



AN ETHNOGRAPHY ON BEIJING'S DIABETIC COMMUNITIES

# STORIES FROM GRANDMA'S KITCHEN





TYPE 2 DIABETES IN

# BEIJING, CHINA

China is one of the fastest developing countries in the world, and rapid economic progress has affected diet and physical activity of the Chinese people. The overall disease burden has shifted from infectious to chronic, as Chinese people face increased wealth, sedentary lifestyles, and an aging population<sup>1</sup>. The prevalence of diabetes in China has increased dramatically in recent years, increasing from 1% in 1980 to an estimated 11.6% (in 2013) of the adult Chinese population. Pre-diabetics are estimated to be 50.1% of the population<sup>2</sup>.

# Diabetes management is a 24/7 hour activity

## MOST HEALTH CARE HAPPENS OUTSIDE THE CLINIC

Diabetes management permeates every aspect of every life. Every time a diabetic patient eats or exercises, considerations of the disease must take place. As illustrated by E.B. Fisher<sup>3</sup>, the number of hours a diabetic has to self-manage his or her own disease is 8760 hours a year (8766 hours in a year – 6 hours a year in the doctor's office). In other words, managing diabetes is a 24/7 job that constantly affects every aspect of one's life. Thus self-management is central to diabetic care.

Peer support networks are an effective way for diabetic communities to manage their disease<sup>3-5</sup>. Such networks provide ongoing help with peers with daily management, social support, and knowledge.

8,766 total hrs per year – 6 hrs a year in provider's office

# 8,760 hours

## ON YOUR OWN

Healthy Diet

Physical Activity

Monitor Blood Sugar

Take Medications

Manage Sick Days

Manage Stress



# A Global Health Ethnography

## LEARNING AND LIVING TOGETHER WITH THE BEIJING DIABETES ASSOCIATION (BDA)

In June 2015 I was awarded a fellowship to conduct an ethnography on the lived experiences of diabetic communities in China, with a particular focus on family dynamics and attitudes towards food. I spent nine weeks with members of the Beijing Diabetes Association, conducting participant observation, semi-structured interviews and focus groups. I ate with, exercised with, lived with, and made friends with diabetic patients who became my dear friends.

I have made several follow-up trips to document the longitudinal experiences of the families and patient-leaders I have met. This project is a co-created effort with the patients I befriended in order to share their stories of leadership in a vibrant community of love and health.



A colorful lunch prepared by Mrs. W, a diabetic who I befriended, lived with, and shared countless meals with.



# DIABETES AS A SOCIAL IDENTITY

The members of the Beijing Diabetes Association (BDA) embraced diabetes as a way to connect with peers in diabetes-focused activities while having fun in daily life. This created a well-rounded community of wellness.



## EXERCISE AND DANCE

This group of friends from the BDA gather on a weekly basis and practice the Red Fan Dance as a form of exercise for physical health, as well as performances for the public.



## GUEST STARRING LIVE TV

*Yang Sheng Tang* is a popular TV program about healthy living and eating. It is watched routinely in China in almost every household. The BDA frequently guest star on the show, with dances and musical performances.



## SOCIAL OUTINGS

Members frequently go on vacations together outside of regular activities related to the BDA. The community of the BDA extends beyond managing diabetes and has formed some members' core friend groups.





# Patients as leaders in their families

## THE STORY OF MRS. W

Mrs. W is a long-time diabetic who successfully manages her diabetes with a diligent exercise routine, healthy eating, and she engages in leadership at the BDA. When I first met her family, Mrs. W's husband was in the pre-diabetic range. The following was her husband's reaction to his health status: "Oh well I'm already 60 so I'm reaching the end anyway". At first diagnosis, her husband did not take his potential illness seriously.

Mrs. W, who previously almost became blind upon discovering her high blood glucose levels, refused to let her husband slip into "diabetes" status and told her husband: "Look at how much I had to suffer, I don't want you to be pulled into the diabetes group and suffer too". She used her experience of managing her disease to prevent her husband from becoming diabetic and experiencing the illness as she did.



# Caring for yourself is caring for your family

## THE STORY OF MR. L

Mr. L directs a martial arts course within the BDA. When I asked for reasons why diabetics would neglect to engage in self-care, Mr. L said “It’s either because they themselves are not educated, or the family doesn’t understand or take responsibility.” When asked how can the individual help the family understand or take responsibility, he answered, “Part of the individual’s responsibility towards the family is to first love and take care of yourself”.

