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Systems Thinking Perspective on Support for Transition and Acceptance of Identity of Chronic Health Disease Health Seeker in Society

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Currently, India is home to diabetes, and it has the second largest diabetic population in the world. The term ‘health seeker' is used instead of the patient since the health seeker is attributed to a person who is motivated to improve his physical and mental well-being (Bate, P. & Rober, G., 2007). Diabetes is a chronic disease that requires the health seeker to modify their lifestyle, which is a transition of their identity.

This transition from a healthy self to a chronic health disease health seeker is often challenged by societal forces and healthcare services. While the patient experiences are personal, the healthcare systems are abstract and impersonal. With the systems thinking approach, the questions we are trying to seek answers to are:

- Where does the boundary of healthcare begin and end for a patient with chronic health disease?
- What are the insensitivities faced by the health seeker while experiencing a chronic health condition such as diabetes?
- What are the support systems that help health seekers in their journey of new medical identity across space and various life activities?

Keywords: healthcare, empathy, diabetes, India

RSD: Health & Well-Being, Mapping & Modelling

Presentation description

One in eleven Indians is formally diagnosed with diabetes in India. (Kannan, 2019) There are three types of diabetes, which are type 1, type 2 and gestational diabetes. This research largely focuses on type 1 diabetes.

- Type 1: The body attacks the cells in your pancreas, which means it cannot make any insulin.
- Type 2: The body is unable to make enough insulin, or the insulin you do make doesn’t work properly. (source:diabetes.org.uk)
- Gestational Diabetes: A type of diabetes that develops during pregnancy.

The inquiry focuses largely on the health seekers' experience and care while they are outside the boundary of the hospital: How does the chronic disease affect their stand in society? What activities do they carry out? Are the formal spaces such as school, work and travel inclusive of such activities?

The research involved a literature review, expert interviews, patient interviews, a hospital system journey audit through field visits and shadowing, a digital consultation audit, focus group interviews, photo journaling and user narrative methods. We synthesised the information gathered through research by mapping the relationships, interactions and transactions between stakeholders of healthcare for a chronic disease health seeker. Through a ‘behaviour over time map,’ we demonstrated life before, during and after being diagnosed as a chronic disease patient.

To understand the leverage points (awareness, support group and tracking devices) and weak links in the system, we used systems thinking tools such as causal loops and systems oriented design process of gigamapping.

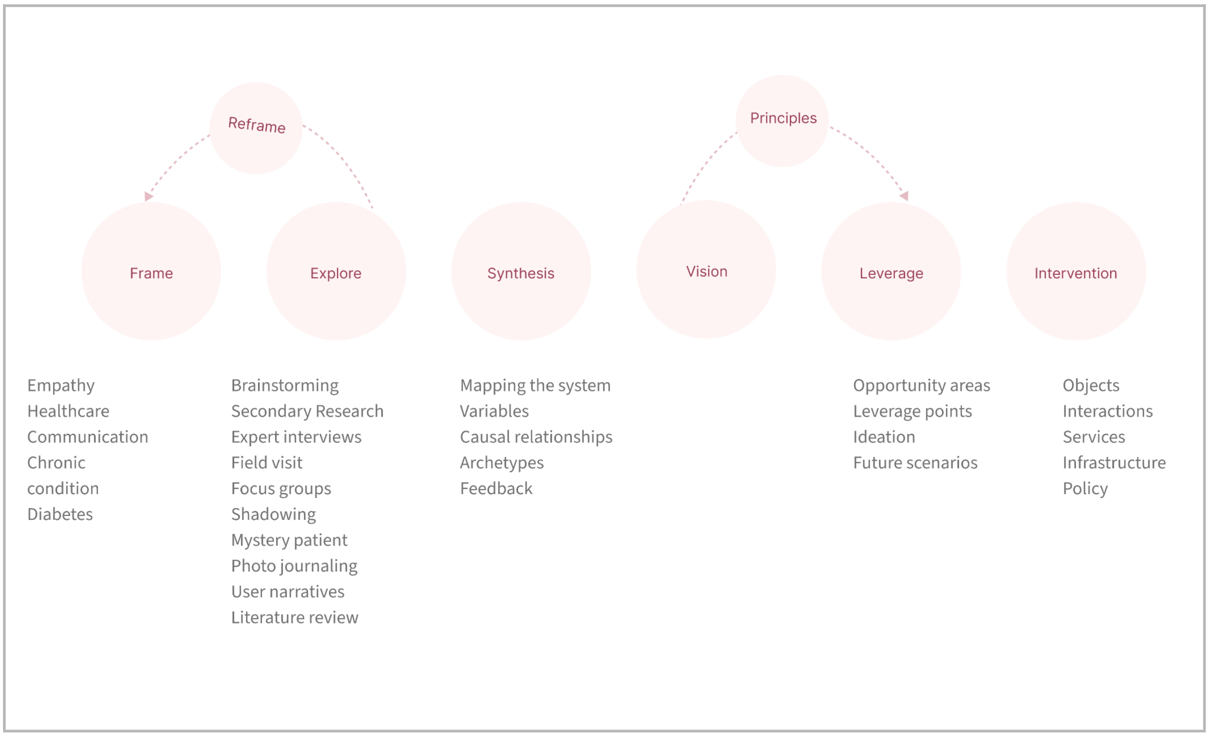

Figure 1. The process followed.

