“Is it even giving the correct reading or not?”: How Trust and Relationships Mediate Chronic Disease Management in India

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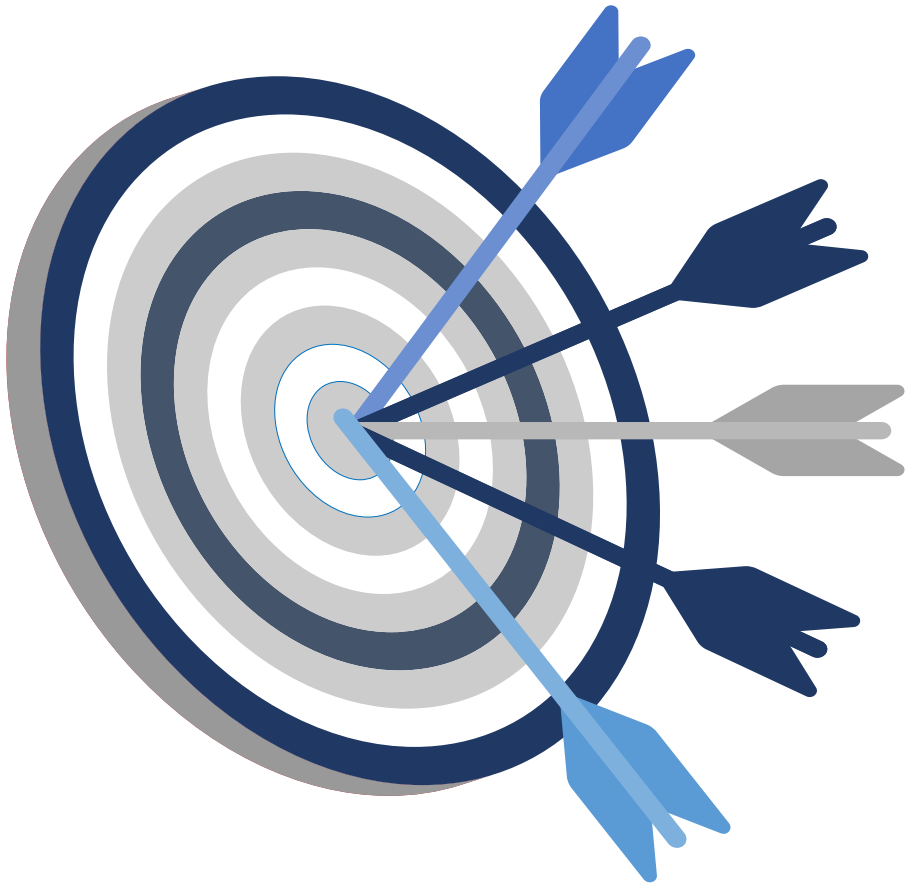
Aim : To understand the ecosystem of blood pressure management in low-resourced Indian communities

Motivation

1. Chronic NCD are leading cause of death
2. Highest burden in the Global South
3. Research in Global North outlines context-specific technological solution
4. Research in Global South focuses on the perception of chronic disease

Goals

To investigate the BP management practices among low-resourced communities of India to better understand:



a) their beliefs and perceptions of chronic disease

b) their trust in existing infrastructure

c) use of technology

d) the interplay of socio-cultural and economic factors

e) adopted strategy for managing chronic health conditions

Methodology

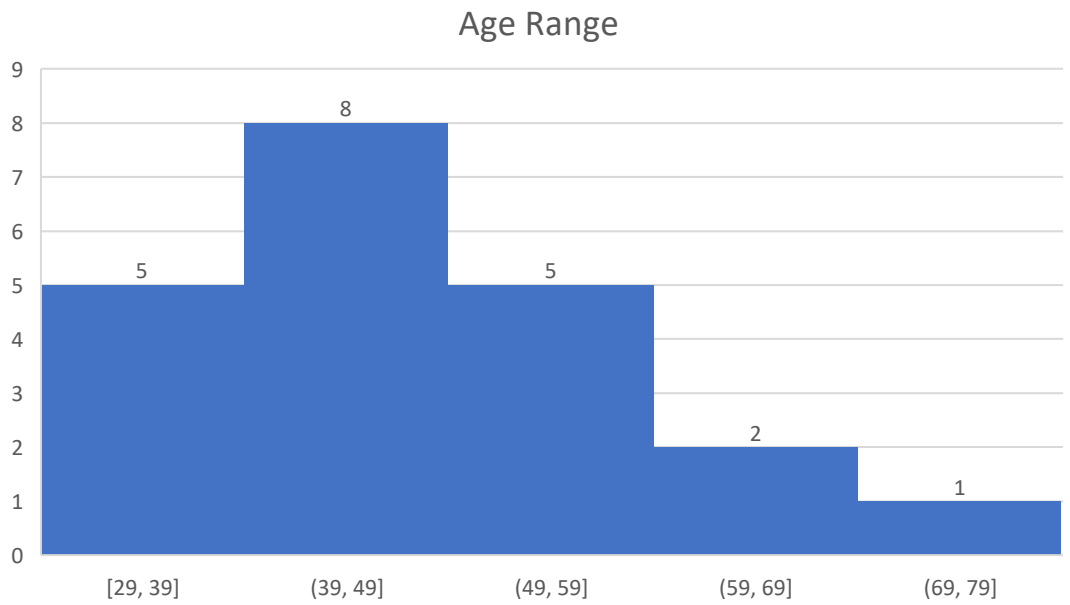
Methodology used:

- Qualitative research methodology, 21 semi-structured interview
- Telephonic interview
- 45 mins- 60 mins

Inclusion Criteria :

- 18+year old
- Suffering from BP (Hypertension/Hypotension)
- Fluent in English/Hindi
- Belonging to a low-resource community

High BP	15
Low BP	6



Theme 1: Experience of living with abnormal BP

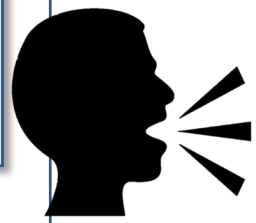
Theme 2: Trust in the care ecosystem

Theme 3:Access to care

Theme 1: Experience of living with abnormal BP

Symptoms and Diagnosis

- Hypertension is a silent killer
- diagnosis is often accidental :7/21 participants



My wife was ill, she had a mild fever, so I accompanied her... While I sat at the doctor's...I started developing a sharp sudden sensation in my legs and began feeling very anxious. My entire face was covered in sweat. I started feeling dizzy. The doctor said you might have BP, you should sit down for some time. I sat there, he checked my BP, and gave me some medicine."

-P6

Theme 1: Experience of living with abnormal BP

Treatment

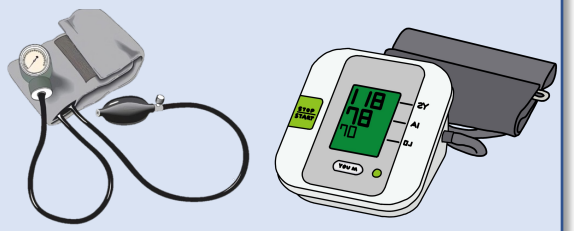
- treating chronic disease as chronic or non-chronic, based on convenience
- Walking, reducing salt: chronic
- Medicine, measuring BP regularly: non-chronic

"After waking up in the morning, I drink tea and I go for a walk. I walk for 2 to 4kms. Then I exercise and do some yoga at home…"
-P12

I can't eat chappatis (Indian flatbread) without salt. –P19

Theme 2: Trust in the care ecosystem

Trust in BP measurement.



One time, I went to hospital, the pregnant ladies were getting tested. There the gynecologist doctor said that manual BP machine is usually better." – P18.

Trust in BP reading is dependent on:

1) type of the device
- Doctors recommend manual BP devices
- discrepancies in the readings of digital BP devices

2) person measuring the BP
- Manual BP machine requires training

Theme 2: Trust in the care ecosystem

Trust in social circles

- Trust in one actor of the BP ecosystem fosters trust in another
- Medicine, BP device, Doctor's suggestion
- Harms of trusting social circle

A friend told me, take medicine from 'this doctor', he is very good. Take medicine from that hakim, he gives amazing medicine. See, the patient wants to be healed, no matter from where I take medicine or what kind of medicine I take, I want relief... So, whenever someone says that this medicine is effective, I buy it. – P1.