“You must take yourself seriously first and then the family will realize that diabetes is a serious illness. People think diabetes is just a state where you can’t eat anything. But it really affects all of your life.” Here, we see that family is a motivating factor for patients to manage their diabetes. Mr. L takes care of himself so he does not worry his family members. Self-care is a way of demonstrating the diabetes as a force of importance that deserves attention.





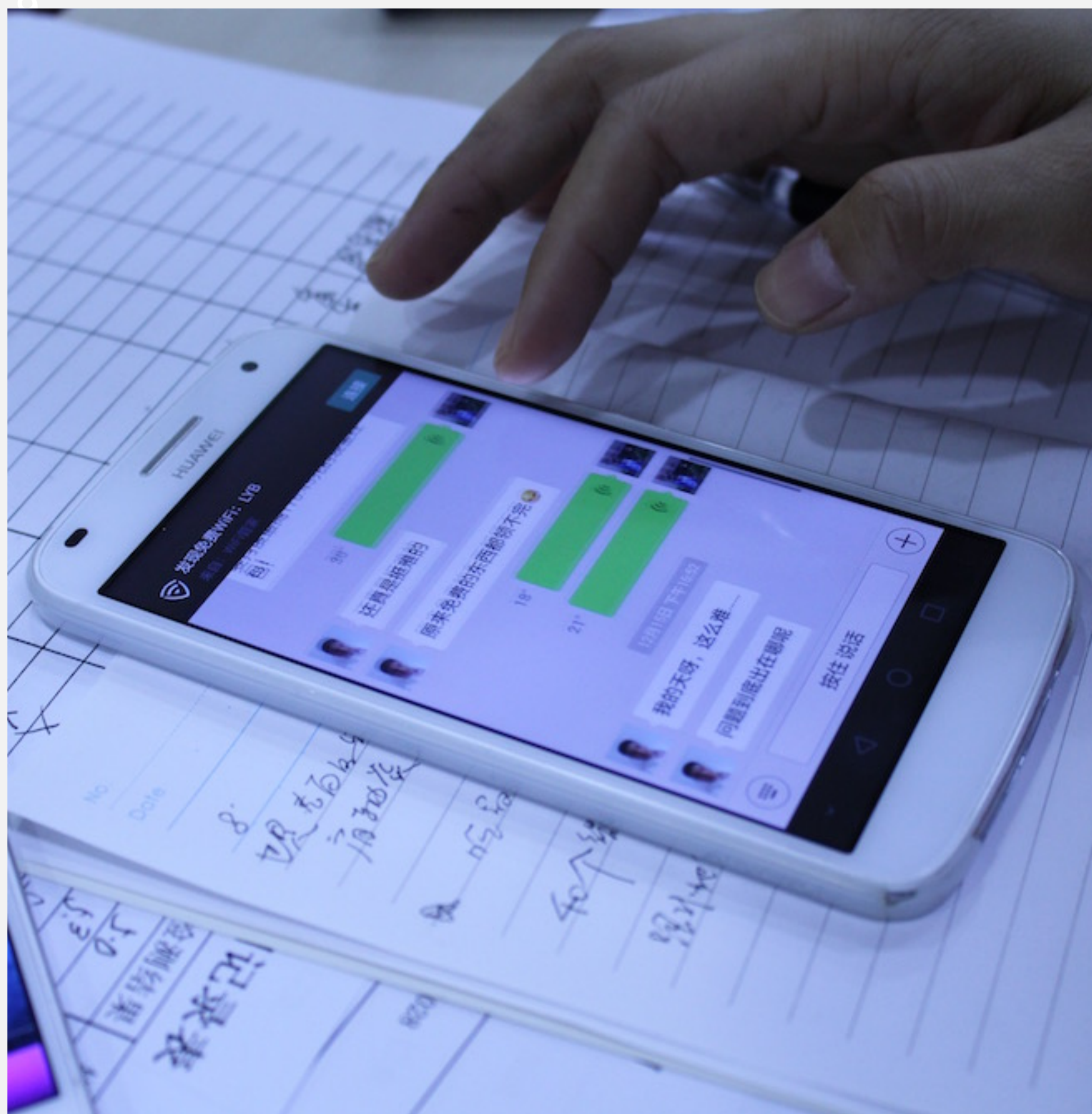


# Patients as community educators

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About one year later when I revisited the community, patients were running their own health fairs helping their community check glucose and A1C levels. They established a corps and developed a curriculum to formally be trained as diabetes educators.





WeChat provides a space for a robust online support community which can inform importance disease severity and management.