Methods

The process followed is illustrated in Figure 1. Appendix 1 provides further details on the research process, and Appendix 2 describes the process of mapping and synthesis.

Summary of themes

1. Strengthening the collective community identity
2. Creating inclusive spaces to carry out healthcare activities
3. Increasing awareness of self to predict and understand condition better
4. Proactive healthcare communication from hospitals and the medical industry that integrates into the life of the health seeker Integrative system of care

Summary of leverage points

1. Awareness: Awareness is an important leverage point in the system. It plays a key role in empowering people to live healthy lives and creates an environment for health seekers that is conducive to managing their condition effectively.
2. Support and care: Along with medication and health care, emotional support is crucial to managing a chronic health condition.
3. Empathy and inclusive policies: Currently, formal and informal spaces are not inclusive of the needs of diabetics, which acts as a barrier to the support needed for the health seeker to manage their condition effectively.
4. Lifestyle management services: When it comes to a chronic health condition such as diabetes, lifestyle is crucial to managing the condition.
5. Finance planning for insurance and medical expenses: Dealing with a chronic health condition also requires one to manage the finances required to manage their health over a very long period.
   Patient-centred tracking and monitoring for creating a system of care: There is a need for technological interventions that go beyond individual wellness to integrate with the system of care.

Four themes emerged

Strengthening the collective community identity.

Transitioning from a healthy self to a person with diabetes needs a positive attitude. One may go through the stages of grief of knowing their newly diagnosed condition. A way to deal with this would be to strengthen the identity of a person with diabetes to make the transition less bumpy.

Creating inclusive spaces to carry out healthcare activities.

Formal institutions like schools, workplaces and offices must be inclusive of the conditions of type 1 diabetes or diabetes in general. Informal spaces such as restaurants, bars and hangout places must be aware of the stigma against people with pumps or other devices.

Increasing awareness of self to predict and understand the condition better.

The first communication missing is knowing what one's body is going through without waiting until healthcare intervenes. The delay in diagnosis must be made shorter and more efficient by understanding the health condition using genetics, tracking devices and others.

Proactive healthcare communication from hospitals and the medical industry integrates into the life of the health seeker to create an integrative system of care.

The healthcare system communicates in a reactive mode. It does not wrap around the health seeker but instead demands their attention. Overload on the healthcare system since a person's lifestyle is an ongoing condition, and the doctors play a role of not just medicating but also end up being a counsellor and mental health professionals.

Leverage points identified

Awareness

- Awareness at the child planning phase.
- Awareness regarding diabetes can educate people on its symptoms and make changes in one’s lifestyle to prevent or delay diabetes.
- Awareness also helps to myth-bust and have a better understanding of diabetes, leading to better management of the condition and physical well-being. Myth-busting also helps with combating social stigma and seeking help from mental health professionals, which leads to better mental well-being.
- Public awareness also leads to support for causes, which leads to the government creating policies to support the causes.
- Information empowers people to seek health services for diabetes which helps patients keep sugar levels under control and prevent health risks and complications.

Support and care

Currently, the healthcare services and the diabetes support communities work in silos as individual entities. By integrating these two entities, the health seeker shall receive credible information and support required to make sense of their health condition and live with it

Empathy and inclusive policies

- Policies to make schools more inclusive for children with diabetes.
- Easy access to medical devices, medicine and care at school, work and travel.
- Awareness camps to reduce social stigma and apprehension of type 1 diabetes in informal spaces such as apartments, restaurants and canteens.

Lifestyle management services

- Service designed with integrated, personalised service catering to the individual need of a person with diabetes.
- Mental health professionals, diet management plans, fitness plans, and medical experts on one platform to provide an integrated system for lifestyle management.

Finance planning for insurance and medical expenses

- Subsidised insurance policies for Type 1 diabetics.
- Policy-level interventions for insurance for people in the diabetic community.
- Policy-level interventions to make medicines and medical devices available at subsidised rates.
- Patient-centred tracking and monitoring for creating a system of care.
- Technological intervention that goes beyond individual wellness to integrate with the system of care.
- Implementing ‘Health I.D’ to track the diseases which are genetically transmitted and to maintain a record of previous health conditions and reports.
- Interventions that motivate and ensure that health seekers adhere to the treatment and management of the condition.

Conclusion

Diabetes is a prevalent chronic disease in a country like India. This disease affects every aspect of the health seeker's lifestyle. The shift in identity from a normal to a chronic patient is an uphill process. On investigating the healthcare system from the lens of chronic disease, we understand that healthcare must be beyond the hospital's walls. The caregiver and the community often support an emotional journey from a healthy self to a chronic disease health seeker. This formal healthcare and informal community could be integrated with technology to support their transition. The support system is spread into multiple subsystems such as child planning, financial planning, lifestyle management, tracking, and monitoring, creating inclusive spaces and integrated healthcare systems. The subsystems reveal intervention points to ensure the person with diabetes receives holistic treatment support beyond the boundaries of conventional healthcare.

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Appendix 1: Research methods

Framing the problem

The boundary of the system research was confined to healthcare, empathy, communication and chronic illness such as diabetes. Financial aspects of healthcare are out of the scope of the project.

