach and began to interact without a rigid idea of “helping” them, I saw a huge transformation within myself and the women.

The women became very comfortable around us and we (Madhavi and I) were treated as one among them. Once they understood that we genuinely cared about them, they began to freely share their stories with us.

I learned about their personal lives, their families, their work and the daily challenges they face. Their experiences redefined how I viewed health - it was more than just a system of symptoms, diagnoses and medicines. It became a holistic concept where elements like socio-economic status, family structure, gender roles and cultural practices were equally, if not, more relevant for their physical and emotional well-being.

From numerous discussions with the women emerged an idea of developing a home remedies booklet in simple Kannada and English. The aim of this booklet was to empower women to effectively manage minor ailments within their families by using easily accessible cheap ingredients found in their kitchen or gardens. During initial focus group discussions, SHG women showed great interest and initiative in being collaborators in composing this book. With their valuable feedback and participation, Madhavi and I were able to make contributions to the composition of the home-remedies booklet during the second month of our fieldwork.

The extraordinary lives of the women, their resilience and loving attitude towards life greatly humbled me. Providing a platform for the women to voice their opinions, identify their problems, build on their strengths and engage with others in the community to arrive at collaborative solutions was, to me, a lesson not only in empowering the women but also in enlightening the “professional” community to understand the power of participatory community action and the need for demystification of health.

SNAPSHOTS FROM THE FIELD

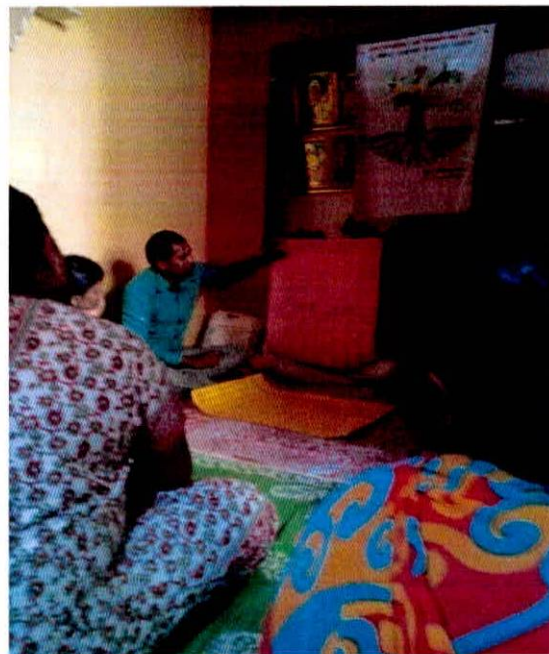
Entrepreneurship Training



SHG Representative Meeting



SHG Members Training



SHG Monthly Meeting



Games at the SHG Monthly Meeting




Working on the home-remedies booklet together



Sample Home remedies Booklet (in Kannada)



ಅತಿಸಾರ/ಜೀರ್ಣ

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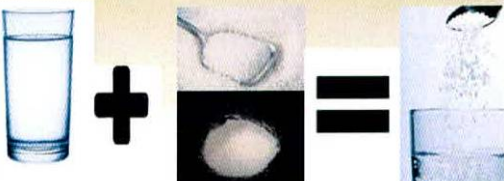
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- ಆಹಾರನಂಜು - ಹಳಸಿದ ಆಹಾರ ಪದಾರ್ಥವನ್ನು ಸೇವಿಸುವುದು ಅಥವಾ ಕಲುಷಿತ ನೀರನ್ನು ಕುಡಿಯುವುದು
- ವೈರಸ್ ಅಥವಾ "ಬ್ಯಾಕ್ಟೀರಿಯಾ" ಸೋಂಕುಗಳು
- ಅಪೊಷ್ಕಿತ - ಪೌಷ್ಟಿಕ ಆಹಾರವನ್ನು ಸರಿಯಾದ ಪ್ರಮಾಣದಲ್ಲಿ ತೆಗೆದುಕೊಳ್ಳದಿರುವುದು


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- ಹೆಚ್ಚಿನ ಪ್ರಮಾಣದಲ್ಲಿ ನೀರನ್ನು ಸೇವಿಸಿ. 4 ಚಮಚ ಉಪ್ಪು ಮತ್ತು 4 ಚಮಚ ಸಕ್ಕರೆಯನ್ನು ನೀರಿನಲ್ಲಿ ಮಿಶ್ರಣ ಮಾಡಿ ಸೇವಿಸಿ.



ಅತಿಸಾರದ ಮನೆ ಮದ್ದುಗಳು

- ಅಲ್ಪ ಪ್ರಮಾಣದ ಜಾಯಿಕಾಯಿ ಮತ್ತು ಅಲ್ಪ ಪ್ರಮಾಣದ ಕುಂಬೆಯನ್ನು ಕುಟ್ಟಿ ನುಣ್ಣುವೆ ಮಡಿ ಮಾಡಿ ಹದವಾದ "ಪೇಸ್ಟ್"ನ್ನು ತಯಾರಿಸಿ.
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4. THE IPH RESEARCH STUDY: MY SECOND FIELD EXPERIENCE TO UNDERSTAND COMMUNITY

Study Details

Title:

Understanding the barriers experienced by the people of an urban slum in Bangalore to utilize the primary diabetes and hypertension care facilitated by the Institute of Public Health (IPH)

Primary Investigator:

Anusha Purushotham

Supervisors:

Dr. Mrunalini Gowda (IPH), Dr. Rahul ASGR (SOCHARA), Dr. Narayanan Devadasan (IPH), Dr. Thriveni BS

Name of the Field:

KG Halli, Bangalore, India

Duration:

August 2014 – October 2014

Affiliations:

Research report prepared as part of the Community Health Learning Program (CHLP) at SOCHARA (Society for Community Health Awareness, Research and Action), Bangalore, India in collaboration with the Institute of Public Health (IPH), Bangalore, India.

Funding Details and Budget:

The researcher was funded through the monthly stipend received in the Community Health Learning Program (CHLP), SOCHARA. All travel costs to the field were covered using these funds.

Ethics Statement:

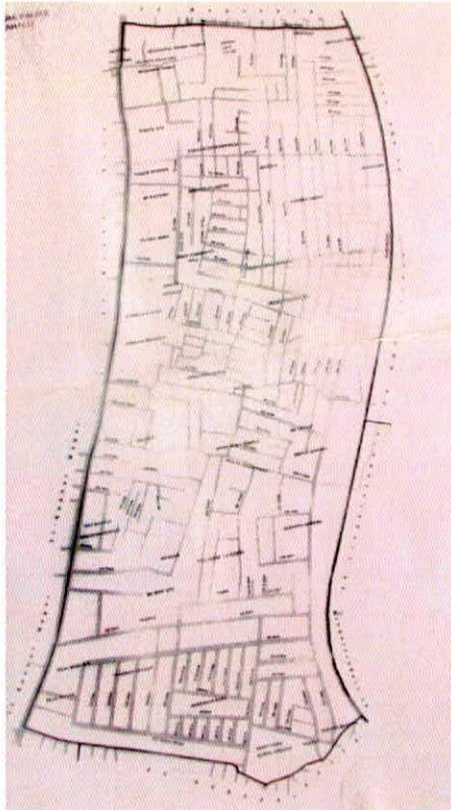
Research proposal was accepted and approved by the SOCHARA Institutional Scientific and Ethics Committee in August 2014.

Background

The world is facing a recent epidemiological shift from communicable diseases to chronic non-communicable diseases (NCDs), particularly diabetes and hypertension. In 2008, 36 million out of the 57 million deaths (53%) that occurred across the globe were caused due to NCDs and 80% of the NCD deaths occurred in low and middle income countries (1). Out of the worldwide total of 970 million people with hypertension and 382 million people suffering from diabetes, approximately 640 million hypertensive patients (65.98%) and 305.6 million diabetic patients (80%) live in developing nations (2,3). Therefore, this epidemiological trend is of particular interest in developing nations, especially India, where the disease burden is consistently rising. The prevalence of hypertension in urban India is 25% and rural India is 10-15% (4). With 65.1 million diabetics (prevalence 7.1%), India has the second highest number of people with diabetes in the world (2). In urban south India prevalence of diabetes has risen from 5% in 1984 to 13.9% in 2000 (5).

This rise in the burden of chronic diseases has been complicated by another phenomenon, urbanization. The rate of urbanization in India is proceeding at a very rapid pace with a quarter of the urban population living in slum areas (6). The urban poor experience a very complex set of socio-economic, cultural, and political barriers that lead to inequity in health care access (7, 8). Among all these reasons, even in the general population, affordability is the second most common reason (first reason being people considering the ailment not serious enough) for not seeking health care in India (9) and recent studies in the Indian context have revealed that cost of care alone could be a driving factor to forego care altogether among the poor (10). It is the second most frequently reported reason (after long waiting lines) that the urban slum dwellers in India perceive as a barrier to health services (11).

Kadugodanahalli (KG Halli) is an urban neighbourhood classified as one of the 198 administrative units in the city of Bangalore, the capital of the South Indian state of Karnataka. KG Halli has an area of 0.7 square kilometers and a population of over 44,500 (12). It is a lower middle-class income area with over 75% of the population earning less than \$2 a day (INR 110) (8). A slum is generally an area where the urban poor reside, typically characterized by poor living and sanitary conditions. In KG Halli, there are presently two registered slums and one former slum, which was razed down in 2011 and replaced by a corporation quarters with better housing facilities for the slum dwellers.



**Figure 1: Map of KG Halli
(Ward 30)**

KG Halli has been the site for the Urban Health Action Research Project (UHARP) of the Institute of Public Health (IPH), Bangalore, since 2009. UHARP was launched with a mission to improve the quality of health care of KG Halli residents by working with the community, the local health services (private and government) and health authorities (13). Over the past five years the UHARP has been working with the community to understand their needs with the help of trained Community Health Assistants (CHAs). CHAs are trained by the UHARP team based on the ASHA modules, and they conduct regular house visits in the community, disseminating information about basic health issues, nutrition, hygiene, immunization and link people to the appropriate health services, under the supervision of UHARP staff when needed. UHARP's other activities include facilitating a dialogue between the various stakeholders in the community to establish a common platform of health service provision, creating health awareness in the form of school health programs/rallies and promoting youth empowerment by establishing a community library and evening computer classes.



Figure 2: Community Health Assistant (CHA) interacting with the community

Figure 3: CHA helping children with their homework in the IPH community library



Figure 4: Computer classes in the IPH community center in KG Halli

An exhaustive census in the form of a house-to-house survey was conducted by UHARP in KG Halli between June 2009 and March 2010 to understand the socio-economic status and health-seeking behaviour of the urban community in the context of a pluralistic healthcare system. This self-reported census data showed, among all diseases, a high prevalence (13.8%) of chronic conditions in the adult population in KG Halli with 6.4% diabetes and 10% hypertension (16). KG Halli has a mixed healthcare delivery system with 2 government and 32 private health care facilities, most of which are small clinics run by general practitioners (GPs).



Figure 4: Community Health Center
(Government CHC)



Figure 5: A private clinic and an
adjacent pharmacy in KG Halli

69.6% of the surveyed households incurred high out-of-pocket (OOP) expenditures for chronic conditions with 16% families facing financial catastrophe by spending more than 10% income on OOP (12). This doubled the poverty rate every month (12). A subsequent study conducted in 2013 revealed that despite the vicinity of abundant healthcare centers, one of the major barriers to care reported by diabetic patients in KG Halli is financial hardship (8). The largest share of healthcare OOP has been on medicines, particularly in chronic care where medication needs to be taken for a lifetime (14). Other reasons that drive up the OOP are: the lack of medication and diagnostic services within government facilities, which forces patients to visit different private facilities for different components of care (8). Hence, all these services need to be integrated in one location in the public sector, the private healthcare sector costs should be regulated and financial protection must be provided to patients against huge impoverishing OOP costs (8).

When details of the study were discussed with the community and health providers, both the stakeholders suggested that increasing the availability and accessibility of low-cost medicines would be the first step in dealing with this issue. Several negotiations were conducted with both the private health providers and the government facilities (CHC and UHC). However, the private health providers were reluctant to prescribe low-cost generic medicines since pharmacies in the area either did not stock generics or sold generics at the same price as brand medications. UHARP's attempt to strengthen the existing government facilities saw no success because the requisites recommended by the government health facilities were not feasible for the project.