“My cousins all have diabetes and they ask where did you get all this information about diabetes? And I tell them it’s from the association! I forward them the links [on WeChat].”

When did you family start treating your diabetes as important?

“Well I kept on telling them, I kept on sending them WeChats and forwarding them information.”





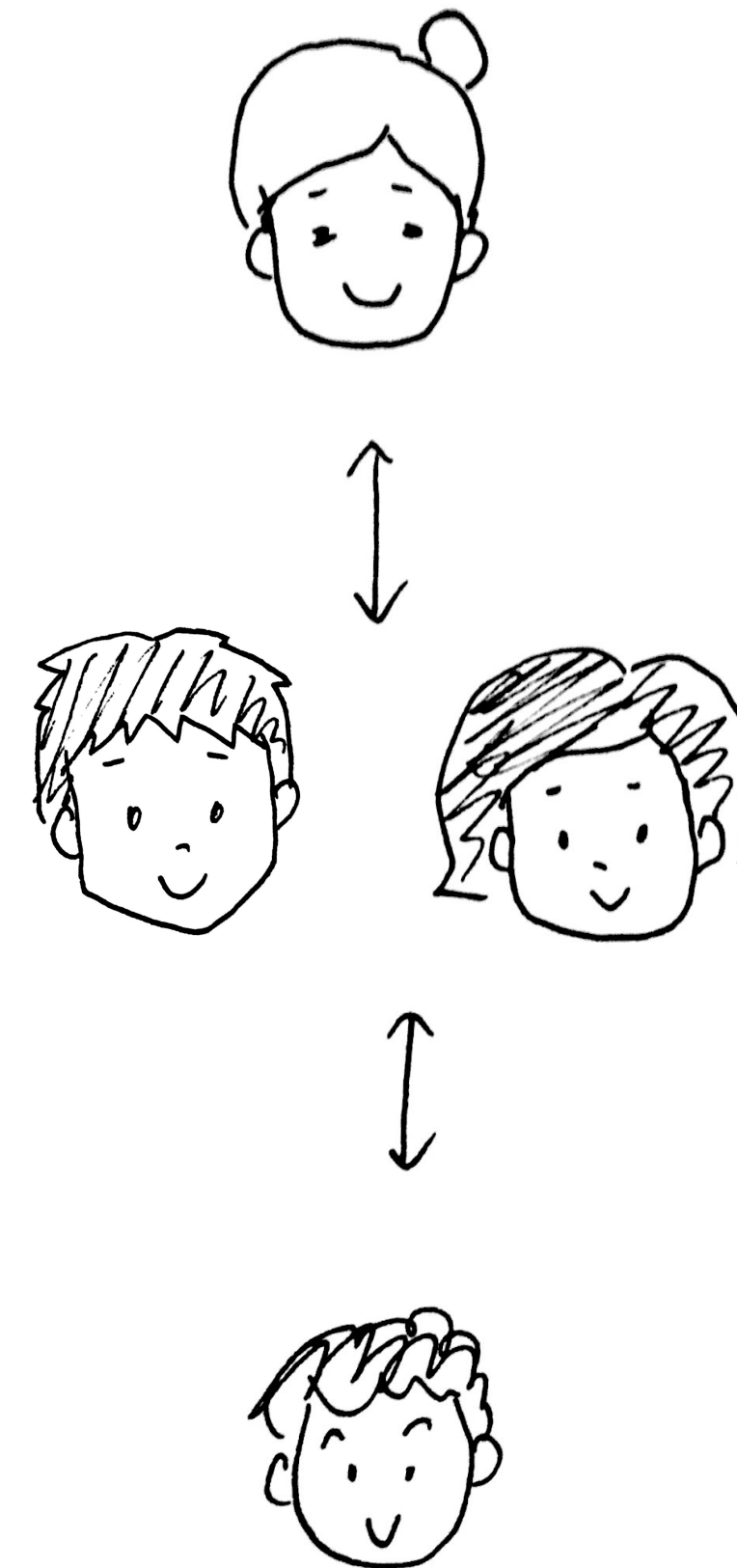
# INSIGHTS

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# Multigenerational care occurs in a two-way direction

Multigenerational care serves as a crucial factor of support for reasons why patients want to take initiative to manage their own disease, as well as prevent disease from occurring to their family members. The diabetic patients themselves have a critical role in caring for both older and younger generations. This feeling of responsibility to take care of their family members is a significant motivating factor for the patients to stay healthy themselves.