Exploring the problem space

Brainstorming

We started working on this project by discussing what empathy means to people in general, tools used to develop empathy, such as diversity dolls and thoughts around communication in healthcare.

At this stage, we jotted our lines of inquiry as follows:

- What do we owe each other?
- How does one cultivate empathy in society?
- What is the patient trying to seek?
- Is the patient data helping in communicating with empathy?
- Where does the boundary of healthcare begin and end?

Figure 2: shows the brainstorming we did as a team.

Secondary research

Secondary research included reading books, research papers, and information over the internet about chronic illness, healthcare models and communication models. For health seekers, self-care and acceptance of the chronic condition are difficult and largely depend on the imposed identity by the diagnosed disease. The quote in the book summarises the feeling. (Kalanithi, 2016). “How does one conceptualise one’s identity or negotiate the present moment when the future, as an imagination, as an aspiration along a linear path of movement, is gone?” (Tamanna Basu)

Expert interview

The expertise of a general physician Dr Nagaraj at NID-Bengaluru, and a counsellor at various organisations. General biases and the prevalence of diabetes were understood. Patient behaviours and fear patterns from an expert perspective are noted.

Problem space: insights and learning

Chronic disease

- Asymptomatic chronic illnesses such as diabetes are hard to capture unless a health check-up is mandated.
- Corporate engages consultants.

Communication protocols

- Empathetic communication: Listen first and advise later protocols are taught in medical schools.
- Alternate ways of treatment often misguide patients.

Health seeker patterns

- Spending on entertainment over health insurance is a pattern among working employees.
- Diagnosis fear as people do not want to be diagnosed with an illness.
- Making sense of the new symptoms requires awareness.

Figure 3: The health counsellor mentions, “Everybody is a patient waiting to be diagnosed.”

Field visit

Field research is a qualitative method of research concerned with understanding and interpreting the social interactions of groups of people, communities, and society by observing and interacting with people in their natural settings. The field visit was conducted at Sparsh Hospital, Bengaluru, where we spoke with the endocrinologist, the patients, the receptionist and the pharmacists.

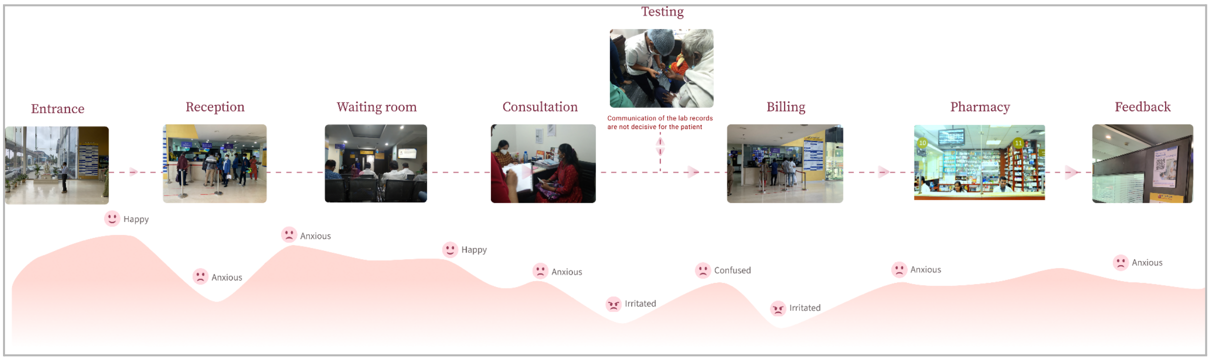


Figure 4. shows the health seekers’ journey at a hospital.

Field visit: insights and findings

- No navigation for the emergency and elective.
- Previous medical history records are required. If the documents are lost, they have to begin the diagnosis again.
- The patient has an idea in which order he should get a consultation but is not sure about the waiting time.
- Most of the time is spent on medical education and emotional support.
- Lack of needed information from the patient can lead to less satisfaction for the patient.
- Doubt about the doctor leads to a second opinion.
- Most of the time, the hospital is advised not to share all the medical records until the patient clears their pending bills.
- Lack of information about the prescribed pills.
- Feedback can be provided using a digital QR code placed in a low-visibility area.
- Healthcare is currently reactive and not proactive.

Figure 5. shows a diabetic community meet-up.

Focus group

At the focus group interview with the diabetic community, ‘Leave No One Behind’ at Cubbon park, Bengaluru, we placed six questions on a message board. We asked people to pin their responses to our questions. Some responses were directly from the patients, while others were assisted responses from caregivers. The participants were given a survey questionnaire based on communication with the healthcare facilities. This was followed by an in-depth conversation with the health seekers and caregivers to understand their pain points better.

To frame the research questions, we ideated how to frame the questions so that the age group between 8 to 35 years can easily understand them. The questions were iterated multiple times, printed, and posted on the board for people to answer.

- How does this condition affect your daily activities?
- When did you get diagnosed with diabetes?
- Do you think the information from the healthcare system was tailor-made for you?
- Does your healthcare system support you emotionally?
- Does your healthcare system involve you in the decision-making concerning your treatment?
- What is wrong with the existing healthcare system?

Focus group: pain points identified

- It is a 24/7 job to self-care with no breaks.
- The current system does not provide insurance coverage and no subsidised insulin.
- Emotional well-being is not currently a part of healthcare but is sought by family and community.
- Lack of clarity in information regarding food intake and diet from healthcare.
- The burden of researching what suits best for an individual is heavily dependent on the health seeker.

