Title: A qualitative study exploring the health literacy issues in the care of Chinese American immigrants with diabetes

Preliminary analysis: Key themes

Culture

1. **Authoritative attitude (patient right)** - patients and doctors relationship, all things learn from doctors, authoritative attitude, no confrontation (don’t ask questions, not to trouble others,) no right to say, originated from hierarchical concept in Chinese culture

I will follow whatever the doctor tells me. It would be strange if the doctor discusses the treatment plan with me, and it is unnecessary for the doctor to do that. I have never accused the doctor for anything wrong. Just like a child and his father—the doctor is like our parent, and whatever he says is correct. If … the doctor has said something wrong, and I notice it … then I know more than the doctor. That’s impossible! (Participant 16, male) TC\_FG4a\_20131019, 55:14-

For new immigrants, say if you provide workshops like this, I would come. Why would I come? Because you are providing this in a hospital, and I believe it has credibility and it is something trustable, and that’s why I come. Say if you have this workshop at other settings other than a hospital, such as a hotel or in a community, I will definitely not come. Let alone giving me a $10 gift card, I will not go with even receiving $100. It is just meaningless. As soon as that workshop started, they started to sell medicine. My retired father has been to that kind of workshops and bought their medicine twice. It was not effective after tried. TC\_FG2\_20131018 ，23：00-24：00，P7/M，

When I first started taking medication, I didn’t keep a recording of my blood glucose. I don’t know what is high, what is low and what is normal. I only know that the doctor told me I have diabetes. I don’t take care of the illness in a special manner. I think, I am just the way I am, nothing serious will happen, I eat whatever doctors give me. I don’t have any special channel [to get health care information]. … I trust doctors a lot, whatever they say I will follow. To be honest, I have no idea about what medications I am currently taking.（TC\_FG5\_20131020， 4：30-7：30 ，P19/M，

My family doctor told me that I have diabetes, and I do not know how to deal with it. Doctor asked me to take medication so I will just take medication. (P23/M, GAV\_FG6\_20131021, 00:46)

It would be great if there has magazines especially for diabetes and published world widely, and we go and buy them ourselves. Because it was researched by the experts, so we believe in it. Right? Official stuff. Currently on newspapers it says something that could cure diabetes, but who knows it works or not? It sounds wonderful…The publication must comes from specialized research institute, so that it will have more credibility, and only then I am willing to trust it. (The magazine you just mentioned are published by research center?) Yes, I mean magazine with authority.）(P24/M, GAV\_FG6\_20131021, 15:10-16:15)

Just offer us health talks on health care. What’s the treatment, and how to take care of it? For example, how to take care of eyes for diabetes patients, how to prevent complications, prevent stroke and heart disease? (Do you necessarily need doctors to provide the health talk?) Not necessary, experts will be fine. (For example how do you think if nurses provide this kind of health talk?) If they have enough experiences in this area, that will totally work out. (P24/M, GAV\_FG6\_20131021, 30:26-32:00)

Of course book would be better, especially by experts with credibility in the field. Isn’t it better if we look at this book? (P28/M, GAV\_FG7\_20131023, 18:37- )

1. **burdensom**e – do not mention the illness (diabetes) to others (including friends and relatives), do not want to see others change the diet pattern/contents due to diabetes

**Do not want to bring burden to family members:** I don’t want they have less tasty food. Shanghainese love sweet stuff, and it is impossible for me to ask them to not put sugar in the food. （P16/M）TC\_FG4a\_20131019

**Do not want to bring burden to doctors and nurses:**

Because the nurses should have the weekends off. … It is impossible for the clinic to provide us with nurse-led support groups in a frequent manner, such as weekly or monthly. In fact, there is an alternative way to do this: all of us can exchange our phone numbers and we will contact with each other if we have time. (TC\_FG5\_20131020 , 23：50-24：25，P18/M )

1. **Ignorance/unaware of self-care responsibility**  (sub theme: passive health seeking behavior) – do not have the concept of self-care responsibility, looking for ‘caring’ or perceive that some one care about me