Therefore, the IPH Hypertension and Diabetes clinic (primary care clinic) was started by UHARP on January 6th 2014 as an experimental model to provide affordable, quality and patient-centric diabetes and hypertension care to the residents of KG Halli. The clinic operates every Monday, between 2pm and 5pm and offers free consultation and counseling services by trained medical doctors and nurses. The clinic also dispenses generic diabetes/hypertension medicines at a subsidized rate. The clinic is equipped with a BP monitor and finger-stick testing for random blood glucose monitoring. For the first three months, the clinic was staffed by a doctor from a Christian mission hospital in the area while IPH was only involved in procuring and dispensing medications. Presently, due to shortage of doctors from the mission hospitals, two UHARP personnel, who are trained medical doctors, operate the clinic while the Christian mission hospital continues to send nurses to the clinic.

Figure 6: IPH Diabetes and Hypertension Clinic

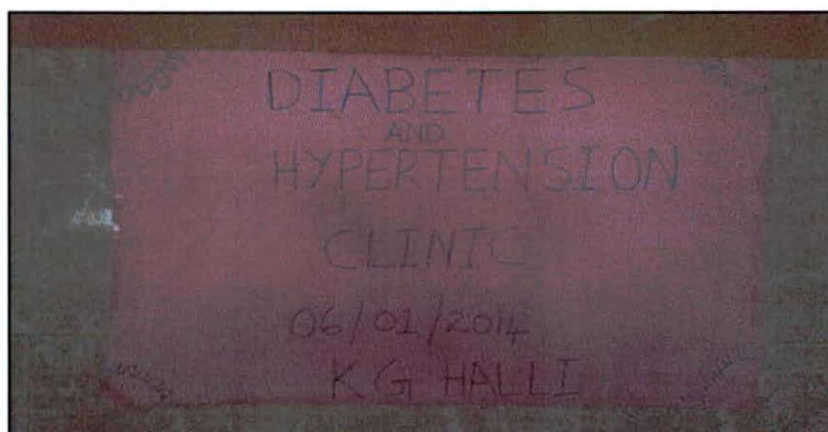


Figure 7: Doctor- patient interaction in the clinic

Figure 8: Patient counseling services



Among the slums in KG Halli, one particular slum, *Slum A*, was identified to be on the lowest rung of the economic ladder, with residents unable to make ends meet (Snapshots of Slum A in *Appendix 4*). Therefore, the UHARP team, along with the support from its funding agency, decided to offer free medicines to the people of this particular slum in addition to the other free services at the IPH clinic. The Community Health Assistants (CHAs) of UHARP who have worked closely with the community over the past four years identified 22 residents (as of May 2013) in *Slum A* who have diabetes and hypertension. The CHAs visited their houses, created awareness about the free services in the IPH clinic and gave “health cards” that qualified them for free medicines and insulin in the IPH clinic. These cards have information such as name of the patient, address, contact information and family member details.

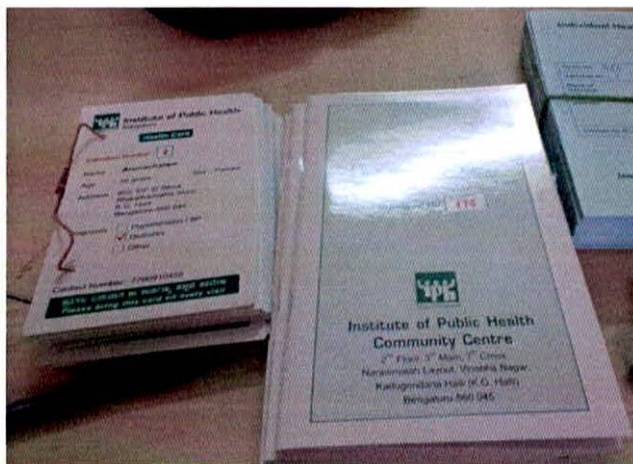


Figure 9: IPH Health Card and Patient Diary

Despite the expressed need by the community, awareness created by the CHAs in *Slum A* and the utilization of the IPH clinic services by residents from various other areas of KG Halli, only 6 out of 22 diabetic/hypertension patients of *Slum A* have come to the IPH clinic as of August 2014. Even among these 6 patients who visited the IPH clinic, only 2 patients visited more than twice and none have returned since March 2014. Currently, there are no patients from *Slum A* who are availing the services of the IPH clinic.

Therefore, there is a need for a systematic in-depth study to understand why the residents of *Slum A*, despite being promised free medicines and treatment at the IPH clinic, are not availing these services.

Aim

This study aims to explore and understand the potential barriers experienced by the residents of *Slum A* to utilize primary diabetes and hypertension care in the IPH clinic.

Objectives

- To identify the socio-economic, cultural, physical, structural and political barriers that are unique to residents of *Slum A* that prevent them from seeking diabetes and hypertension care in the IPH clinic.
- To understand the history of disease(s) in the diabetic and hypertensive residents of *Slum A*, their health-seeking behaviour and healthcare expenditure.
- To understand their perceptions regarding the quality of care at the IPH clinic and particularly explore their attitudes regarding generic medicines dispensed in the clinic.
- To list the learnings from the study that could benefit the UHARP team to modify the current functioning of the IPH clinic and improve the utilization of diabetes and hypertension care to the residents of *Slum A* and KG Halli as a whole.

Methods

Participants:

A qualitative approach using in-depth interviews was adopted for this study. The study population comprised of people from Slum A who have diabetes and/or hypertension. The participants were identified using the following inclusion criteria –

- a) Must be a resident of *Slum A*.
- b) Must have diabetes and/or hypertension (self-reported).
- c) Must have the IPH Health Card prepared under their name.

An exhaustive sampling approach was adopted to obtain all the viewpoints of the problems since the population size was small.

Materials and Procedure:

In-depth interviews were conducted in the households or any location within the neighbourhood of *Slum A* that was convenient for the participants. Sixteen in-depth interviews were conducted. The first six interviews were conducted by the Primary Investigator (PI) and one of the study supervisors. The next ten interviews were conducted by the PI alone. In order to avoid unnecessary distractions to the participants, the interviews were conducted in a relatively quiet location. Prior to the interview, verbal consent was taken from the participant if they were comfortable having family members, neighbours or others present during the interview. Apart from the participant, interviewer(s) and translator (CHA), all others were instructed to not intervene during the interview unless they acted as a secondary source of information. Informed consent was obtained from the family members who acted as a secondary source of information. Interviews were carried out using one of the following local languages – Kannada, Tamil or Urdu. A semi-structured interview format was followed using a topic guide (*appendix 1*). Prior to the launch of the full study, three pilot interviews were conducted in a neighbouring slum – *Slum B* which is also located in KG Halli and is comparable to *Slum A*. The final topic guide was evolved based on the preliminary responses in the pilot. The PI conducted the interviews in Kannada and partly in Urdu. Interviews in Tamil and Urdu were conducted with the assistance of a CHA who acted as a translator and translated the interview between Kannada and Tamil/Urdu *in situ*. Details of the study were explained in the language the participant could understand and the informed consent for participation was signed

prior to the interview. If the participant was illiterate, a thumb print was obtained in the presence of a literate witness of the participant's preference. With the consent of the participant, interviews were recorded using the SONY MP3 Digital Voice IC Recorder (Model: ICD-UX71F) owned by UHARP in KG Halli, Bangalore. If the participant was uncomfortable with the audio-recording, the PI instead wrote down the interview verbatim in a notebook after translating into English *in situ*. A soft-copy version of the English transcript was then prepared post-interview. All audio-recordings of the interviews, on the other hand, were translated from Kannada to English only after the interview and the soft-copy versions of the English transcripts were simultaneously prepared.

The data was analyzed thematically using Atlas.ti software. First, all the transcripts were coded using Atlas.ti and the preliminary codes were reworded/reviewed for any repetitions. Then, similar codes were organized into categories. Several iterations of this categorization were done until the final themes were recognized.

Ethical Considerations

Listed below are the four ethical principles for research and how the study addresses these principles –

1. **The Principle of Non-Maleficence:** The risks involved in this study were minimal and no harm to the physical, mental and psychological health of the study participant or the community is anticipated. The interviews were conducted in the comfort of the households or neighbourhoods of the participants as per their preference and thus, no physical harm was expected. Researchers were trained to conduct interviews with utmost respect to the participant's emotional, mental and psychological wellbeing so as to not cause any unnecessary harm or distress.
2. **The Principle of Beneficence:** This study was undertaken with the intention of understanding the barriers to accessing free diabetes and hypertension care in the IPH clinic and in turn, proposing measures to address these barriers to improve the clinic accessibility to the Slum A community. Although there were no direct monetary benefits from participating in the study, the information participants provide will aid in future research and activities that will contribute to improving the overall quality of care in their neighbourhood.
3. **The Principle of Autonomy:** Protecting the rights and dignity of the participants was the top priority throughout the duration of the study. Participants had complete autonomy over the decision to participate in the study or withdraw their participation at any point during the study. At the beginning of the study, participants were provided with a written informed consent and details of the study were explained verbally in the local language. Even after the completion of the study, at any time in the future, participants will have the right to revoke their consent to use information obtained from them for present or future research purposes. Participants were clearly informed that they are not required to provide any reasons for these decisions and none of their decisions would jeopardize their relationship with IPH.
4. **The Principle of Justice:** All study participants were treated fairly and no discrimination was made on the basis of gender, age, color, socio-economic status, religion, language, caste or creed. The study protocol remained the same across the study population and no individuals or

Results

The details of the sixteen interview participants are mentioned in *Table 1*. For the column titled “Attended IPH clinic” the number in parenthesis indicates the number of times the people have attended the clinic.

Out of the 22 people identified by the CHAs to be eligible for the IPH health card, 6 were not included in the study for the following reasons –

- 1 resident was not available for interview
- 2 residents were deceased
- 3 residents were wrongly identified as having diabetes or hypertension

The in-depth interviews were used to first understand issues related to the history of the disease, health-seeking behaviour and health expenditure of the participants in order to set up the context before exploring the constraints residents of *Slum A* faced in accessing the IPH clinic.

History of disease and health-seeking behavior

All the 16 participants interviewed had been diagnosed with either diabetes or hypertension for at least 1 year. The duration of disease ranged from 1.5 – 20 years with 4 participants having the disease for more than 10 years. All but 2 participants reported symptomatic disease detection i.e. they were diagnosed with the disease only after they experienced symptoms.

“First I had dizziness and they took me to a private hospital. There they told me I had BP. There they gave me tablets for BP. I took BP tablets for 4-5 years. It was normal after that. Suddenly I had problems with my eyes and they took me to Bowring hospital. There they told me I had BP and sugar.” [P5, female 77 years]

There was mix of healthcare facilities where the disease was first detected – participants went to both government and private clinics when they were first diagnosed. However, very few participants chose to continue treatment at government facilities and instead switched over to private providers either due to their own experiences at government hospitals or due to reviews they heard about private providers from others.

Table 1: Details of the interview participants

| Participant No. | Age (yrs) | Sex | Diseases | Duration of disease (yrs) | Interviewer | Language of interview | Religion | Occupation | Attended IPH Clinic |
|-----------------|-----------|-----|---------------------------------|---------------------------|-------------|--|-----------|-------------------------|---------------------|
| | 45 | F | DM | 15-20 | AP and MG | Kannada | Hindu | None | Y (2) |
| | 43 | F | DM | 6 | AP and MG | Urdu | Muslim | Beedi-maker | Y (1) |
| | 55 | F | DM and HTN | 15 | AP and MG | Urdu | Muslim | None | Y(4) |
| | 56 | F | HTN and DM | 5 | AP and MG | Kannada | Christian | Rag-picker | N |
| | 77 | F | HTN and DM | 2 (DM) 5 (HTN) | AP and MG | Urdu | Muslim | None | N |
| | 50 | M | DM | 2-3 | AP and MG | Urdu | Muslim | Faith-healer | N |
| | 55 | M | DM | 3 | AP | Kannada (primary) Tamil (secondary) | Hindu | Construction worker | Y (1) |
| | 60 | F | DM and HTN (both under control) | 1.5 | AP | Kannada | Christian | Hospital cleaning staff | Y(2) |
| | 59 | F | DM and HTN (HTN under control) | 2 | AP | Urdu | Muslim | None | N |
| | 50 | F | HTN | 6 | AP | Urdu | Muslim | Clinic cleaning staff | N |
| | 48 | F | HTN | 16 | AP | Kannada | Hindu | Beedi-maker | N |
| | 42 | F | HTN | 7 | AP | Kannada(primary) Tamil (secondary) | Hindu | Office cleaning staff | N |
| | 38 | M | DM | 8 | AP | Kannada | Hindu | Domestic worker | N |
| | 70 | M | HTN | 20 | AP | Urdu | Muslim | None | N |
| | 70 | F | HTN | 4-5 | AP | Urdu | Muslim | None (begs alms) | N |
| | 55 | F | DM and HTN | 5 | AP | Urdu | Muslim | None | Y (2) |

DM – Diabetes Mellitus, HTN – Hypertension, AP – Anusha Purushotham, MG – Mrunalini Gowda

Patient does not know where the clinic is located or does not know the timings of the clinic.