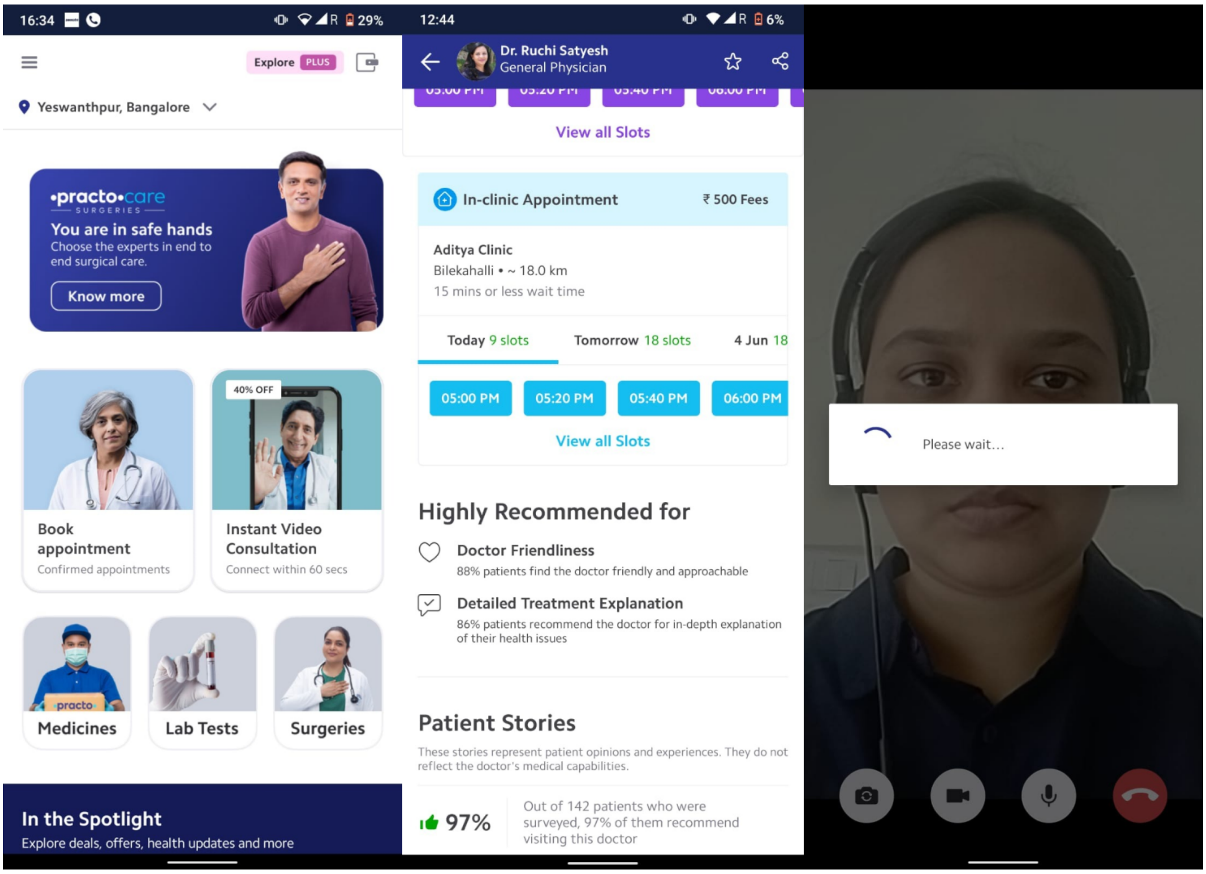
Shadowing the endocrinologist

The activity of shadowing an endocrinologist (Dr Lakshmi) was conducted at Sparsh Hospital, Bengaluru, for a day. Patient interactions and pain points while conversing with the doctor, information goals and the emotional state of the patients are noted.

Shadowing: insights

- Health seekers depend on doctors for information regarding the disease. They wanted to understand how it affected their activities, such as taking a trip.
- Doctors are also the burden of counselling for needle fear and other general apprehensions about health conditions. The doctor feels that an external counsellor and diabetic educator will offload the burden. In rural areas, it is far more challenging to educate people.
- The doctor suggests changes in diet, medication, and dosage. Information is passed on to the immediate caregiver.
- The social-economic conditions of the patients are a significant determinant in prescription and lifestyle-related suggestions.

Figure 6. shows shadowing the endocrinologist.



Choose the experts in end to end surgical care.

Explore deals, offers, health updates and more

88% patients find the doctor friendly and approachable

86% patients recommend the doctor for in-depth explanation of their health issues

These stories represent patient opinions and experiences. They do not reflect the doctor's medical capabilities.

Out of 142 patients who were surveyed, 97% of them recommend visiting this doctor

Figure 7. The mystery patient.

Online mystery patient consultation

Mystery patient methodology is a form of participatory research that provides a unique opportunity to monitor and evaluate the performance of healthcare providers or health facilities from the perspective of the user of services such as health consultation platforms like Practo.

Mystery patient: insights and findings

- In an ideal scenario, one of the pros of online consultation is having to spend less time waiting for one's appointment. One can simply pick a time slot at their convenience and be ready a few minutes before the scheduled appointment.