I went to not so much health talks. Nobody asked me to go. I would go if someone call me to go.(P6/M)

There are not so many available health talks here. Usually it is a lot better for adults aged 65 years and older with Medicare, however one cannot have Medicare unless he or she reaches 65. (P4/M)

I know that health net has health talks, but I do not belong to any health net, therefore I received less information. （P2/F）H\_FG1\_20131017, 37：20-38：20

When I started taking medication, I have no idea about what counts as high blood glucose, what counts as low, and what is normal. I only know that doctor told me I have diabetes. Usually I don’t take care of I particularly. I think I am the way I am and nothing serious will happen to me. It has been a long time that I take whatever doctor prescribes. I do not have any special way. It is just fine that doctor said that I am doing OK. I am the kind of person who believes in doctors a lot. Whatever doctors told me I will follow. To be honest, I do not even know what kind of medication I am currently taking. （TC\_FG5\_20131020， 4：30-7：30 ，P19/M）

 (1) (P26/M, GAV\_FG7\_20131023-2, 00:12) When I first knew that I am diagnosed with diabetes, I did not care about it. I did not take the medication that doctor prescribed. After two years, it got worsen. I did not think that is something needs my attention. (02:10) Why I did not take the medication? Because my spouse always says that all medications have side effects.

1. **Seeking incentive (positive reinforcement):** Incentive / positive reinforcement is expected; this affect the willingness to attend health talk; Chinese do not always receive positive reinforcement; looking forward to receiving more positive reinforcement; monetary incentive vs psychological incentive

It would be great if someone can remind me. At least I will not make mistakes with the instructions from professional nurses. When you are not doing well there is someone that tells you to be mindful, eat less, and exercise more. Or if you got any questions or feeling uncomfortable there is someone to ask, or talk to. It is good to have that once or twice a week. H\_FG1\_20131017，48：40-49：20 ，P3/F

1. **collectivity, peer learning, being together:** Collectivity – someone call me, I will go; need peers to support; needs spouse to accompany or make decision

I enjoy learning together; it is so boring and not easy to learn by oneself. We can discuss together, exchange our experiences. [I] don’t know what can be done by one person P9/F

Although I prefer to exchange ideas with others, I do not have opportunities to do so. My brother’s [referring to another participant] experience must be different from mine, as our age is different. My brother must be very experienced in what he has been practicing in diabetes care. Also, I am good at what I have been paying attention to. Therefore, it is beneficial for us to exchange our ideas. TC\_FG2\_20131018 ，29：50-30：30，P7/M

(P28/M, GAV\_FG7\_20131023, 08:53) I have a friend at senior center who ate a Zongzi last week, and his blood glucose goes up to 200 plus and 300 plus, very series. After that doctor gave him insulin and then he’s condition was in control. I will ask him what brand of the insulin he’s taking and I will discuss that with my family doctor. (So you and your friends with diabetes discuss with each other about diabetes care?) Always.

(P26/M, GAV\_FG7\_20131023-2, 01: 20) Because there are a lot of people have diabetes, so we get to share with others a lot. And it also brought me more attention on diabetes through communication with each other.

1. **Familism** (family member   关心别人) relates to theme 2

 (1) (P29/F, GAV\_FG7\_20131023, 05:04-5:29 ) My family has diabetes history. My father, my big sister, and my younger brother had been diagnosed with diabetes many years ahead of me. So I got a lot of information from them.