People, who had heard about the clinic and had the card, did not know where it was located. They were confused about the location of the clinic or stated other primary reasons that prevented them from taking the effort to know about the location of the clinic. Some people also were unsure about the timings of the clinic.

"I came twice to the address you told me and I looked there. I did not find the clinic, so I went again to Bowring." (P5, female 77 years)

"She told me and gave me the card and all. I myself have not gone. I didn't get time and didn't know how to go there." (P12, female 42 years)

Patient confused about IPH clinic and other organizations

There are several NGOs that work in *Slum A* on health and other related issues. Hence, people tended to confuse IPH with these other organizations. Due to the proximity of the government Community Health Center (CHC), which is located less than a kilometer away from the IPH clinic, some patients also confused the IPH clinic with the CHC.

"No, my daughter went there for delivery. Also took the kids for checkup. Near the police station. They check the weight of the kids." (Participant talking about the CHC when asked about what she knows about the IPH clinic) [P10, female 50 years]

2. Inadequate follow-up/misidentification of patients by Community Health Assistants (CHAs)

Timings of the CHAs not matching with the availability of patients

Lack of communication between the CHAs and some sections of the community was a critical barrier that emerged during analysis of the interviews. Mismatch in the work timings of the CHAs and the people proved to be a major reason for this inadequate communication. The CHAs visited the community between 10am and 5pm on weekdays and therefore, missed out on interacting with many people who went out for work during the day.

"They [pointing to CHA] also come and when they come to check, I am not there. That is the problem." [P11, female 48 years]

No health card given to some patients

6 out of the 22 identified patients were not given the IPH health cards primarily due to the reasons mentioned above. Although the cards were printed with their names, they were not distributed to the patients. Among the 6 patients with no cards, 1 reported partial awareness about the clinic since the CHAs spoke to her while surveying the area, 1 patient was deceased and 1 patient was not available for the interview. The remaining 3 patients said they had no knowledge about the clinic. These were the same patients mentioned in the theme titled *"Patient does not know anything about the clinic."*

Interviewer: "Did you get a card? [Pointing to a IPH health card that we had] Like this, did someone give you a card?"

[P10, female 50 years]: "No, no. No one gave."

Lack of follow-up by CHAs

Although a majority of the people mentioned that they recognized the CHAs and that they visited them many times, few people reported rarely seeing or interacting with the CHAs.

Interviewer: "You did not find the clinic. Did you tell anyone among the three of them (CHAs) that you did not find the clinic?"

(P5, female 77 years): "No, no one came."

Wrong identification of patients

3 of the 22 patients were wrongly identified as having the disease (DM and/or HTN). This was due to the inadequate understanding of the disease symptoms by both the patients and the CHAs.

3. Perception of medications

The 6 participants who had been to the IPH clinic at least once had a general positive opinion about the clinic and the staff. Most of them recounted that they were counseled about their disease and information was given about self-care, exercise and diet. They also said that the doctors and nurses were friendly. Overall, when asked about their experience in the clinic, people mostly said "good."

"The doctors come and check sugar and BP. They tell this and that. They tell that it will become better... Yes, the computer is there no. In that they told me to see. They show for 15-20 mins and I have seen it... "You have the disease. Do this, be proper and take care of yourself. Take care of your health," it says all of this." [P15, female 70 years]

However, when probed further, people felt that although the clinic was "good", they had a problem with the medicines dispensed. Perception of the generic medications dispensed in the IPH clinic was one of the major reasons that people cited for not utilizing the clinic. People formed different opinions about the medicines either through their own experience of consuming the medicines or were influenced by others.

"It (IPH clinic) was good. There were a lot of people. I thought, "Let me go see." So I went there. When the (private) doctor told me that the medicine did not suit me, "Don't eat this, ma, this other medicine. Use whatever you used before." I stopped taking it and I am using this only." [P1, female 45 years]

Experiencing side-effects

Of the 6 patients that came to the IPH clinic, 2 patients reported side-effects from the medicines. Patients reported taking the medicines for at least one month before they started experiencing side effects and felt that their disease was not under control.

"I took for one month. Nothing happened. I took the next month. After eating, BP and diabetes both became high. I became weak – hands and legs.There was burning here. And then the whole feet. I put on vicks, I put on iodex. I put on a turmeric cloth. Afterwards, with iodex it became less. The pain." [P3, female 55 years]

Family doctor's perception about the effectiveness of the medicines

When patients showed IPH medicines to their family doctors, the doctors informed them the medicines were ineffective and they needed to revert back to their old medicines. The trust in their family doctor's opinion influenced patients to stop coming to the IPH clinic.

"I went to [Private] Clinic and they said, "Power is less in these tablets. You take this only. That does not suit you." [P3, female 55 years]

Poor quality of medicines

One patient reported that the medicine became powdery when she tried to open it. She complained of no side-effects, however. The patient insisted that this was the main reason for not coming to the clinic and she would come if the clinic gave "good medicines."

"No pain or anything. That medicine, it would become just like a powder. Like a powder. When I ate, I didn't feel right.... If you give good medicines, I will come." [P16, female 55 years]

Experience of neighbours

One person in the community fell ill and was hospitalized. Word spread in the community that the IPH medicine was the cause of this incident. People began discussing among themselves about the experiences they had or heard from others about IPH medicines and came to the conclusion that the medicines were not suitable for anyone.

"They all ate no. It became more for all of them. That old lady was admitted for 5 days in the hospital. Then I thought we don't have money with us right now to get admitted. All our money went away. We don't have anything. We earn money and eat. That is why I didn't eat any tablets because I was scared." [P2, female 43 years]

Fear of changing to a new healthcare facility or medication

Among the people who had heard about the IPH clinic but had never been to the clinic, their preference and trust in their current healthcare provider far outweighed the monetary benefits of trying a new free clinic. People went on to say that they would only come to the IPH clinic if they received the same brand of medicines that they are currently taking.

"My mind tells me, "Don't take any other medicines. Continue this tablet only." That is why I take this only... I have been going since 20-30 years to [Private] clinic. That is why I will not take it anywhere else. If I eat anything else, after eating my face becomes like this [puffs up her cheeks]" [P15, female 70 years]

"If you give us tablets, I will come. If you give us our tablets, we will come." [P2, female 43 years]

Mistrust in government health facilities and confusion about IPH clinic as a government facility.

Most people expressed mistrust in government facilities either based on their own experiences or experience of others. Due to the inadequate awareness about IPH clinic and the perception in people's minds that "free medicine" is synonymous with "government medicine," people were skeptical that the clinic dispenses poor quality "government medicines." Therefore, they refrained from coming to the clinic altogether.

"...thinking that government tablets don't suit me either, even I didn't eat. I never take government tablets. My stomach starts burning and my health gets bad..... The old lady said that "It is free, government medicines.""[P2, female 43 years]

4. Distance

Unable to walk the distance to the clinic and afford extra cost of travel

Distance was a physical barrier that people reported in utilizing the clinic. The clinic is located about <2 kms away from the neighbourhood and while some felt that this was within walking distance, many said that they need to take the bus or the auto to come to the clinic. Most of the diabetic patients complained of pain in their feet which made it even harder for them to walk the distance to come to the clinic. People who felt that the clinic was too far cited the extra money for traveling was a constraint from coming to the clinic.

"I came back and told her [looking at the CHA] that "I am not coming. I can't go that far. If I go walking then my feet hurt. My feet hurt all night."[P3, female 55 years]

"I will come to get the tablets if you can help with the travel to and from there."[P14, male 70 years]

Other health facilities are closer

Due to the abundance of many private clinics in the vicinity that had established trust with the community, some people preferred continuing to seek care in those clinics as they found the location of the IPH clinic inconvenient.

"I go walking. It is close by. Behind."(when talking about her current clinic)[P3, female 55 years]

5. Restricted Timings

Clinic timings conflicting with work timings

In addition to the distance, timing of the clinic was an important limiting factor that decreased the accessibility. The clinic is open only on Mondays, between 2pm and 5pm. This restrictive timing prevented people who go to work during the day from utilizing the clinic. Majority of the patient population who work were daily wage labourers and hence, taking even a day off amounts to the loss of a day's pay.

"The timing doesn't match. If I don't go to work for a day, they cut the wages. That is why. There if my wages get cut.." (P12, female 42 years)

Other health facilities with more convenient timings

Other private health facilities in the area were open for longer hours - during the evenings and sometimes, even on weekends. This made it convenient for people to utilize the clinic after work and thus, they preferred these clinics over IPH clinic.

Interviewer: "What time do you go to [private] clinic?"

[P11, female 48 years]: "I go in the evening, amma.... I have not gone (to IPH clinic) because I don't have time, that's all."

6. Health-seeking behaviour

Attitude about own disease

The past health-seeking behavior of the respondents gives some insight into why they decided against coming to the IPH clinic. Many people felt that they needed to go to the doctor only when they had symptoms and there were long periods of time (6months – 3 years) when they would not see any doctor. Some of them did not have a preference for any particular doctor and would seek treatment at any facility that was convenient at the time of illness. Therefore, since such patients had not experienced any severe symptoms recently and did not feel the need to go to a doctor, they might not have come to the IPH clinic.

"I go anywhere and everywhere.... I have it (tablets), I buy that and eat....If I get fever, cold or body aches, I would go. If not, I would not go." [P12, female 42 years]

Among the others who exhibited irregular health-seeking behaviors, some had accepted that death was inevitable, so they did not feel the need to comply with their doctor's instructions or take medications regularly.

"Anyway, one day we all should die, so leave it" thinking that I stopped (taking tablets)." [P7, male 55 years]

Among the 16 participants, only 1 mentioned that her diabetes and hypertension were currently under control and since she was told by several doctors that she did not need any medications, she stopped coming to the IPH clinic. This patient showed a high level of understanding about the disease and strictly adhered to the treatment regimen and diet. She continues to get her sugar and BP levels monitored monthly.

"After I got diabetes I became very scared. After that I went to so many places and got my blood checked, do you know? Any place people told me I went. Even when they say pay Rs.50 and get it checked, I would. The reason being, in (private) hospital I see, right? Hand amputation, leg amputation and all that! That is why I used to get it checked regularly. I was afraid. That is why now I don't have anything. It is normal." [P8, female 60 years]

Source of payment of health expenditure

Some patients said that the only reason that they were able to afford the cost of the medications and treatment in private clinics was because they were receiving financial assistance from their family members or from their place of work. If they did not receive this support, they would have come to the IPH clinic for the free medicines.

"I don't pay. The people whom I work for, they pay... They give me money and I buy it. Fees whenever I go to the doctor I only pay 100 rupees. For tablets they give..."

[Speaking about what she will do if her employer doesn't pay for medicines]

I have to pay or my kids have to. Otherwise I have to go to this [IPH] clinic. That is what. I am talking about it openly. If they did not give me, my kids get salary every month otherwise I have to go to this clinic. To them only [pointing at the CHA].”[P11, female 48 years]

Alcoholism

One of the respondents reported that his habit of drinking alcohol was the main reason that prevents him from coming back to the IPH clinic. Although he did not admit it himself at first, after much discussion, his wife informed us that he is afraid to take diabetes medication while drinking alcohol as he is aware of the ill-effects of mixing the two. Despite being hospitalized twice due to complications from diabetes, he chooses to not comply with the treatment.

P7’s wife: “If he takes the medicine, he won’t be able to drink liquor. So that is why he stops.”

[P7, male 55 years]: “Yeah, that is the reason. Nothing else.”

The wife went on to tell us the various measures, including faith healing that they have taken to stop his alcoholism in vain. The entire family, including the children, has supported him to rid himself of the habit and convinced him to take care of his health.