- Lack of connection with the doctor, finding it difficult to explain problems verbally, makes one unsure about the diagnosis.
- Technical issues and the ability to use technology largely affect the quality of the consultation.

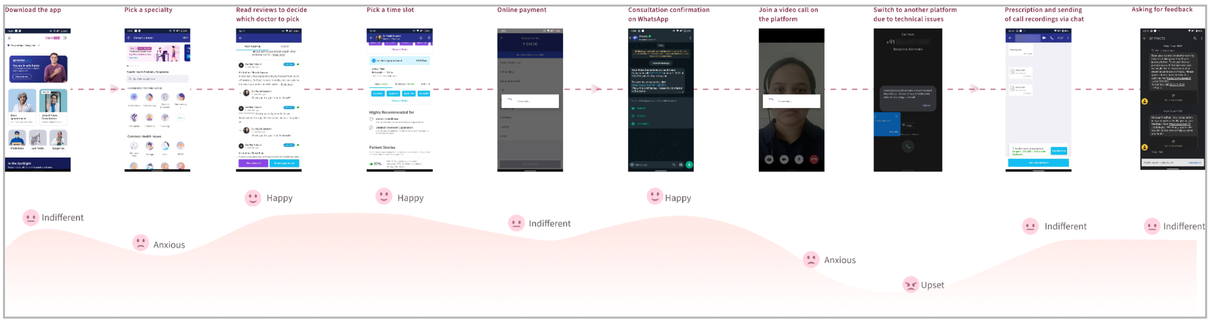


Figure 8. shows the journey of online consultation.

Photo journaling

Prompts to click pictures of a day in the life of a type 1 diabetic were shared with a research participant. This gave us insights into the instruments, medical routine and lifestyle of type 1 diabetic health seekers.

Photo journaling: insights

Stigma and a lack of awareness amongst the general public make it difficult for diabetic health seekers to inject insulin in public places.

- Difficulty in tracking the exact insulin requirement as it is based on multiple factors such as body mechanism, body weight, carbohydrate intake and physical activity.

Figure 9: A photo journal of a type 1 diabetic person.

User narratives

User narratives helped empathise with the journey of the health seeker and their caregiver by uncovering problems they have faced over time. Several other experiences are collected as stories.

User narratives: insights

- Parents of juvenile diabetics face exclusion from social settings such as canteen and birthday parties.
- A lack of understanding among peers of juvenile diabetes regarding their condition is due to a lack of awareness, which prevents the health seeker from being at ease in social situations.
- There is a dire contrast in how juvenile diabetics and non-diabetic children are treated.
- Ignoring symptoms of high sugar levels among type 2 diabetes patients thinking it's a part of ageing.

Appendix 2: Mapping and synthesising

Stakeholder relationship mapping

The health seeker's communication with the stakeholders of the system reveals the perceived relationship, transactions and interactions. The line thickness in figure 10 shows the frequency/ intensity of the communication. In the current system, the relationship with the caregiver, doctor and the community is high, but this communication is currently carried out in silos.