1. **no confrontation, harmony relationship** – save face  (relates to theme 1)

What you just mentioned is because older people have more life experiences so they tend not to confront with you although they may think they cannot do that at all. They will give you enough faces. It is another story that they will actually do that or not. Confucius said people who turn 70 years old tend not to break rules. So older people have more control over rules while young people tend to be more insolent and so on. It depends on the age group. （TC\_FG5\_20131020 ，42：35-43：40，P20/M）

1. **(less critical thinking)** or so called ‘**practical’:**

Sometimes we get really busy so we prefer something that could be easily understood rather than complicate stuff. For diabetes patients like us, it is good to be down to earth and let us know what to eat, and how much exercise should be done for a day. We are not medical students so it is not helpful for the doctors to tell us about the complicate pathology. We only need to know the things relate to our condition. （TC\_FG2\_20131018，11：17-11：55，P8/M）

Barriers

1. insurance (low-income) group insurance rate: as Immigrants with low income,

uninsured, not in big company, cash payment as salary

I want to have his eyes and legs checked very much. I don’t know if his vessel is blocked or not. I plan to take him back to China Mainland and get physical check for him. Like in China Mainland, doctors will help you check on your eyes, legs, and vessels periodically since you take the medication. There is nothing here; they only have you checked blood glucose. Big hospitals have those kinds of services but it is way too expensive and we cannot afford. I have been to a big hospital once and the high expenses scared me to death. I have only been there for transfusion and blood glucose test, and it cost me more than $3000. It’s so terrified and I won’t go there any more. Who can afford that? I believe that the equipment is definitely better here in the U.S., however we cannot afford. There is no solution to that. We can only take medication and have no other requests. In China Mainland we have all the big hospitals that have everything, however this small clinic only has the equipment for blood sugar test so we cannot have other tests. TC\_FG2\_20131018 ，1：04：35-1：59：50，P8/m

There is no way to ask for help. I cannot afford to visit doctors because I do not have health insurance. When I was first diagnosed with diabetes, the cost of diabetes medication was one dollar per pill, which was extremely high. [And I] need to take several pills per day. H\_FG3\_20131019， 45：20-47：50 ，P13/F

I have got a lot of bills to pay here in the U.S.. At least a total of eight or nine hundred dollars for a month. In China we have our own apartment, so besides pay the cost for buying the apartment there is no need to pay the tax. The utilities fee are very flexible, you pay more when you use more. Also I can go eat at friends’ places, say if go to Zhang’s for today and Li’s for tomorrow. In the U.S. everybody are just so busy so people have no time to have dinner with you. It’s more stressful here living in the U.S.. TC\_FG5\_20131020 , 47：40-48：25，P18/M

1. transportation: do not drive, wait for children to drive them, restrict to live in the neighbourhood

 (1) (P23/M, P22/F, GAV\_FG6\_20131021, 28:28) (Where do you think the health talked should be provided?)

The closer to us the better. We cannot go if it is far away.

My blood glucose goes up and down, which is unstable. My daughter keeps calling me and wants to pick me up because I fainted on the street twice. I told her that I would be going home by public transportation. She was still worried and asked me to be careful. TC\_FG5\_20131020，44：58- 45：30，P21/F

1. accessibility of information; different measurement, read Chinese web, never read ADA website, inconsistence between the scale in Chinese website and American system

Although I am in America, I still look for things [health information] from China. That stuff [health information] works for me better

Language barriers. We do not understand English. There are so many mails in the mailbox that we do not understand. For example if you use a American way to send me a mail, I have a look at it and it is all English. It feels like looking at a blank paper. I do not understand. It is useless. TV programs in English and website pages in English are useless for me because I do not understand. TC\_FG2\_20131018 ，25：53-26：50，P7/M

When I was in China we used scores of 6, 7, 8, 9, 10. I was already confused with Chinese measurement of blood sugar. Now I still use it. In China people talks about 6, 7, 10… I had 17 something in my worst time, is it the same as 17% here on this? I just do not know how to calculate this into a Chinese way. When I found I have 17 something I did not know that I have diabetes. It said 17 something in the Chinese measurement. I just don’t know how to calculate it. Now in the U.S. I have a hundred something. I have not look into it. Although I am in the U.S., I still go and look into Chinese materials. Their stuff fit me better. P16/M， 16：15-20：00， TC\_FG4a\_20131019

Public education on diabetes is limited in the Chinese-speaking community. There are many English-speaking programs; however, these programs do not suit us. These programs can be costly. Although United States has good welfare, it is still limited in this area. It is impossible for health professionals to reach out to every household. **TC\_FG2\_，**26：28-27：00，**P8/M，**

1. understand the American health care system: doctors are not for primary care, but patients expect doctors to educate them in self-care

**Themes identified in older adults’ focus groups**

1. **barriers**: can learn by themselves by reading, prefer quiet reading, not willing to join health talks

 (1) (P23/M, GAV\_FG6\_20131021, 01:00-01:22) I want to learn knowledge on treatment and prevention. I wish that I could receive hard copies of the information.