“We have tried so much, madam. He promises on all of us. He even promises to God. When he goes to the hospital what he tells, “From today onwards I won’t drink. There are a lot of difficulties at home.” He thinks about all of this when he is on the hospital bed. When he comes back home, he goes back to it. What to do? That is why we don’t send him to work, we ask him stay at home itself. If he goes out for work and earns money, he will drink. That is why we don’t send him.” [P7’s wife]

The patient on the contrary feels like he can stop drinking whenever he wants if he makes up his mind. He states that he has stopped drinking in the past for as long as 6 months when he was hospitalized. Therefore, he can stop anytime and come to the clinic.

“I don’t have anything like that, madam. For everything it is my mind that is the reason. If I want to stop then I can stop, I am like that.... When I take medicines, I will be afraid that I can’t drink, right. If I stop taking meds only then I drink. If I take meds, I can’t drink right.”

Despite the patient’s confidence, his wife felt less assured about the promise because the patient had been recently discharged from the hospital but had already returned to his drinking. His alcoholism was deeply rooted and she felt they needed more assistance to tackle the problem effectively.

7. Family Structure

Family dynamics also played an important role in the decision-making of the patients when it came to choosing their health-care facilities. Majority of the patients said that they had very supportive families who gave them complete autonomy over any decisions they made regarding their health. Their families did not influence them to choose one health care facility over the other or discourage them from going to the IPH clinic. However, there were other subtle familial factors that indirectly became barriers to utilizing the clinic.

Need someone to accompany to the clinic

This was a significant theme that emerged among the elderly patients we interviewed. Older patients depended on family members to take them to the clinic and if no one was available to accompany them, they would not be able to go anywhere. If the clinic was too far, they would instead prefer a closer clinic so that it would be more convenient for their family members. Thus, these patients did not have complete independence to choose when and where they wanted to go for treatment.

"I have pain in my feet, so I can't go anywhere. Also, my grand-daughter is too young to take me to the clinic. My daughter stays at home with her 5 children and she cannot take me. My son goes to work and my daughter-in-law also has 5 kids. I went in auto 2-3 times to the clinic with 2-3 people. Because they stopped, I also stopped going. That is why I stay at home itself." [P16, female 55 years]

Lack of communication between family members

When the CHAs distributed the IPH health cards, some cards were given to the patients' family members and not directly to the patients (if they were unavailable or at work). This sometimes resulted in the message not being conveyed to the patients because of the lack of communication within the family and thus, the patient had little or no awareness about the IPH clinic.

"No, she (wife) did not tell me. She has her own tension at work. In the morning she has to take care of the kids. I only come at 9-9:30 at night. I eat dinner and sleep. That's all." [P13, male 38 years]

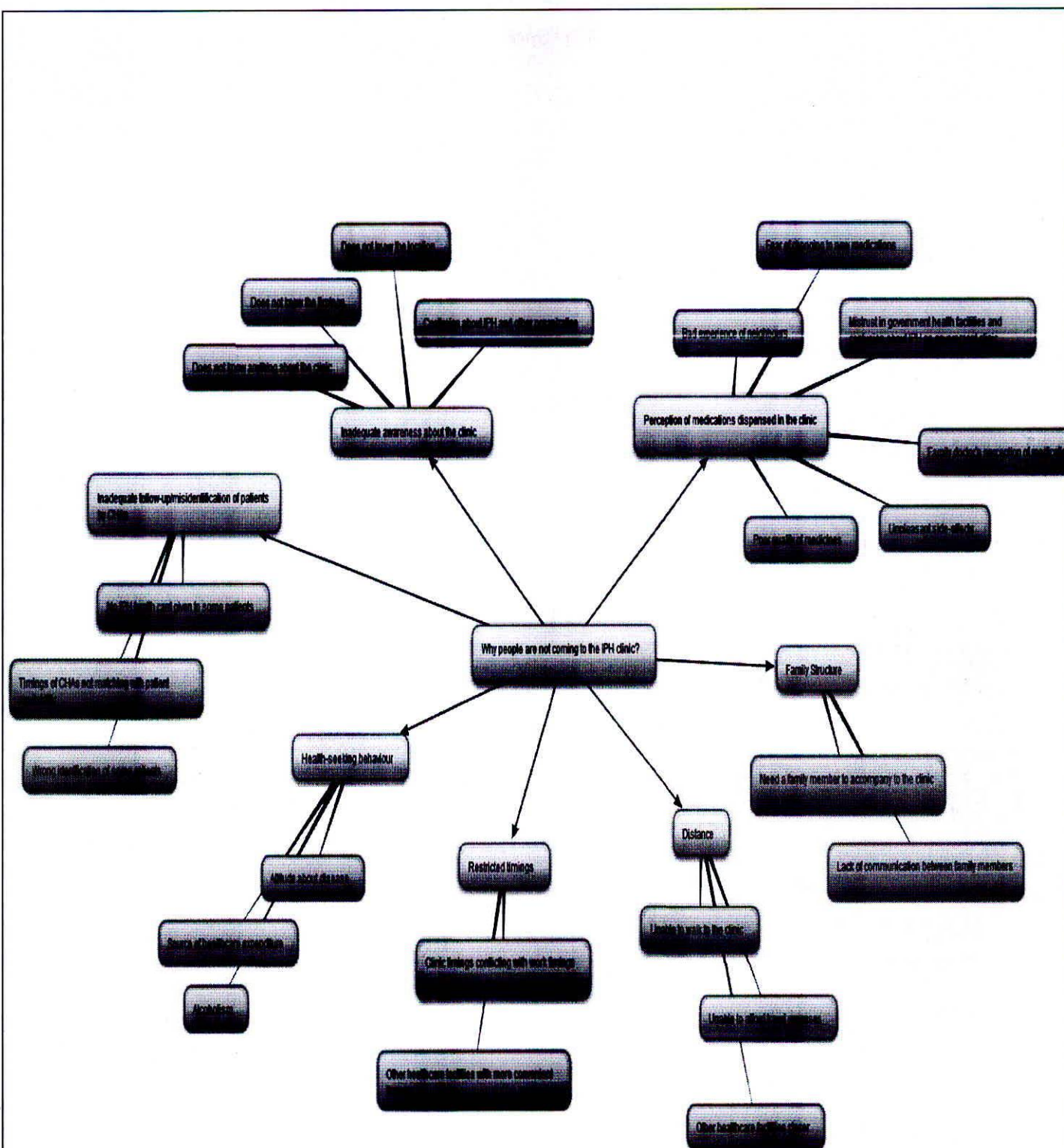


Figure 10- Schematic diagram representing the major themes of why people are not utilizing the IPH clinic: Thematic analysis of the 16 in-depth interviews showed seven main barriers that prevent people from utilizing the IPH clinic. The major themes are represented in yellow and the sub-themes under each major theme are represented in green.

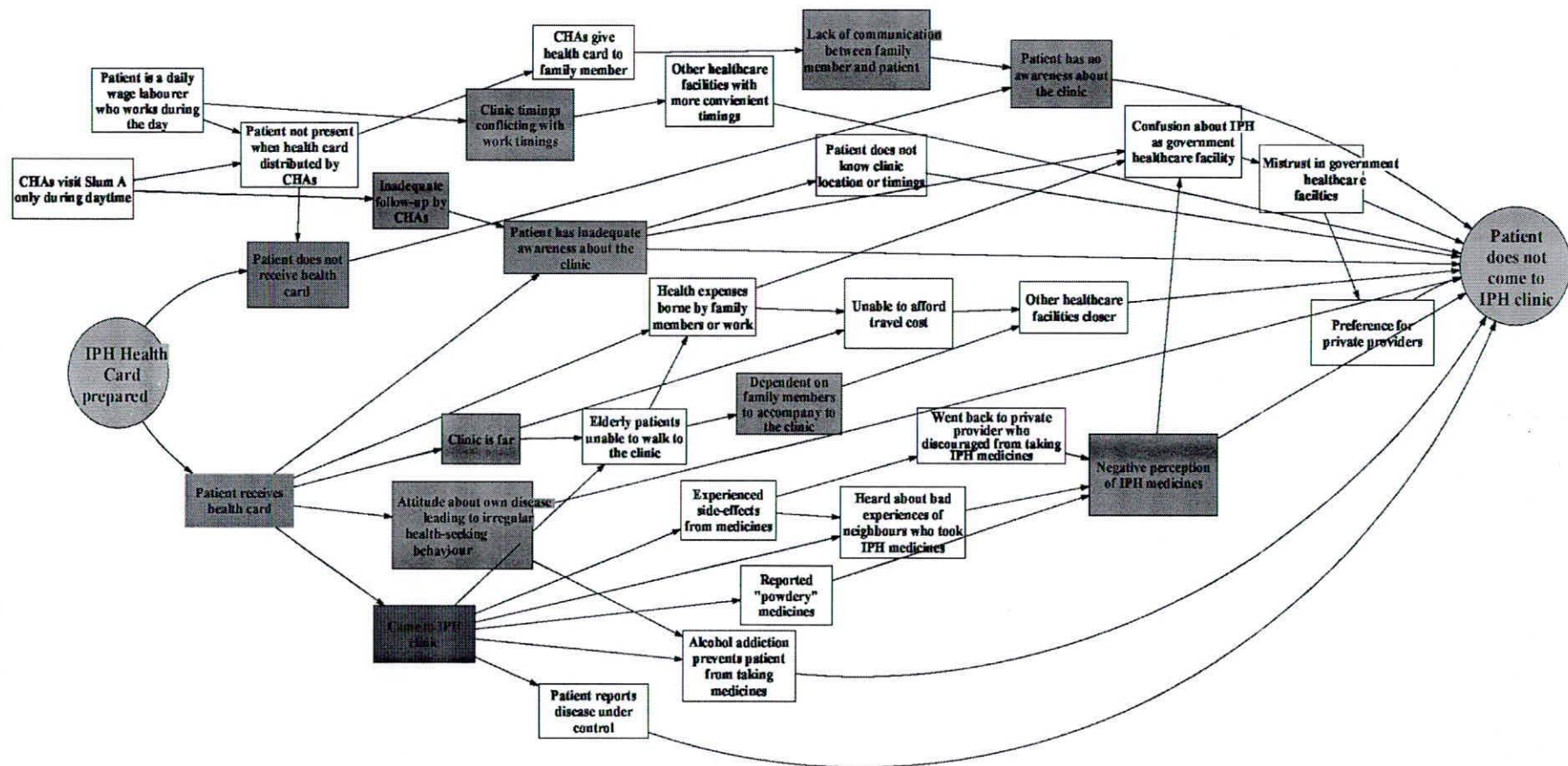


Figure 11 - Pathways elucidating why people from Slum A are not coming to the IPH Clinic: This diagram captures the various pathways from the starting point – *IPH health card is prepared* to final point – *Patient does not come to the IPH clinic*. These are tentative pathways that explain why people from Slum A who were identified to have diabetes and/or hypertension are not coming to the IPH clinic. The two main scenarios are that the patient either receives the IPH health card or does not receive the health card. Based on these two situations, different pathways can be traced. The seven major themes – lack of awareness about the clinic, inadequate follow-up by the CHAs, negative perception of the IPH medicines, timings, distance, health-seeking behaviour and family structure are highlighted. This diagram illustrates that the 7 themes are not acting in isolation but are interlinked.

Discussion

With the intention of addressing the financial burden of medications and thereby increasing compliance and continuity of treatment in diabetes and hypertensive patients, IPH set up a clinic in January 2014. Despite their eligibility to receive free medicines and treatment, the residents of *Slum A* reported several constraints that prevented them from coming to the clinic. This study describes these barriers: lack of awareness about the IPH clinic, inadequate follow-up/misidentification by CHAs, perception of IPH medications, distance, restricted timings, health-seeking behaviour and family structure.

Lack of awareness about the IPH clinic was one of the major themes that emerged in the study. This goes hand-in-hand with the next barrier - inadequate communication between the CHAs and the community. Some patients said that they did not know specific details like timings/location of the clinic while others stated they had never heard of the clinic. In order to further understand this implementation gap, informal discussions were conducted with the three CHAs who worked in *Slum A*. All three CHAs (including a fourth one who is no longer with IPH) had surveyed *Slum A* in September 2013 to identify the diabetes and hypertensive patients in the area but only 2 of the CHAs went in January 2014, just before the opening of the clinic, to distribute the health cards. Some houses were missed since they were locked during the survey and/or card distribution. The CHAs reported that these houses belonged to daily wage labourers who worked during the day. Although they went back again 2-3 times to the same houses, even during the weekends, they were still locked. Therefore, 6 patients who were identified during the survey were not given health cards because the CHAs only went to *Slum A* during the daytime. These patients with no cards mentioned that had they been aware, they would have come to the clinic to receive the free medicines.