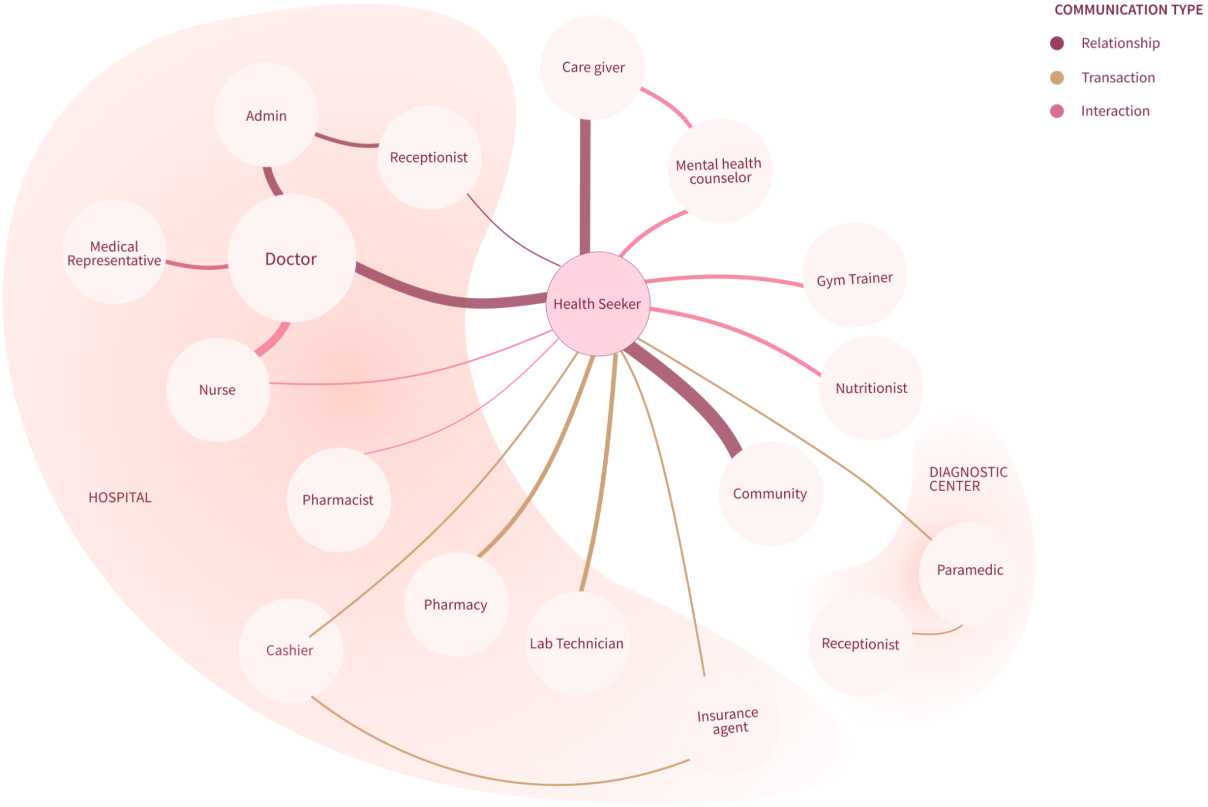


Figure 10. Shows stakeholder relationship mapping.

Health seeker journey mapping

The emotional and mental states during the journey marks the intervention points that need strengthening. The “behaviour over time” map helped the researchers to understand and visualise the transition from a healthy self to diagnosis, acceptance and living with a chronic condition. The condition does not just affect a person physically but also emotionally and mentally.

We mapped three states in the journey from a healthy self to accepting a chronic condition such as diabetes. Dealing with diabetes on a daily basis and learning risk factors associated with diabetes for a lifetime are illustrated in Figure 11.

1. Life before the chronic condition
    a. Physical aspects: Encounter unusual symptoms such as increased thirst, increased hunger and increased urination. Feeling sluggish, having vision changes, losing weight etc., are some of the signs too.
    b. Emotional aspects: When a healthy individual experiences certain symptoms, either through tracking devices or through the awareness of the chronic condition, the chances of encountering healthcare are further determined by the sensemaking process. Beyond this point, affordability and comprehension are the barriers to the next phase.
2. Encounter healthcare
    a. Physical aspects: The first consultation with the doctor is done, who then asks for conducting blood and urine tests for diagnosis. The sugar levels and ketones are checked. Sometimes due to a lack of awareness, the complications become severe over time and lead to an emergency.
    b. Emotional aspects: Post the first consultation, the health seekers often follow through to get the test results. If the health seeker is in disbelief or experiences dissonance in accepting the chronic condition, low coping ability and low triggers in the environment act as a barrier to going to the next phase.

3. Living with a chronic condition

    a. Physical aspects: Living with diabetes involves a lifelong series of expenses and making constant adjustments. The health seeker tests blood sugar levels about 6 times a day and documents it on apps to keep track of all the readings. These are then shared with doctors and analysed.
    b. Emotional aspects: The lifestyle changes induce a sense of loss in the health seeker. In a positive scenario, the health seeker learns to cope with loss and follows through with the medical requirement. In successful cases, it is coupled with forming a collective identity with similar health-seeking individuals. In a negative scenario, burnout or ignorance of new deviance in health leads to complications and life-threatening conditions.

Systems mapping

Mapping explored the relationships between the diabetic population. Physical and mental health were mapped with causal relationships (Figures 12 & 13).