"I got to know yesterday that if BP is low, then one should not eat potato! Someone in my neighborhood told me, the boutique owner... He said 'Bhabhi, your BP is low, you should not eat potato.' I didn't know this."
-P13

Theme 2: Trust in the care ecosystem

Misplaced Trust

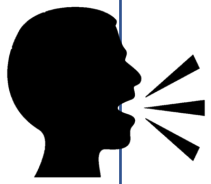
- A participant using iCare app to measure blood pressure has been found to lack clinical validation.
- was once among the 25 most popular medical apps on the App Store, with over 1M downloads and an average rating of 4.5.

"My daughter-in-law and my son measure (my BP) on their phone... They ask me to place one finger on the top of the phone and one finger on the backside. I keep my hands like this until the BP reading shows up."

-P19

Theme 3:Access to care

- patterns of both opportunistic and deliberate sharing of devices
- Existing implied social norms around the boundaries of that sharing
- Intermediate usage of BP device



"Our neighbor has a BP machine. So I went to him... But lately, my habit has gotten worse. I feel bad... like without any reason, we are going to their house daily for measurement. It is not that people don't have work... So, now I have stopped going to their house (just for measuring BP).
-P3

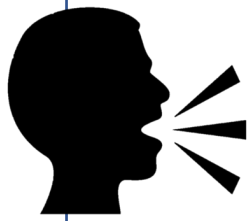
"I don't bring their machine to my home. They measure it. Their child does it, he is a 26-year-old. They tell me the BP reading. I don't know what is the range of normal, low or high BP."

-P13

Theme 3:Access to care

Hidden costs in accessing devices

- BP measurement was free of cost or low cost
- Additional cost: companion cost, transportation cost, lost wage cost
- Moral obligations to not exploit any free service
- Treating BP as a non-chronic disease



"I go by public transport (to the hospital). It takes almost 2 days of wages—the wage of the day on which I am not going to work, and another day's worth of wage is spent on conveyance... Also, when one goes to the market, expenditure happens."

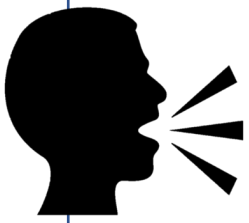
– P8.

Theme 3:Access to care

Women's access to care and Family as care giver

In-built social structures and gender dynamics strongly shape access to BP care

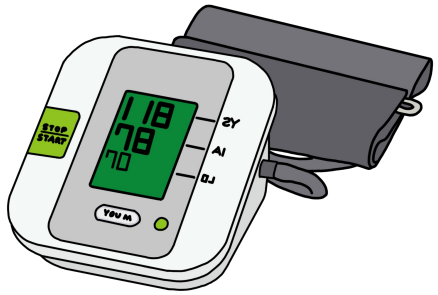
I don't have time to go to the hospital. I keep on working... I have buffaloes. I have two small kids too. The distance to the hospital is an issue... this is the third year since I was pregnant... since then, I haven't visited the hospital.
-P9

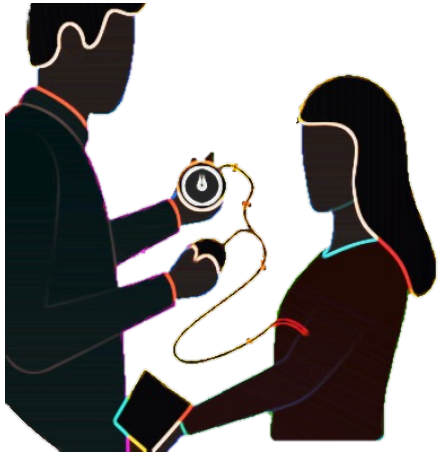


"My wife adds more salt in pulses"-P4

P3's daughter helps him tie the cuff across his hand for measurement

Discussion





- **Relationship between trust and access**
- The easier a new technology is to access, the more likely someone is to experiment and observe potential inconsistencies in the readings offered.