A possible suggestion to tackle this problem of mismatched timings between the CHAs and the community would be for the UHARP team to consider modifying the work timings of the CHAs such that they can visit *Slum A* in the evenings for few days a month so as to reach out to this section of *Slum A*. This could also address the issue of lack of awareness about the IPH clinic and inadequate follow-up by CHAs since the CHAs would have more opportunities to periodically interact with the all/or most of the patients from *Slum A* in the evenings, receive their feedback and listen to their concerns.

During the study, it was also discovered that 3 patients were wrongly identified by the CHAs to have the disease(s). The CHAs stated that when they conducted the survey, patients who reported that they had the disease(s) gave a different answer when they were interviewed for this study. Upon further probing, we attributed this oversight to the lack of understanding of disease identifiers by the CHAs and patient confusion about their own disease. Therefore, there is a need for further training and monitoring of the CHAs so that they are able to spend more time with patients and have better knowledge about the specific questions they need to ask before identifying patients.

Perception of IPH medications was another significant constraint. Experiences of neighbours or personal experiences of side-effects from IPH medications made a huge impact in people's minds and thus,

patients refrained from taking IPH medicines. Further investigation is needed on this topic to understand why these patients experienced unpleasant symptoms, if these symptoms are truly side-effects of the generic medicines and what the quality of the generic medicines was in comparison to their branded counterparts. A possible explanation, if the side-effects are confirmed to be true, is that the generic drugs may have inactive ingredients that are not suitable for these particular patients (17).

The poor opinion of other general practitioners' in the locality regarding the effectiveness of generic medicines dispensed in the IPH clinic played a huge role in influencing patients' perception about the medications. Informal discussions with the CHAs revealed that these physicians were usually linked to local pharmacies that sold only branded medications and thereby, generic medicines were not preferred by either the pharmacists or the physicians. This finding is consistent with another study conducted in South India, which showed that community pharmacists and drug retailers had negative perceptions of generics either due to low understanding about generics or preference to dispense branded medicines that met the largest profit or incentive payments (18). The attitude of these professionals proves to be a critical barrier to generic drug usage and calls for effective policies at a state or national level to tackle this issue and promote the use of affordable rational therapeutics. At the community level, innovative efforts can be re-initiated with health practitioners to support the use of generic drugs.

Most people who never came to the clinic confused IPH medications with "government medicines." They had pre-conceived notions that "free medicines" were "government medicines" and thereby, were of "poor quality" and did "not suit them." The CHAs too recognized this issue during their field visits and stated that patients do not value the medicines because they are given free of cost. Patients have told them repeatedly that they are willing to come to the IPH clinic only if they are given branded medicines. None of the patients identified these medicines as "generic" and this could be possibly due to the lack of knowledge regarding generics. Among those we interviewed, only two patients and their family members felt that "government" and "private" medicines were equally effective.

Some of the older patients were afraid of switching over from a known drug that they had been using for several years to an unknown drug. All these patients, despite their financial difficulties, were willing to spend money and buy what they called "good" medicines instead of risking eating other medicines. When asked how we could help, they asked that we provide them with either these "good" medicines or give them money to buy those medicines. Therefore, this suggests a pressing need to remove the stigma around government/generic medicines and create more awareness and trust among people regarding their benefits. There are very few studies in the Indian context that explore patient's perception of generic medicines (17) and the findings presented in this study from a patient's perspective is an important contribution to this growing database of knowledge.

The work timings of many people conflicted with the clinic timings (Monday 2pm – 5pm). Since taking a day off to come to the clinic would mean the loss of a day's pay, utilizing the clinic was out of question for such patients. These patients requested that the clinic be open past 5pm, like the other private clinics in the locality. Previous studies also show that limited opening hours is an important barrier in accessing health services (19). Therefore, this problem could be addressed by opening clinics in the evenings to accommodate more patients.

Distance of the clinic was another constraint that was mentioned, particularly by the older diabetic patients. A common complaint they had was that the pain in their feet restricted their daily activities including walking and therefore, they could not walk to the clinic on their own. They had to rely on family members to come to the clinic. Some patients said they had to use an auto/bus and this extra expense of traveling was a concern. Instead, they preferred going to clinics that are closer to their homes. CHAs reported that patients had asked if they could bring medications to their houses instead. This is a possible option that could be explored to make the free medicines more accessible to the elderly.

The role of family dynamics was also explored in the study. Many elderly patients were dependent on their family members for financial support and also needed them to physically accompany them to healthcare facilities as mentioned earlier. This limited their decision making power with regards to their own health. Some elderly patients had no family support or government welfare options (pension cards), and thus relied on begging for alms. Extra attention could be given to such patients and address their unique needs like helping them with getting pension cards or travel assistance.

The complex health-seeking behaviour of patients is also critical in understanding why they chose not to come to the IPH clinic. Some patients felt that since death was unavoidable, health was not priority for them. CHAs too expressed similar accounts of their interactions with patients who preferred spending money on eating meat rather than spending on medicines. These patients did not have any problems specific to the IPH clinic, but had a general attitude that prevented/restricted them from going to any healthcare facility regularly. Certain habits like alcoholism were also explored in this study and necessitates the need to look into such behaviours.

It is important to note that the 7 themes identified in the study are not working in isolation, but are inter-related as represented in *Figure 11*. Various factors come together and act in different pathways to produce the final effect: preventing residents of *Slum A* from utilizing the IPH clinic.

In addition to the seven themes that emerged from the interviews, there are other issues that came to light during the study. There are several organizations that work in *Slum A* on several aspects including health and livelihood and unfortunately, people have been subjected several ethically questionable practices. People have been recruited for clinical trials without their complete knowledge and sometimes, organizations also make false promises that they ultimately don't deliver. One of the CHAs who has worked in *Slum A* for the past 4 years also described several instances where institutions bring their students to conduct studies/surveys in the community for a short period of time and disappear without any follow-up activities that benefit the people. This has also been recognized in an earlier study conducted in KG Halli by IPH in 2013 (8). Despite the rapport and trust the CHAs have established with the community in *Slum A*, these past experiences have understandably left some people in *Slum A* very skeptical about the motives of any organization that works in the area. Therefore, stronger positive relationships need to be established with the community and the UHARP team. Measures can also be adopted to collaborate with some of the trustworthy organizations (NGOs) that work in the area and create a more amiable environment for both the people and the organizations.

In order to gain a better insight about what the community wanted and expected, participants were asked about how IPH could help them. While many people spoke about health-related issues like free medicines or medical attention for other diseases, some requested help for the elderly, getting ration cards and pension cards, help with the education of disabled children and monetary assistance. This threw light on other concerns the community had that were not related specifically to diabetes and hypertension. Since people felt like these issues were significant enough to mention in their interviews, it could allude to the possibility that people considered these problems to be of high priority. This was consistent with the conclusion of the informal discussions we conducted with the CHAs - the community had other more pressing needs than diabetes and hypertension. Thus, if the UHARP team is able to address these concerns effectively and in turn help with their overall well-being, trust will be built in the community about IPH and they will take more interest in the health promotion activities conducted by CHAs and utilize the clinic.

Another important learning from the study is that some people spoke about many health issues that they or their family members faced. Therefore, if the clinic is able to provide overall primary health care in addition to diabetes and hypertension, patients might be willing to come to the clinic as it would be a one-stop shop for all their basic healthcare needs. An alternate option would be to re-instate efforts to strengthen the existing CHC and UHC as a first-step, make generic medicines (particularly diabetes and hypertension medications) available in the CHC/UHC to meet the demands of the patient population and introduce counseling services in partnership with the Christian mission hospital. The CHC/UHC can then take over both the tasks of procuring medications and provide counseling services when they see the benefit of such services to the patient population.

The overall objective of the study was to understand the barriers faced by residents of *Slum A* from a socio-economic, cultural and political perspective. During the initial interviews, we did not get a sense of any political constraints that people felt in accessing the clinic. Perhaps, repeated interactions with the people by the PI would have increased the comfort level of the participants and this might have helped them talk about any political reservations they had about the clinic. Another study limitation was that the participants were interviewed in the presence of a CHA from IPH who acted as a translator. This might have affected the response of those patients who recognized the CHA and could have influenced them to speak about the clinic in a more positive light. It also needs to be acknowledged that few interviews were of relatively shorter duration (15 mins) due to either the participants' busy schedule or in the case of some elderly patients, their inability to concentrate for longer periods of time. This might have compromised the results to a small extent. Due to the small scale of the study, the results may not be applicable to the general population of the urban poor in India.

Conclusions

This study shows that despite the availability of free medicines and primary diabetes and hypertension care facilitated by the IPH, residents of *Slum A* experienced several barriers to utilize the clinic. This experimental model in providing free healthcare for NCD (diabetes and hypertension only) patients revealed many critical factors that need to be considered before implementing a similar program in the future. The foremost learning is that extensive awareness about the particular program must be created and the program must be designed such that it addresses the community needs. Due to the complex environment in *Slum A* created by some organizations, more efforts are needed to establish a positive trusting relationship between the community and the UHARP team so that the community can express their interests freely to the UHARP team and they can work together to meet the needs. CHAs need further training and supportive supervision so that they are able to reach out to all sections of the community. Structural barriers like timings and transportation should be accounted for.

This study demonstrates the important role of family support and extra assistance needed for the especially vulnerable elderly patient population. It also shows that perception of generic medicines and attitude about one's own health are crucial factors in utilization of health services. Therefore, this calls for extensive efforts from all sectors (private and public) to change the mindset of not only the patient population but also the healthcare providers.

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APPENDIX 1: *Topic Guide for in-depth interviews*

1. Self Introduction

Introduce myself and briefly explain the study. Inform them about their rights as voluntary participants of the study and make sure they are comfortable to start the interview.

2. Patient history of diabetes and hypertension

Question: I am aware that you have diabetes (and/or hypertension). Can you tell me more about it?

Probes:

- For how long have you had the disease?
- What were your initial symptoms?
- Who diagnosed you and where?
- How many doctors did you go to before being diagnosed?
- Which clinic do you go to?
- Who is your doctor?
- Where do you get your blood sugar levels checked?
- How far is the clinic/diagnostic center from your house?
- Do you go to the same clinic/doctor/diagnostic center everytime?
- How often do you see the doctor?
 - When was the last time you saw the doctor?
- Do you go to the doctor for follow up as suggested by her or him?
- Are you currently taking any medicines?
 - If not, what are the reasons?
 - If yes, what are the medicines? If you have the necessary medicines with you NOW, can you please show them to me?
- Do you take the medicines regularly?
 - If not, what are the reasons?
- Where do you buy the medicines?
- How much do you spend on the medicines per week/per month?
- How do you manage to pay for these medicines? Where do you get this money?
- How much do you spend per month in total for your diabetes/hypertension care? This includes consultation fees, lab tests, travel costs and other miscellaneous expenses.
- Have you been admitted to any hospital with diabetes or hypertension? If yes, please provide the details.
- Does anyone in your family have the disease?
- How often do you eat in a day? (explore diet)

- At what times do you eat breakfast, lunch and dinner?
- Do you eat in-between?
- How often do you eat non-veg food/fried food/sweets?
- What do you usually eat and what do you avoid?
- What do you do for exercise?
 - How often do you exercise?
 - For how long?
- What do you do when you are stressed?

3. Awareness about the IPH clinic

Question: Have you heard of the IPH clinic? Can you tell me what you know about it?

Probes:

- Who told you about the clinic? Where did you find out about the clinic?
- Where is the clinic located?
- What are the timings?
- Who treats you there? (doctors, nurses etc)
 - What do you know about the doctors at the clinic? (MBBS, Ayurvedetc)
- What are the services offered in the clinic?
 - Do you know that you will be given a health card?
 - If yes, what do you know about the benefits of the health card?
 - Do you know that medicines are also dispensed?
 - If yes, what do you know about the medicines that are dispensed? (Branded, generic etc)
 - Do you know if counseling is provided?
- Do you know that you are entitled to get all this for free?

4. Reasons for not utilizing the IPH clinic:

Question: It looks like you are not coming to the IPH clinic. Are there any reasons for not utilizing the services?

Probes:

- How far is the IPH clinic from your house? (Explore physical barriers)
 - (if they say distance is a problem) If the Community Health Workers (CHWs) deliver the medicines every month to your house and you come to the clinic ONLY once in 3 months, what do you think about it?
- What do you feel about the IPH clinic timings?(Explore physical barriers)
- What do you feel about the medicines that are dispensed in the IPH clinic?