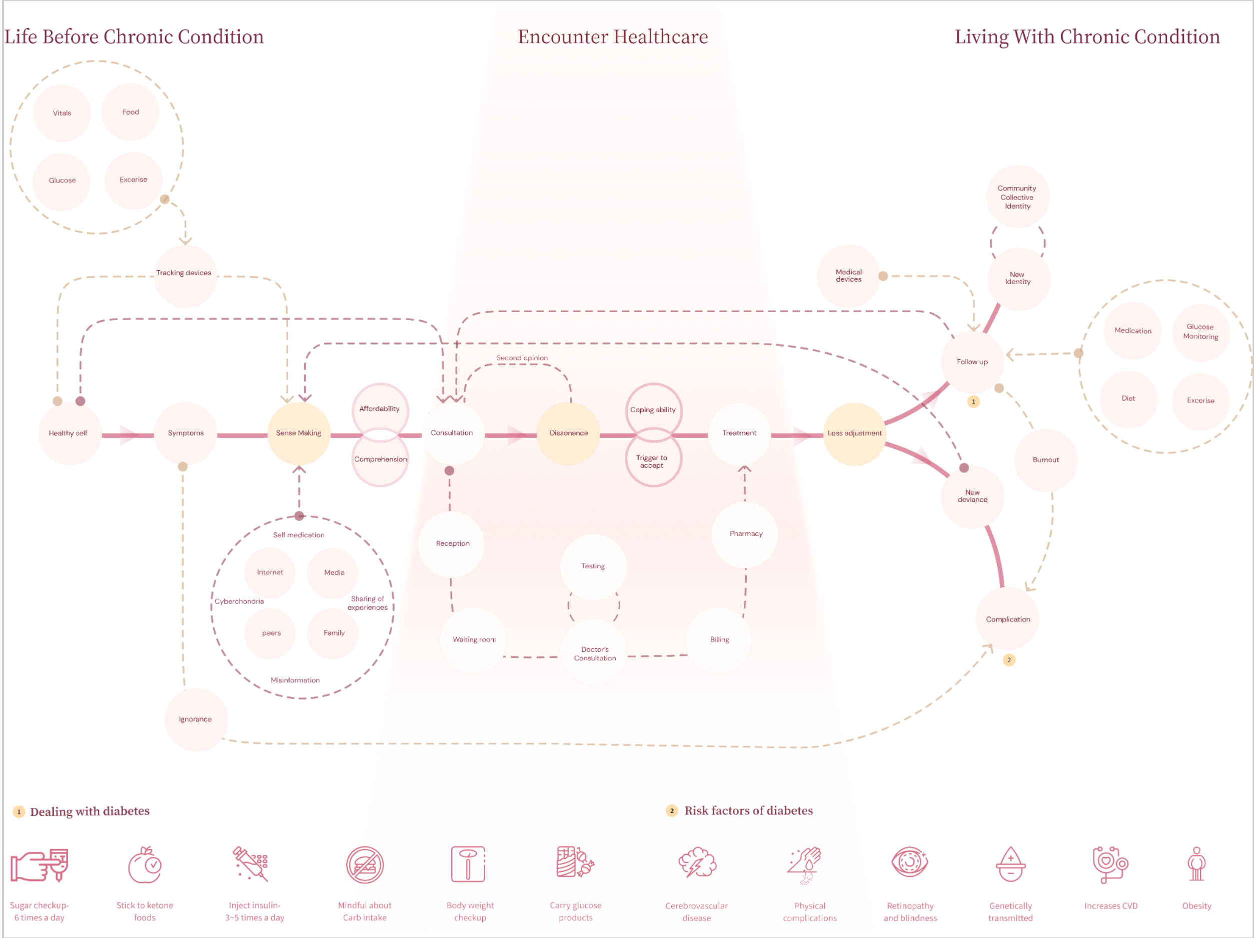


Figure 11. Behaviour over time mapping.