 (2) (P22/F, GAV\_FG6\_20131021, 09:29) Usually I read magazines and newspapers, something like that. I have a clear knowledge in this area.

 (3) (P23/M, GAV\_FG6\_20131021, 19:15-19:35) Just give us the information of the current treatment on diabetes, things need to pay attention to, and exercises that are helpful to us via hard copies.

 (4) (P24/M, GAV\_FG6\_20131021, 24:24-24:42) People like us with higher education level do not need to read this comic book. It costs more to make these picture books, and it is meaningless to look at this pictures and figures. However for patients with diabetes, every single word in this leaflet is helpful to them.

 (5) (P23/M, P22/F, P24/M, P25/F, GAV\_FG6\_20131021, 38:25-39:27) I prefer to read books by myself because it is so hard to arrange for the time of a study group.

 (6) (P28/M, GAV\_FG7\_20131023, 15:00-15:50) It is better to read things. If not understand something by the first time you can always go back and read again, ask others for explanation, or discuss with others. It is hard to understand and unclear to listen to audio materials. It is easy to read.

 (7) (P27/F, GAV\_FG7\_20131023, 15:50-16:35) Our life here is very boring and simple, so we have plenty of time. We got memory loss a lot, so we need to read over and over in order to remember things. It is hard to remember things by listening to audios, and it is hard to focus one’s attention by listening.

(8) (GAV\_FG7\_20131023, 27:30)

P27/F: We read by ourselves because different people have different ways of dealing with problems.

P28/M: It is better to study with others. Through communication there is always new information.

P29/F: It depends on whether the study group organizer is trying to popularize knowledge or disseminate the most updated knowledge.

1. **contents**: any new information (all new information is dispatched in English – no Chinese is available), interested to know how to access to the information – Chinese translated information is not the original source, even write to the editor will not be to respond

 (1) (P24/M, GAV\_FG6\_20131021, 13:37-15:27) Now I gather information from books and magazines which are very limited. Now there are books on bitter melon says it can be used as treatment for diabetes. There are other new things coming out that are effective. These new things are not medicine. They could be alternative medicine. They seem like medicine but they are not. I don’t know if we can take them. I heard there is an expert coming to the U.S. from China Mainland, and he has the patent of a product that can cure diabetes. There is so much new information coming out on diabetic treatment. I want to know which are true and which are false. I hope there is something work as a guide to tell us honestly. It would be great if there has magazines especially for diabetes and published world widely, and we go and buy them ourselves. Because it was researched by the experts, so we believe in it.

(2) (P24/M, GAV\_FG6\_20131021, 36:32-37:00 ) (How often to provide a health talk?) It depends on your information. If there were something new then I would love to accept. It depends on your research findings. It is impossible to have new findings everyday. After a period of time new things come up just introduce them to us and that will be fine.

(3) (P29/F, GAV\_FG7\_20131023, 05:52-06:49) But now many things are very superficial, and not comprehensive. If someone who does not have this disease, he wont even know something like this. It is better to go more in depth. The reasons should be told.

(4) (P27/F, P29/F, GAV\_FG7\_20131023, 17:40- 18:10)

P27/F: He now cares about the most up to dated and the most advanced treatment that are easier to bring recovery for diabetes.

 P29/F: I hope to get new knowledge, the most updated ones. These old information like “what is diabetes” I already understood by myself.

(5) (P29/F, P28/M, GAV\_FG7\_20131023, 18:49-19:44)

P29/F: The information on this pamphlet is very basic and already popular. It is no longer needed. It has been a long time so the basic information is no longer needed.