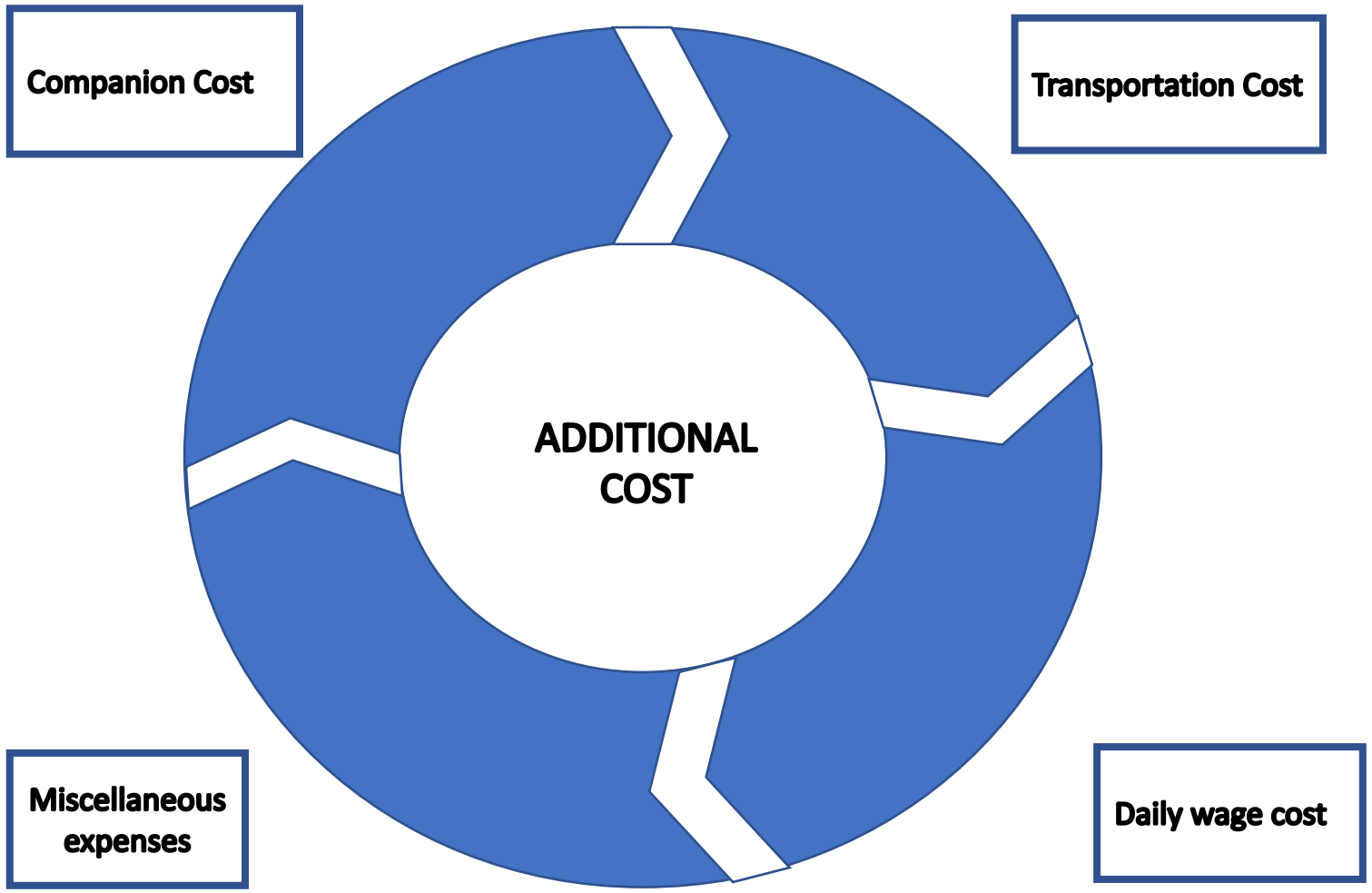
119/83 mmHg and 125/79 mmHg

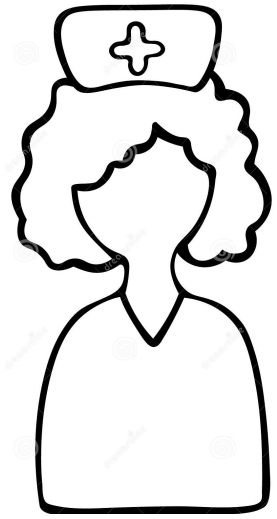
DR1: Design personal BP devices to explain and interpret data, not just measure it