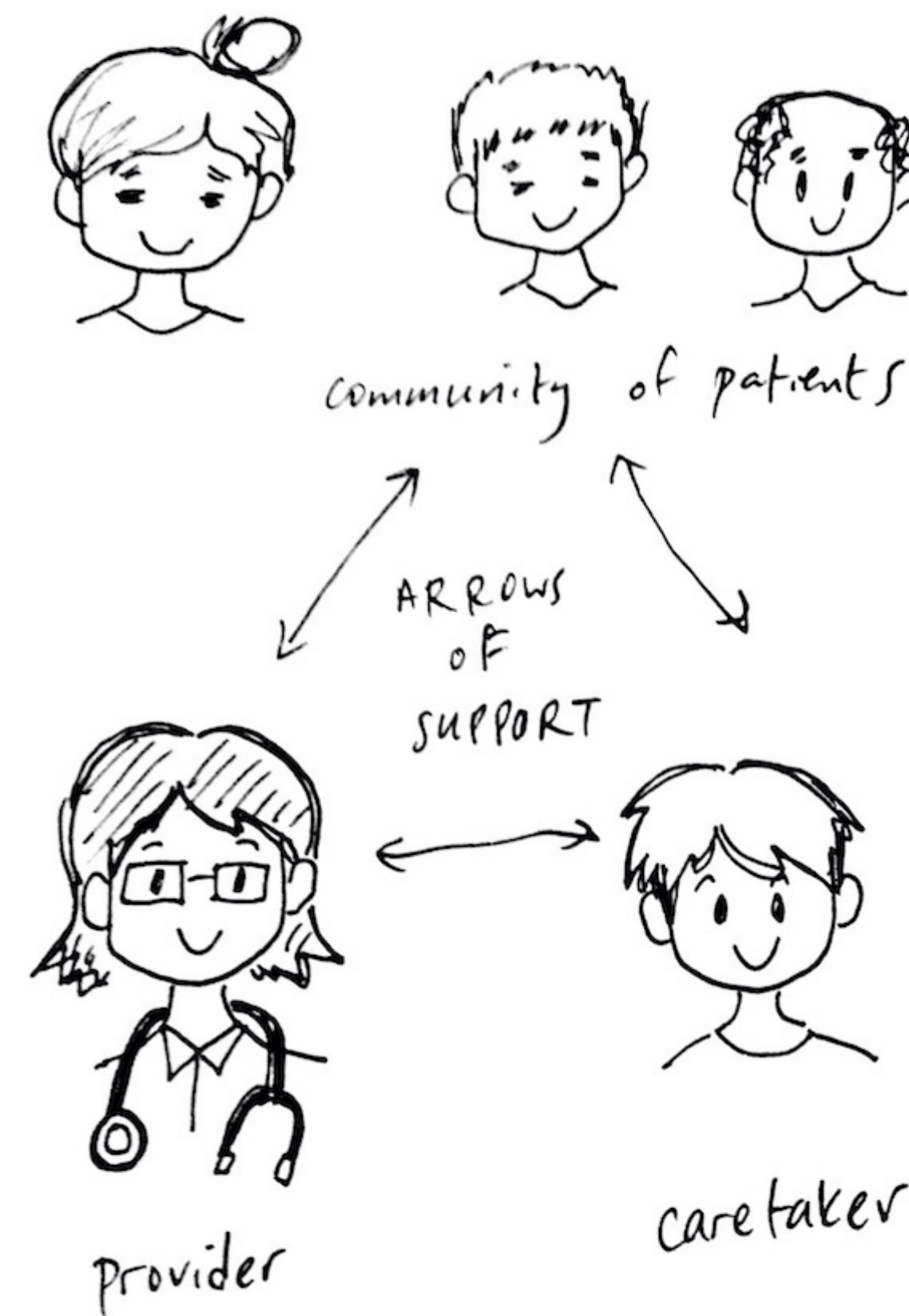




# Patients are **not passive** receivers of care, but caretakers with capacity to **support others**

The many years of experience of being diabetic give them power and credibility to become health leaders within their peer and familial networks, in which the patients use their personal experience with the disease to influence others to have healthier lifestyles.

Patient's illness experience is a valuable source of expertise that should not be overlooked by healthcare providers and their stakeholders. Traditionally, patients are only seen as those who are "taken care of". Patients in this study are fully caretakers who have and feel a responsibility towards their families.







# How might we tap into the innovative potential of all patients?

This is essentially a **human centered design** question!

**Patients** are the **end users** we must bring to the drawing table in healthcare innovation.



# References

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