- What is your opinion on low-cost medicines?
 - What do you know about generic medicines?
 - Have you used generic medicines before? If yes, what has been your experience?
- Do you know the building in which the IPH clinic is located? (If yes, ask the following)
 - Do you know who is in charge of the building? (Explore political/cultural barriers)
 - Do you know that there is a dialysis center in the same building?
 - What do you feel about having two centers – the IPH clinic and the dialysis center in the same building?
- (If patient is going to another clinic) What are the reasons that you go to 'x' clinic and not go to the IPH clinic?
- (If patient had been to IPH clinic before and is now going to another clinic) What made you shift from the IPH clinic to your current clinic?
 - What do you feel about the IPH clinic when compared to your current clinic?
 - What do you like and dislike about your current clinic?
 - What do you feel about the doctors in your clinic when compared to the IPH clinic?
 - What are the services in your current clinic that are not available in the IPH clinic? What do you like about these services?
 - What are the services in the IPH clinic that are not available in your current clinic? What do you like about these services?
 - How do you cope with the extra expenses of your current clinic when compared to the IPH clinic?
- What does your family feel about the IPH clinic? (Explore familial barriers)
 - Does your husband/children/other family member approve of you going to the IPH clinic?

5. Suggestions

- **Question:** You mentioned certain positives and certain negatives about the IPH clinic (Summarize them). Can you please tell us how we can improve the clinic?

Probes:

- What should we do in the community to increase awareness about the clinic?
- What other services would you like? (Ask for suggestion both inside and outside the clinic)
- How can we help you in the long-term to manage your disease?
- Is there anything else we can do at the community level to help people with diabetes and hypertension?

APPENDIX 2: Participation Information Sheet

Title: Understanding the barriers experienced by the people of an urban slum in Bangalore to utilize primary diabetes and hypertension care in the Institute of Public Health (IPH) Clinic

My name is AnushaPurushotham. I am a student of the Community Health Learning Programme in an NGO called SOCHARA (Society for Community Health Awareness, Research and Action) in Bangalore. As part of this programme, I am conducting a research study along with the Institute of Public Health (IPH) in your area to understand more about people living with diabetes ("sugar") and hypertension ("BP"). I would like to kindly request your permission to participate in this study.

This note provides an explanation of the nature of the research. This sheet may contain words that you do not understand. If there is anything you need clarity on, please feel free to ask me. At the end of this information sheet you will find my contact details.

Non-communicable diseases (NCDs) like diabetes ("sugar") and hypertension ("BP") have increased over the past few years. People with these diseases face many problems in managing their care because of several reasons. One such reason is the high-cost of treatment. I would like to understand why people who are eligible for free services and medicines for diabetes and hypertension in the IPH clinic are still not going to the clinic.

I would like to ask you a few questions about the history of your disease, your past and current experiences in different clinics/hospitals and your opinions about the IPH clinic. Your answers will be extremely important in helping us understand the reasons that prevent people from utilizing health care.

The questions can be very personal in nature and you can refuse to answer them if you do not feel comfortable. Your participation in the study is voluntary and you can withdraw at any time during the interview. You do not have to give any reasons for not answering questions or withdrawing from the interview.

The interview will be approximately 15-20 minutes long. With your permission, I will record the interview on a digital voice recorder. If you are not comfortable with this, please let me know and I can record the interview in writing instead. Also, with your consent, your words will be reproduced verbatim for the purposes of creating a report that may be published. I assure you that everything you say will be confidential and your identity will be protected. All confidential data will be handled only by me and the research team at the Institute of Public Health. All the information you provide will be used only for present and future research purposes. If the information is published, any details that identify you will not be made public. You have the right to view the information we collect from you and also the right to deny usage of your details at any time.

There are minimal risks in participating in the study. Absolutely no physical risks are involved and the interview will be conducted with utmost respect to your privacy. You will not receive any resource benefits for participating in the study. However, the information you provide might help us offer suggestions to improve the services in your area.

Your consent is required for your participation in the study. You can decide to participate or not. You will be given a consent form to sign before the interview. Please let me know if you have any questions or concerns. I will happy to answer them.

For further information or clarification, please contact us as follows –

AnushaPurushotham, Phone: +91- 9740396872

Dr.Mrunalini, Phone: +91-9611260563

Email: mail@iphindia.org

Postal address: 250, 2C Main Road, 2C Cross, Girinagar 1st phase, Bangalore - 560062

Thank you for your time. This sheet is for you to keep.

APPENDIX 3: *Participant Consent Form*

Title: Understanding the barriers experienced by the people of an urban slum in Bangalore to utilize primary diabetes and hypertension care in the Institute of Public Health (IPH) Clinic

I have read and understood the participation information sheet (or it has been read to me). I understand that it involves me taking part in an interview. I have been explained the purpose and procedure of the study. I have been informed that there will be no direct benefits for me. I understand that the information I will provide is confidential and will not be disclosed to any other party or in any reports that could lead to my identification. I also have been informed that the data from study can be used for preparing reports and that reports will not contain my name or identification characteristics. I have been provided with the name and contact details of the researcher whom I can contact. All my questions have been answered to my satisfaction. I had enough time to decide whether I am going to participate or not. I know that I am participating as a volunteer and I can step out of the program whenever I want and it is not necessary to give an explanation. I know that research team will see my details. I give consent for my details to be used for the research purposes mentioned in this form. All information regarding consent and purpose of the study has been explained to me in the language I understand.

I provide consent to the following-

- | | | |
|---|------------------------------|-----------------------------|
| • Participation in the in-depth interview: | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| • Audio-recording of the in-depth interview: | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| • Publishing of words/sentences spoken in interview verbatim: | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

.....
Name of Research Participant

.....
Name of Researcher

.....
Signature of Research Participant

.....
Signature of Researcher

Date

Date

If illiterate

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Name of witness _____

Thumb print of participant

Signature of witness _____



Name of participant _____

Date _____

REVOCATION OF CONSENT

I hereby wish to **WITHDRAW** my consent to participate in the study described above and understand that such withdrawal **WILL NOT** jeopardise my relationship with the Institute of Public Health.

Signature of participant

Name of Participant

Date

OR

Thumb print of participant

Name of Participant

Name of Witness

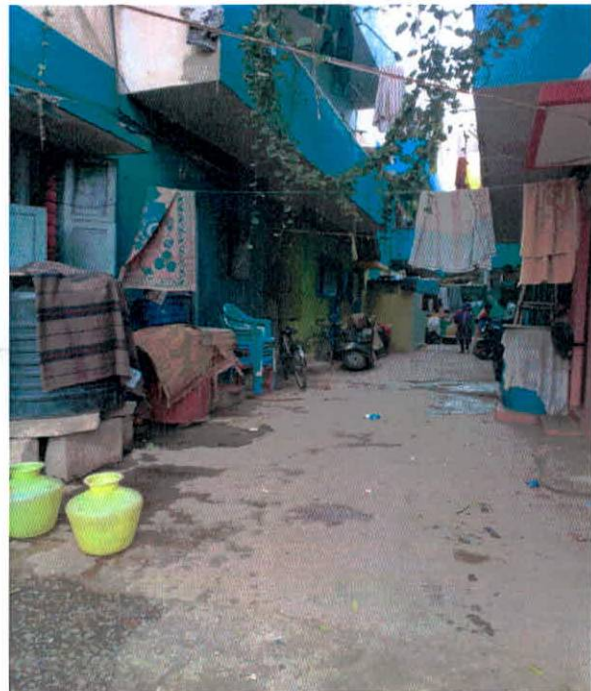
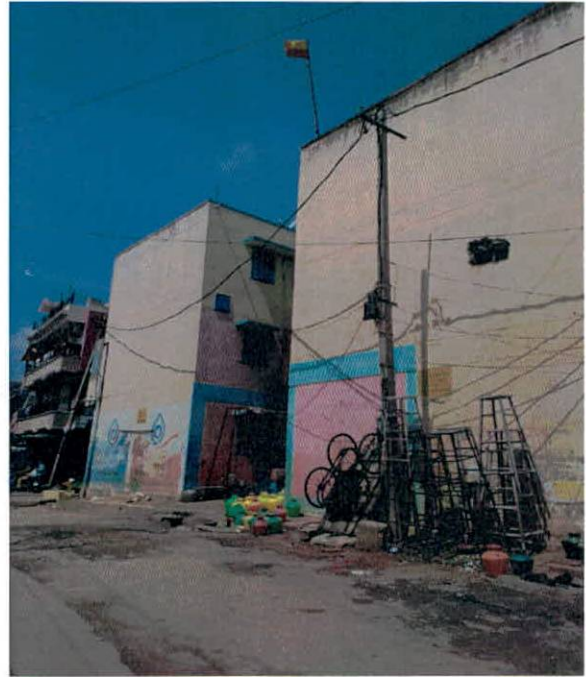


Signature of Witness

Date

APPENDIX 4: *Snapshots from the field*

Snapshots of Slum A



Generic medicines stock in
the IPH Clinic



Dispensing generic
medicines in the IPH
clinic



A private School in KG Halli



Aerial view of a neighbourhood in KG Halli



Street view of a neighbourhood in KG Halli



Corporation quarters: A former slum in KG Halli that was razed down and replaced by building quarters



5. THE ST. JOHNS RESEARCH INSTITUTE EXPERIENCE: FINAL FIELD PROJECT

For my final field project, I decided to observe communities with whom the Prospective Urban Rural Epidemiological (PURE) study team at St. Johns Research Institute (SJRI) works with. PURE study is a large-scale (involving 17 countries) prospective cohort study that was started in 2001 to find out the occurrence of chronic non-communicable diseases (myocardial infarction, stroke, cardiac failure) in middle-aged adults (35-70 years) and their underlying physical, biological and behavioural risk factors.

I was primarily interested in the study because it looks at how environment influences lifestyle choices. It measures four levels of risk factors:

- societal determinants (built environment, nutrition and food policy, tobacco environment, psychosocial/socioeconomic factors)
- household factors (family structure, socioeconomic status)
- behaviours (smoking, physical activity, diet)
- biological risk factors (Hypertension, Diabetes Mellitus, Obesity)

In India, there are 5 study sites – Bangalore, Thiruvananthapuram, Chennai, Jaipur and Chandigarh. SJRI is the national coordinating center and coordinates the data collection in Bangalore Urban and Palamner in Rural Andhra Pradesh.

I joined the Bangalore Urban study team when they had just begun their 2nd re-survey (1st re-survey was done in 2008-2012). This survey included a household questionnaire, health systems questionnaire (about health care accessibility and payment) and a cognitive questionnaire (Montreal Cognitive Assessment). The team covered 7 slums and 1 middle class neighbourhood totaling to a population of 3400 participants.

I visited 2 slums with the team and informally interviewed 10 study participants after the PURE Study team completed their individual surveys. All the study participants whom I interviewed were women, mostly elderly. Therefore, my field observations cannot be generalized to both the genders.

My field observations were as follows:

- Most of the elderly women lived with their husbands or alone. Among those who were living with their children, few lived in a separate room where they did their own cooking and some lived in a room outside the main house.
- Most of their grandchildren (both girls and boys) went to school and stayed with them during the day when their parents were at work. There were very few children who were not allowed to go to school or dropped out of school.
- Among the women whom I interviewed, even the ones with hypertension, paid little attention to their diet and physical exercise. Some of them were domestic workers and hence, felt they did not need any exercise.

- Most women complained of body pains which could be psychosomatic. They either seek help from the doctor or take over the counter medicines from the pharmacy.
- The elderly women who stayed at home alone spent time either talking to neighbours or watching TV. They reported feeling lonely and stressed.
- The elderly women who stayed with their children, spent time looking after their grandchildren. Although they complained of some neglect from their children, they did not report feeling lonely.
- When asked to answer the MOCA – Montreal Cognitive Assessment Questionnaire, women were extremely shy at first and later would start clapping their hands, get involved in answering and enjoyed themselves. It was a positive sight.