Inconsistent readings lead to distrust in the BP device

Ideal device would mimic a healthcare worker's ability to interpret BP reading

DR2: Reduce total cost of accessing care





Trusted Community Health Worker

DR3: Combat interactive disinformation

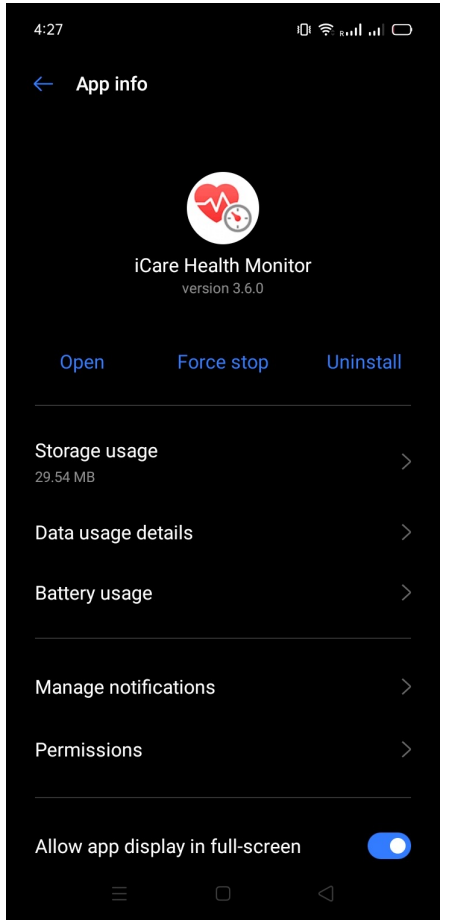
Measure blood pressure,heart rate,vision,hearing,SpO2,breath rate only by phone. Try it, please~
#health @iCareMonitor
Google Play: http://play.google.com/store/apps/details?id=comm.cchong.BloodAssistant
App Store: http://itunes.apple.com/us/app/icare-health-monitor-mobile/id1062204827

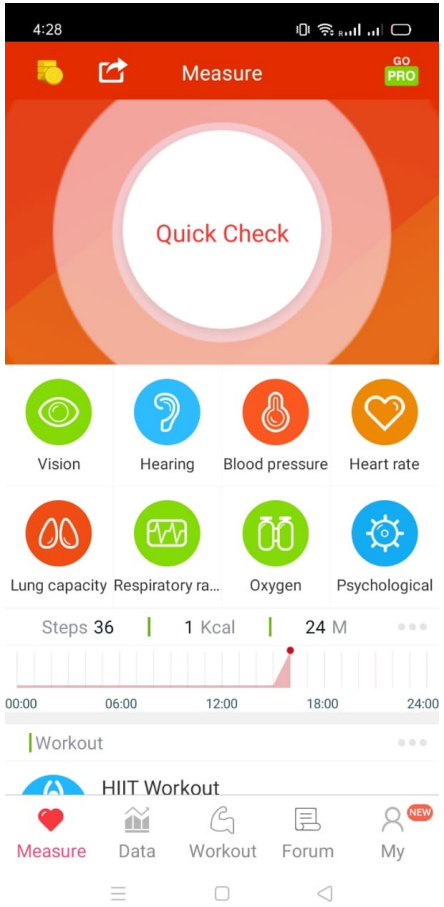
‘interactive disinformation’.

- an interactive system that may misinform its user
- a superset of media misinformation

Health Permission Model

“Do you give this application permission to make medical recommendations, which might not be accurate?”





Conclusions

- studied the BP management-related practices and ecosystem of BP management in low-resource communities in India
- offered insights into the patient's perspective of BP management
- proposed design recommendations to make health technologies and supporting human processes more attuned to the surrounding social context
- Future recommendation: Design mobile diagnostic tools for human intermediaries like ASHAs
  As we invent more accessible mobile diagnostic tools, we should ensure that human intermediaries (such as ASHAs) stay in the loop as users of the tools to preserve the trust of patients. Simply increasing end users' access to technology without preserving trust is unlikely to lead to sustained usage or benefit.

THANK YOU ☺