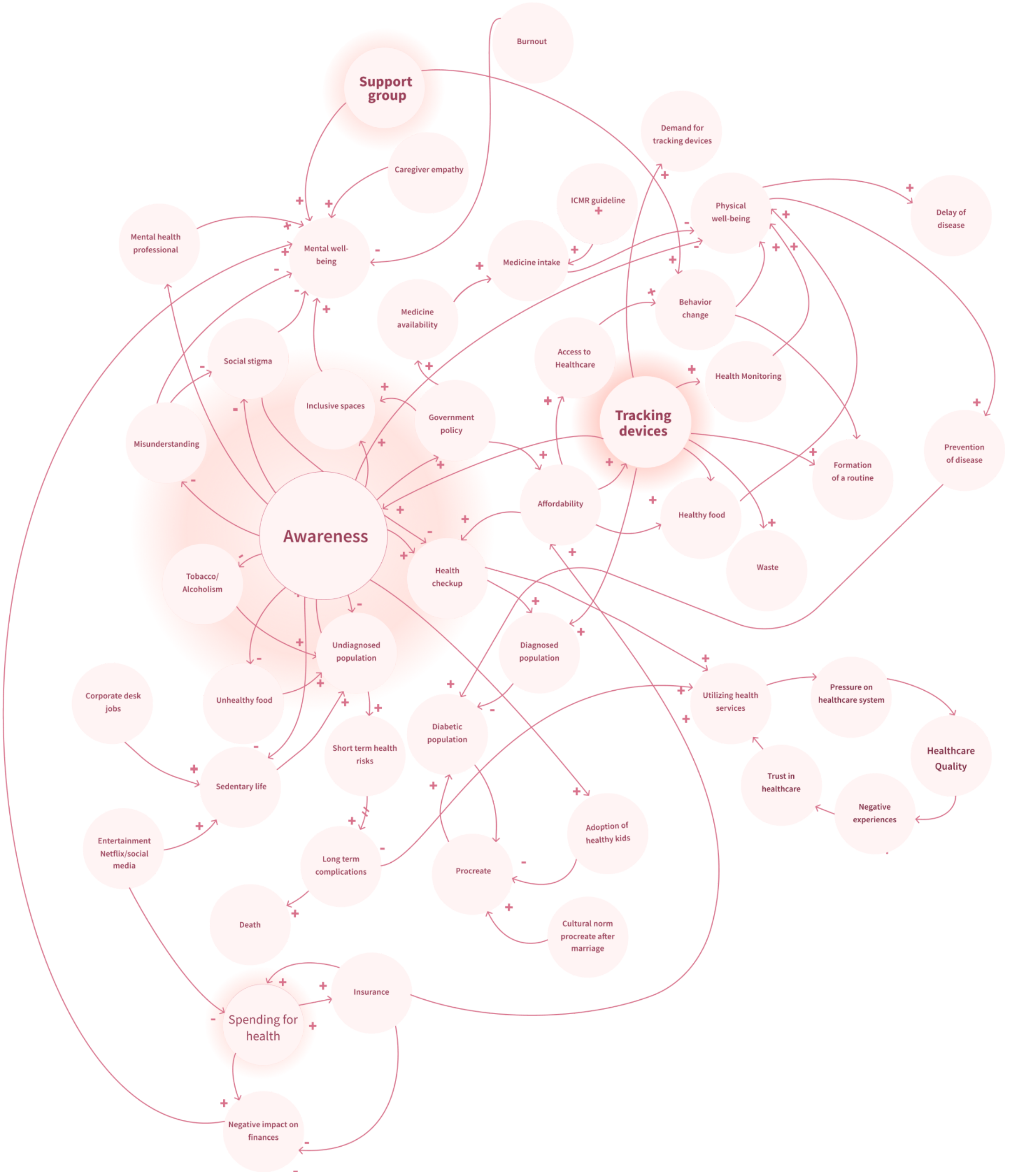
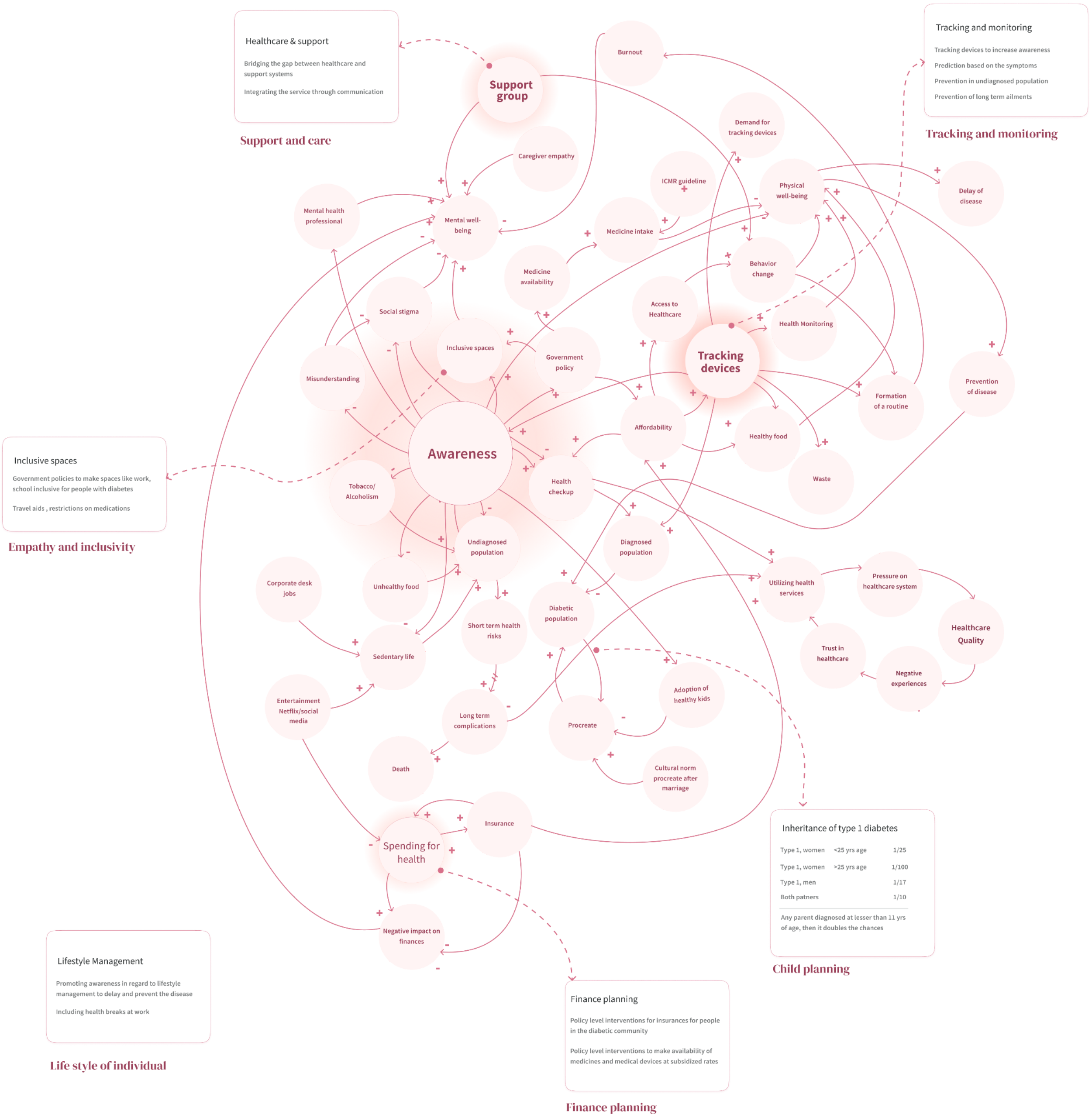


Figure 12. Causal relationships.



Healthcare & support

Bridging the gap between healthcare and support systems

Integrating the service through communication

Support and care

Tracking and monitoring

Tracking devices to increase awareness

Prediction based on the symptoms

Prevention in undiagnosed population

Prevention of long term ailments

Tracking and monitoring

Inclusive spaces

Government policies to make spaces like work, school inclusive for people with diabetes

Travel aids , restrictions on medications

Empathy and inclusivity

Inheritance of type 1 diabetes

Type 1, women	<25 yrs age	1/25
Type 1, women	>25 yrs age	1/100
Type 1, men		1/17
Both patners		1/10

Any parent diagnosed at lesser than 11 yrs of age, then it doubles the chances

Child planning

Lifestyle Management

Promoting awareness in regard to lifestyle management to delay and prevent the disease

Including health breaks at work

Life style of individual

Finance planning

Policy level interventions for insurances for people in the diabetic community

Policy level interventions to make availability of medicines and medical devices at subsidized rates

Finance planning

Figure 13. Causal loops with leverage points.