With respect to their health-seeking behaviour, the following themes emerged:

- Health literacy with respect to medication and prognosis was generally poor. However, everyone who was interviewed was able to identify the illness (diagnosis) they had.
- Some knowledge regarding diet and exercise was present but most of them did not follow any particular diet or exercise regimen.
- Family structure and financial dependence on children was an important factor in the choice of the health facility the women visited.
- Most participants preferred going to a private doctor. When asked the reason, the most common answer was that they trusted the doctor as he was their family doctor and was located close to their house.
- Others reported going to Bowring Hospital (government) and St. Johns Hospital (private charitable)

After reflecting upon my experiences in the field, I realized that the PURE study had a very limited approach in understanding risk factors of non-communicable diseases. Although it attempted to measure societal determinants, it still took on a community medicine approach: screening, early diagnosis and treatment was the primary goal in addition to informing policy changes at a later stage. Also, the study team visited the slums only during data collection and a medical camp would be conducted at the end of it. There were no other community activities in the interim period. Dr. Prem Mony, the Principal Investigator from SJRI too acknowledged the limitations of such a large study and expressed interest in looking at a community health approach. However, due to time constraints, I could not explore further.

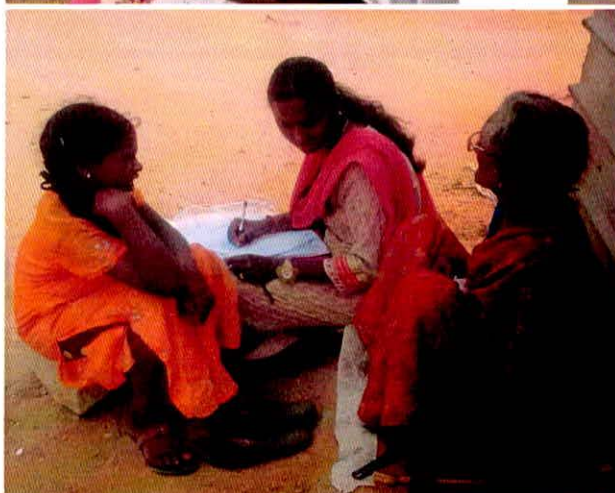
With the help of Dr. Ravi, I was able to understand the difference between community medicine and community health. Community medicine makes decisions for the community and later looks at ways for involving them into their programme (ex. NPCDCS – National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular diseases and Stroke). On the contrary, community health starts and ends with the community at every step. While community medicine focuses on screening, treatment, awareness creation about diet and lifestyle changes, community health focuses on understanding the needs of the affected individuals and their families. It creates support groups for caregivers and

individuals, looks at ways for home-based treatments, attempts to fix the Public Distribution System (PDS) to meet dietary needs, provides systems for emotional/psychological counseling to the affected individuals and focuses on other social actions.

My last two field experiences – at the Institute of Public Health and St. Johns Research Institute, helped me understand the difference between public health and community health. Public Health tends to be top down where experts decide what the community needs are and then proceed to interventions. Therefore, the approach is not very effective for all health situations, especially in non-emergency situations like chronic disease prevention because the community lacks ownership and their actual voices are not heard.

These experiences have thrown light on the huge need for community health action in chronic disease prevention and management.

SNAPSHOTS FROM THE FIELD



6. CONFERENCES, FIELD VISITS

AND MORE...

FIELD VISITS

- FIELD VISITS TO SAKALWARA PHC AND NIMHANS CENTER FOR WELLBEING
- SOCIAL MAPPING/PREFERENTIAL SCORING WITH THE COMMUNITY IN RAJENDRA NAGAR SLUM
- KERALA FIELD EXPOSURE VISIT
 - SHANTI PAIN AND PALLIATIVE CARE SOCIETY, WAYANAD
 - KANNUR ASSOCIATION FOR INTEGRATED RURAL ORGANIZATION AND SUPPORT, KANNUR
- SEVA-IN-ACTION
- FOUNDATION FOR REVITALIZATION OF LOCAL HEALTH TRADITIONS
- MILANA
- SNEHADAN

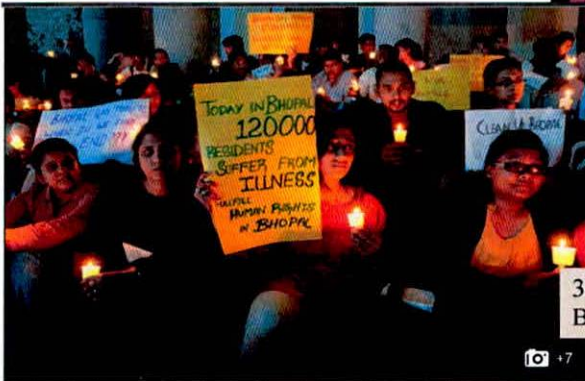
CONFERENCES/WORKSHOPS/EVENTS

- INAUGURATION OF THE NATIONAL URBAN HEALTH MISSION
- 5TH NATIONAL BIOETHICS CONFERENCE - 'INTEGRITY IN MEDICAL CARE, PUBLIC HEALTH AND HEALTHCARE RESEARCH', BENGALURU
- 1ST YOUNG ENVIRONMENTAL HEALTH RESEARCHERS MEET, BENGALURU
- SOCHARA – CEU 10TH ANNIVERSARY, CHENNAI
- MEDICO FRIENDS CIRCLE 41ST ANNUAL MEET - 'MENTAL HEALTH, RIGHTS AND CARE', PUNE

PROTESTS

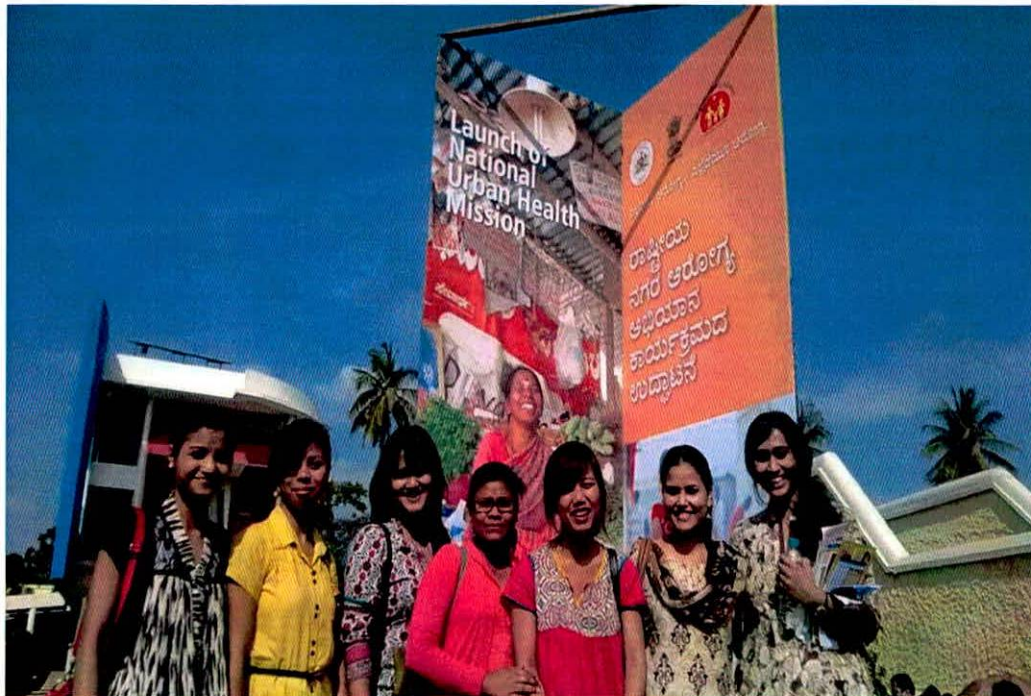
- 'MARCH AGAINST MONSANTO'
- SOLIDARITY CANDLE LIGHT PROTEST ON THE 30TH ANNIVERSARY OF THE BHOPAL GAS TRAGEDY

MARCH AGAINST MONSANTO



30TH ANNIVERSARY OF BHOPAL GAS TRAGEDY

Members of student groups and activists of social organizations participate in a candle light vigil to express solidarity with the Bhopal gas tragedy survivors on the eve of its 30th anniversary in Bangalore, India, Tuesday, Dec. 2, 2014. Thousands of people died after a cloud of methyl isocyanate gas on Dec. 3, 1984, escaped from a pesticide plant operated by a Union Carbide subsidiary in Bhopal in central India, affecting the lives of many. (AP Photo/Ajaz Rahn)



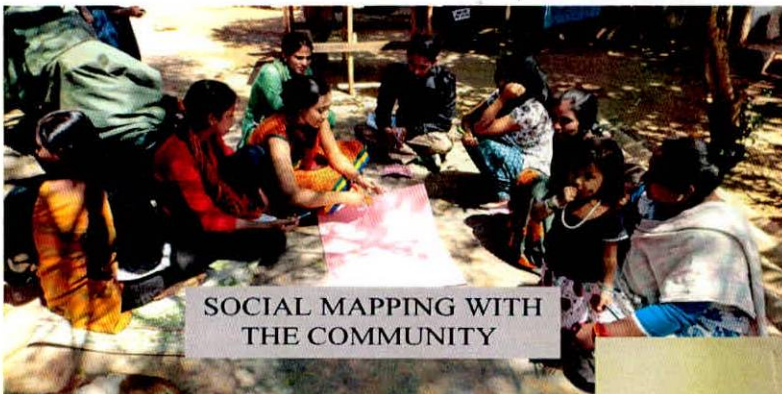
INAUGURATION OF NUHM



SAKALWARA
PHC



NIMHANS WELLNESS
CENTER



SOCIAL MAPPING WITH
THE COMMUNITY



SHANTI PAIN AND PALLIATIVE
CENTER IN WAYANAD, KERALA



1ST YEHR MEET

5th NBC



41st MFC

41st MFC



7. REFLECTIONS ON COMMUNITY HEALTH

Human beings are social animals. Much of our early history points to interdependence on each other for survival. Indigenous (or tribal) groups, even in the present day, are largely collective and cohesive societies that live in harmony with the natural world. The concept of community and the ability to relate to one another, therefore, is ingrained in our being. Connectedness with each other and all aspects of nature not only benefits the larger community but also ensures our own wellbeing. It is an integral part of being human.

However, much of the modern world has been driven by individual interests outweighing the collective good of the society. Interests of the few are overshadowing the interests of the many. The larger neo-liberal economic and political forces are slowly eroding the sense of community among people and replacing them with individualism. Accumulation of more and more material wealth is portrayed as a surefire way to happiness. This has led to unfair distribution of power, wealth and resources, which has created an unjust socio-economic system that has in turn resulted in health inequities.

What happened to the powerful Alma Ata Declaration that called for 'Health for All' by 2000 A.D? Thirty nine years have passed since and the health inequities are only growing larger. Fortunately, there have been alternative processes and people's movements across the globe that have challenged the ill-effects of the neo-liberal globalization.

One such movement is the Global People's Health Movement that was launched in 2000 with the vision, "Equity, ecologically-sustainable development and peace are at the heart of our vision of a better world - a world in which a healthy life for all is a reality; a world that respects, appreciates and celebrates all life and diversity; a world that enables the flowering of people's talents and abilities to enrich each other; a world in which people's voices guide the decisions that shape our lives...." (Source: People's Charter for Health, 2000). In India, the People's Health Movement was named as Jan Swasthya Abhiyan (JSA) and one of the strongest pillars of this movement has been the Society for Community Health Awareness, Research and Action (SOCHARA).

My introduction to SOCHARA in the year 2014 could not have come at a better time. I had always been interested in understanding how science could solve the problems related to the quality of human life. Well into my undergraduate education in Molecular Biology, I realized that these questions could not be tackled by arming myself with biomedical scientific knowledge alone. My further work experiences in the United States healthcare system revealed that neither healthcare service delivery nor biomedical research can adequately solve the health challenges of people. The holistic understanding of 'patients' as 'people' is often lost in these models of care. The biology of their disease becomes more important than the psychosocial, economic, cultural and environmental factors influencing their health.

It was at SOCHARA and through the alternative framework of community health that I was finally able to start finding explanations to the questions that I had long been asking about the stark disparities in opportunities for people to live a fulfilling, healthy life with dignity. I gained a deeper understanding of

health as more than just physical health. Health is a composite of physical, emotional, psychological, social and spiritual wellbeing that is influenced by individual, societal and global factors.

Community health, to me, has various connotations. On a personal level, I have found communities to be healing. Communities - be it family, friends, colleagues, neighbours or any group of people with shared interests - provide a sense of belonging. When space is provided for people to express themselves and when there is acceptance by their community, the well-being of individuals is greatly improved. In turn, the individuals develop a sense of responsibility towards the community as a result of enjoying their rights. During my field experiences working with diverse communities across Bengaluru City and field visits in Karnataka and Kerala, I have found this to be true time and again. People from communities that are built on trust, mutual understanding and shared concerns for each other are healthier and more resilient than others, especially in times of adversity.