P28/M: Just hope to have new materials. Such as recently, there is a TV show called “Yangsheng Tang”which introduced a way of injecting insulin by an expert on diabetes. By using this method one only need to get one shot and then the condition will be under control, also there is no need for further injection. However just by listening to it is not helpful. If he is writing that down in a book for us to read that will be more detailed.

1. **Still rely on the TV in overseas: proactively contact the TV channels**

(1) (P28/M, GAV\_FG7\_20131023, 08:21-) (So what other new ways you want to get information on diabetes?) Now it is just through watching TV, such as Chinese TV programs, such as “Yangsheng Tang”. Every channel has health talk programs. There is also “Oriental Medicine” that has health talks. I hope watching these programs can cure my diabetes someday.

(2) (P28/M, GAV\_FG7\_20131023, 19:00-21:20) Just hope to have new materials. Such as recently, there is a TV show called “Yangsheng Tang”which introduced a way of injecting insulin by an expert on diabetes. By using this method one only need to get one shot and then the condition will be under control, also there is no need for further injection. However just by listening to it is not helpful. If he is writing that down in a book for us to read that will be more detailed

(If you saw a new treatment on TV, will you try to get more information on that by any means and try it? Or you just want to learn about it?)

I want to look for it. I have been mailed with “Chinese Medicine”in Beijing Channel. However I don’t know how to get connected with “Yangsheng Tang”. However “Yangsheng Tang”showing things too fast without displaying the medicine. It goes away very fast.

(So the TV Channel is not from the U.S.?)

No. It’s by CCTV. Our English is not good so we cannot watch English TV programs. So we just watch Chinese Channels.

**Other key points for GAV seniors**

1. Not following others, test and adjust by self.

(1) (P24/M, GAV\_FG6\_20131021, 03:48-04:14) I used to see elders in my company got diabetes and became very sin, and then they died. I used to ask them and they are hesitating to eat this and that. So I don’t want to be like that. I eat everything. I check my blood sugar and see if it is within the normal range. How much does it go up, or below? I eat things according to this, and keep this habit until now.

(2) (P25/F, GAV\_FG6\_20131021, 09:50-10:54) Basically I seldom have my blood sugar within the normal range, so that’s not right? I have taken medication for two months and then stopped. After that my blood sugar is always within nighty something. Then I visited doctor and the doctor said I still need to take the medication. You must follow doctor’s instruction. So now I take medications everyday. It is also not good to take too much medication.

 2. Influenced by their physical condition

(1) (P25/F, GAV\_FG6\_20131021, 25:17-25:21) I haven’t use internet and apps before because my vision are very bad now.

(2) (P22/F, GAV\_FG6\_20131021, 25:26- 26:00) We are old now, sometimes we are forgetful. I do not want anything [health education]. I used to learn how to use a computer. When I learnt it, my eyes were not capable, my lower back was not capable. I cannot sit for a long time. So I want the simplest [health information], I don’t want those complicated things.

(3) (P23/M, GAV\_FG6\_20131021, 33:30-34:45) Health talks cannot last long. Elders cannot sit for a long time, at most twenty to thirty minutes.

(P23/M, GAV\_FG6\_20131021, 34:49) (Do you want to do any activities?) No activities. Because for my age, I will not have any more energy to listen after an hour class. Just keep it simple.

(GAV\_FG6\_20131021)

32:10: Traditional Chinese Medicine.

33:33, 33:50 Health talks should be thorough.

37:45: Health talks should be attractive and vividly. People don’t understand jargons. It should be easy to understand.

39:30: It is good for the teacher to have simple and direct way of teaching. Don’t make it too complicate. Implanting style will be OK.

42:40: I prefer to call and ask nurses and doctors directly. (P24/M)

 Too much phone calls will be annoying. I am afraid of advertisement.

45:12, 47:02: Old people do not want to bring burdens to young nurses. (P22/F)

(GAV\_FG7\_20131023)

05:38-05:52: The more variety of types the better. (P29/F)