On a professional level, I view community health as an alternative approach to the current dominant myopic biomedical model of health that commercializes human distress. Community health enables and empowers people to take care of their own health and increases individual, family and community autonomy over health and over organizations, means, opportunities, knowledge and supportive structures that make health possible (Community Health Cell, 1987).

Based on my readings and field experiences, I can summarize the community health approach into the following broad categories:

- 1. Breaking down of hierarchical structures, and bringing 'community' back into 'community health' and 'public' back into 'public health'**

The present biomedical superstructure of healthcare is highlighted by over-professionalization and compartmentalization where the doctor/healthcare institute wields control over the decision-making responsibilities and people are seen as passive recipients of care. This hierarchical structure is created with the intent of protecting the power and commercial interests of those at the top.

One of the biggest obstacles to an equitable and healthy society is commercialization of health. In the presence of a profit-margin, health becomes a commodity and people become consumers. Market logic dictates that information asymmetry is an important tool in creating a demand for the product – in this case, health. Thereby, the drive for the corporate health sector is to tightly protect health information/technology/skills and market drugs/advanced healthcare technology as the main solutions for all health problems. This invariably creates an atmosphere of dependence on the health sector by the public, who view themselves as mere consumers without any autonomy or understanding of their own health.

Community health challenges this asymmetrical power relationship between the doctor/health institute and patient by empowering people with the awareness to make informed choices about their own health. An example of this is the success of the National Health Mission (NHM) in India, which has a strong emphasis on community participation in the public health system.

Communities are involved in the planning, decision-making, implementation and monitoring of the health systems through various mechanisms, including the creation of Village Health, Sanitation and Nutrition Committees (VHSNCs), Rogi Kalyan Samitis (Patient Welfare Committees) and introduction of ASHAs (Accredited Social Health Activists).

Urban-ASHAs of the NUHM (National Urban Health Mission) and Mahila Arogya Samitis (MAS) have contributed to the success of the NUHM in terms of improved health status of the communities as well as increased accountability of the health system. My interactions with Urban Ashas in Bengaluru and MAS in Raipur have solidified my belief in a democratic, participatory and non-hierarchical government-run health system for health equity and justice.

2. Rights-based approach to health

Article 3 of the Universal Declaration of Human Rights (UDHR) states, "Everyone has the right to life, liberty and security of person." Although 'Right to Health' is not stated as a constitutional right in the Indian Constitution, India has ratified the UDHR, which means every Indian citizen has the right to life, which in turn necessitates the right to health (including the right to social determinants of health). With this approach, people can demand health as a right without any discrimination against caste, class, gender, economic status or religion.

The Constitution of India also recognizes Government's duty to ensure people's health, "The State shall regard the raising of the level of nutrition and the standard of living of its people and the improvement of public health as among its primary duties." Therefore, health action requires awareness about one's own rights and the government's responsibility in enabling people to live healthier lives.

During my fellowship at SOCHARA, I participated in protests/rallies against Genetically Modified Food and the Bhopal Gas Tragedy. During these events, I could experience first-hand, the energy of people's movements and how strong community voices can influence policies. An example of this is the recent plastic-ban in Bengaluru that was the result of a strong citizen's movement calling for a healthy environment by reducing plastic waste.

3. Enhancing the sense of community

The highly iniquitous nature of society, especially Indian society that is entrenched in caste and religion, makes it harder for people to consider themselves belonging to the same community. Therefore, the community health approach involves building communities on their commonalities and strengths. When I was at Headstreams during my first field placement working with women's livelihood programmes, the women of the Self-Help Groups (SHGs) came from different religions, linguistic backgrounds and occupations. However, the common glue that held them together was their interest in financial self-sufficiency, motivation to take care of their families through better management of their finances and overall improvement in their self-confidence.

As a result of regular meetings and interactions, the women were able to break barriers of caste and religion to come together based on their shared interests. They worked as a single group to help each other solve their familial problems as well as problems within their neighbourhoods. The women from some self-help groups even supported each other to start their own small businesses including tailoring shops and food catering business. This created a sense of community that enabled the women to not only bond with each other and increase a sense of security but it also gave them the confidence to organize themselves to fight for their rights.

4. Demystification of health

For equal participation in health action, knowledge about health concepts needs to be widely shared among people in a language that is simple, easy to understand and succinct. In the biomedical model, information is not readily shared within the professional community, let alone the larger public. Even the limited information that is shared is usually full of jargon and mostly in English, thereby excluding a large proportion of Indian citizens. With the advent of peer-reviewed limited access journals, patents and intellectual property rights, knowledge-sharing is even more commercialized. Only those within the medical community and with access to monetary resources can access this information.

Community health aims to demystify knowledge about medicine and other health concepts by creating awareness among communities using local language and media like street plays, songs, and public announcements by teachers, panchayat members or other local leaders. Health education should also be included as part of the school curriculum and education materials in the form of pamphlets, booklets or handbooks should be easily available.

A prime example of this community health approach is the training of ASHAs under the NHM. ASHAs are women from the communities (villages or urban areas including slums) who have basic educational qualifications (literate and in some cases, up to 10th standard). They are trained to recognize common ailments and provide basic level of care using the drugs and equipment provided in their drug kits (paracetamol, folic acid, ORS, bandages etc).

Among the other skills, ASHAs also assist with delivery and care of newborns. ASHAs are well informed about the symptoms of various disease conditions, the services available in each health center and the latest government health schemes. They are able to recognize and refer people to the appropriate health centers based on their health conditions. The biggest strength of ASHA is her accountability as a member of the same community. She is able to closely interact with members of each household, especially women and teach the skills/knowledge that she has acquired.

Empowering people with the right knowledge about health and resources available to remedy health problems will ensure that they have more power as well as responsibility to make informed decisions.

5. Focus on a new social paradigm of health

Community health shifts the paradigm from an intracellularist to a balloonist view of health. We move from differential diagnosis to a community diagnosis of a health problem. A community diagnosis involves understanding the social, economic, political, cultural, ecological determinants of a health problem. Thereby, community health practice involves adopting various socio-economic-political-cultural-economic processes to address the multidimensional causes of health issues.

My first experiential learning in this model of health came during my fieldwork at Headstreams. Fresh from a biomedical research setting, I didn't understand why I was doing my field placement in an organization that works on women's livelihood and children's education. The first two weeks were very confusing. I didn't quite understand why teaching women how to maintaining a savings account or balance a cheque book related to health in any way or form. After one month, I slowly began to understand how economic independence had a direct impact on physical and mental health.

Many women, prior to joining the Self-Help Groups (SHGs) had very little awareness about their rights as 'women' or 'as employees' or as 'citizens.' They were employed as domestic help or construction workers and many were exploited both at home and at the workplace. The Headstreams SHGs provided them with a safe space to express themselves as individuals and share their problems. Equipped with a new social support mechanism as well as awareness about their own rights, they began to take small strides to improve their quality of life. They demanded better pay and working conditions. They also began to avail the various schemes of the government, including the Right to Education for their children and the Janani Suraksha Yojana during pregnancy. The savings scheme of the SHG helped protect their small investments from either their exploitative husbands or other family members. They also exercised their political right to vote during elections and some women, even went on to become local leaders within their communities. This financial security combined with social/emotional support from their fellow SHG members greatly improved their overall wellbeing.

6. Emphasis on prevention of diseases and promotion of health

Curative healthcare services are towards the tail end of the spectrum of health. It can be compared to mopping a floor in a room that is flooded with water due to a leaky tap (Source: Dr. Ravi Narayan). Our goal, in community health, is to not mop the floor but instead fix the leaky tap, which is the root cause of the problem.

As mentioned before, a healthy community needs more than just good doctors and healthcare facilities. In order to prevent diseases and promote health, we need to focus on ensuring all people have adequate nutrition, quality education, appropriate livelihoods, safe housing, clean drinking water and sanitation facilities, proper waste management, pollution free-environment and awareness about their rights/responsibilities. This calls for intersectoral collaboration

between the different departments within the government as well as partnership between public and private institutes from various disciplines.

The close association between ASHAs/ANMs/Medical Officers of the NHM and Anganwadi Workers (AWW) of the Ministry of Women and Child Development in Anganwadis, whose main focus is early childhood development and nutrition of mothers and children is evidence that health promotion and disease prevention requires an integrated approach.

7. Use of local knowledge, traditions and resources

Much of the biomedical model does not take into account people's traditional knowledge. Western medicine tends to dismiss any other knowledge system that does not conform to the concept of 'scientific evidence.' Community health approach, on the other hand, acknowledges the presence of local traditional knowledge that has predated some of the western medicine. Alternative medical systems such as Ayurveda, Yoga, Unani, Siddha and Homeopathy (AYUSH) are now formally recognized under the Department of AYUSH, Government of India.

Studies conducted by the Foundation of Revitalization of Local Health Traditions (FRLHT) in Bengaluru have shown modern scientific evidence to some of the undocumented local traditional practices, like how the use of copper pots for storing drinking water is beneficial because of the antimicrobial properties of copper. Similarly, many community health projects like the Association of Northeast Trust (ANT), which works on community mental health in Assam has respected the space of traditional healers. In their experience, common mental disorders like depression and anxiety are better handled by traditional healers because the community has tremendous faith in them. When patients with complex mental disorders go to traditional healers, they are referred to ANT which has psychologists, psychiatrists and psychotropic medicines. By recognizing and embracing the local practices, ANT has successfully included traditional healers as part of the health process and experienced better prognosis in the communities they work with.

8. Linking with other social movements to enable 'Health For All'

'Health For All' requires that the People's Health Movement to join hands with other social movements like the environment movement, science movement, education movement, women's rights movement, anti-war and peace movement to name a few. All these movements are based on similar philosophical values and challenge the current neo-liberal agenda that have led to an inequitable society. Joining forces will enable 'Health For All' to become our reality in the near future.

8. REFLECTIONS FROM THE JOURNEY

When I first joined the Community Health Fellowship Programme in January of 2014 as a flexi-fellow, I was extremely confused about my career. I found it oddly reassuring that both Dr. Thelma and Dr. Ravi told me the same thing: "It is good to be confused. It means that you are thinking!" It was refreshing to be surrounded by individuals from such eclectic backgrounds who had found their calling in community health. After a long time, I slowly found myself feeling like I belonged to this group: my co-fellows, facilitators, mentors and staff became my extended family.

The serendipitous journey, which started in January, continued beyond June when I got the opportunity to stay as a full-time fellow for 12 more months. I feel incredibly fortunate to be one of the few people who could continue their community health journey at SOCHARA for such an extended period of time. Not only did I have the flexibility of transitioning from a part-time to a full-time fellow, I also got the chance to meet fellows from three batches (10,11 and 12) who came from various geographic and professional backgrounds. It was truly enriching to learn from their diverse individual experiences.

The challenges of my fellowship were mostly during my last two field placements. I began to realize how there was a mismatch between the work of the organizations and the community needs. Considering that both these organizations were primarily research institutes, they scrupulously followed the stipulated biomedical and public health ethical guidelines. However, I felt that there were certain unwritten ethics that were being violated. Although the projects were initiated with good intentions, they were top-down and conducted with the assumption that they (experts/previous research evidence) knew what was best for the community instead of engaging with community early in the decision-making process. Also, once the research project was completed, the results were not shared with the community themselves. These experiences made me appreciate the values instilled in me by the CHLP and understand how to conduct community health research for social change in the future.

I learned and unlearned many things in the programme. The biggest lesson was to do away with all professional titles, preconceived notions and understand that we are all part of the same family – "Vasudhaiva Kutumbakam." This sense became even stronger when I saw both Dr. Ravi and Dr. Thelma address and treat everyone, including us fellows as equals. SOCHARA is a unique organization with the least hierarchy. The fact that the principles and values of community health are reflected in the organization adds more credibility to the idea of community health. The second most important lesson was "learning by doing": to learn what was discussed in collective sessions by experiencing it ourselves on the field was very unique. The encouragement to think critically and question without accepting anything at face value was extremely liberating and made for some lively debates. The session on inside learning, to reflect whether we truly practice what we believe in and the message "Only if you can live the values of the society you want to build, can you be successful" was truly inspirational.

It is not easy to summarize all the learnings from my one and half year experience in the community health learning programme. However, this report is an attempt to give a glimpse of the wonderful journey that has led me to discover myself through the community around me.

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