

**Research Article**

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# How Misconception of Insulin Therapy Affects Type 2 Diabetes Mellitus Patients' Acceptance on Daily Injection



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## Abstract

**Objectives:** To find out the development of misconception that leads to Psychological Insulin Resistance in type 2 diabetes mellitus patients.

**Methods:** 24 focus group interviews of 124 insulin naïve Chinese patients were held in 11 primary care clinics. Thematic analysis of the interview transcript was based on patient's expectation of insulin injection in their physical, psychological and social view, to identify the origin of negative attitudes.

**Results:** Three main sources of misconception are: 1) lacking adequate knowledge, 2) conflicting medical advice, and 3) hearsay from community. Most participants never saw the insulin pen. Patients deferred insulin commencement because they could choose among different clinicians' medical advice. Patients commonly keep peace of mind rather than trying daily injection. They took daily injection as a stigma and ignored the possible DM complications.

**Conclusion:** Different parties contributed to the development of misconception on insulin therapy. Clinicians should identify and control patients' possible misconceptions.

**Keywords:** Qualitative research; Treatment refusal; Insulin; Diabetes mellitus type 2; Therapeutic misconception; Hyperglycemia

## Introduction

Type 2 diabetes mellitus (T2DM) is increasingly prevalent worldwide. In order to reduce complications, insulin replacement therapy is frequently required because of the progressive nature of T2DM [1]. However, patient refusal of insulin is often found [2] as a result of psychological insulin resistance (PIR), which means a strong negative attitude against insulin therapy [3]. When comparing to the western countries (28% [4]), the prevalence of PIR has been particularly high in Asia (70.6% [5]). PIR involves such a wide range of adverse emotions and practical concerns as questioning the necessity to intensifying medication by insulin, pain, phobia, failure, fear of side effects, operation of insulin pen, economic cost for insulin therapy, language barrier, inadequate knowledge, poor social support, perceived damages on personal image, social life and perceived clinicians' negative attitude towards insulin [4]. In line with the higher PIR in some ethnic groups, it was well-documented that female [5], people

with lower income, lower educational level [6], older age group [7], lower glycosylated haemoglobin (HbA1c) level [8], being insulin naïve [9] were more unwilling to commence insulin.

Clinicians have tackled PIR as a complex and multifactorial phenomenon by patient-centered approach and through the recommended clinical practices. Most countries including Hong Kong have at the same time adopted newer insulin delivery devices, commonly insulin pen, with shorter and thinner needle that enables injection ease and reduces pain. It is therefore pressing to examine why PIR still commonly circulates among T2DM patients, especially those relatively older, with lower income and lower educational level. This study adopts a qualitative research approach to take a close scrutiny of how patients acquired different knowledge about insulin therapy, and why negative perceptions and emotions are resulted from this knowledge [10]. The findings from this study advance insights

for formulating proactive strategies that may possibly enhance the acceptance rate of insulin injection.

**Methods**

**Setting**

The study sites were eleven government-funded primary care clinics, where provide health care for more than 25,000 people with T2DM in urban Hong Kong annually. The majority of the visiting patients are older Chinese, relatively less educated, and from the lower social economic class [11]. The consultation fee for each visit is USD6. All prescriptions and investigations are free of charge. Some patients not only consult the clinicians in public setting, but also pay out of their own pockets to attend the private clinics and other practitioners for health care services

Since 2009, some of the public primary care clinics have provided insulin commencement for indicated T2DM patients. Free-of-charge injection pen and vials of insulin are provided. Patients only need to pay for the needles of injection pen and the consumables for self-glucose monitoring. However, the successful cases of commencing insulin remain a few. From 2010 to 2012, only less than 4% of patients with T2DM had successfully started on insulin therapy [11].

**Participants**

This study included insulin naïve T2DM patients on maximum tolerated dose of oral antidiabetic agents (OAs). Their latest haemoglobin A1c level was  $\geq 7.5\%$  (58.5 mmol/mol). Subjects under 18-year-old or being pregnant were excluded.

**Study design**

The moderators conducted focus group interview by asking

broad views from participants about insulin therapy, before asking focal questions on the development of misconceptions. Focus groups were used in order to collect group interaction that encourages participants to explore and clarify attitudes, priorities, group norm and cultural value [10]. All participants offered their written informed consent.

The interviews were conducted in clinic meeting rooms from June 2013 to May 2014. Each focus group interview ran with 3 to 8 participants and lasted for 60 to 90 minutes. One moderator (one of the authors) and one observer (research assistants) were arranged to conduct the focus group interview in Cantonese (one of the Chinese language) according to the standard interview protocol-(Supplementary Data S1). Investigators avoided interviewing our own patients. The focus groups interviews were terminated when data saturation was reached after 24 focus groups, where adding participants to the existing samples unlikely to generate any new ideas [10].

**Data analysis**

All focus group interviews were recorded as digital audio files and transcribed verbatim into Chinese. The transcript was entered into NVIVO 10® (QSR international) in Chinese for data analysis. A coding tree with definition and operational guidelines for each code was formulated. The authors employed thematic analysis to identify important themes, patterns, features, meanings as well as issues and stories. Finally, FU translated the selected data into English. Cheung then translated the transcript back into Chinese to assess translational equivalence. Discrepancies between the original Chinese items and back-translated items were reviewed and modified by all authors.

**Results**

**Characteristics of participants (Table 1)**

**Table 1:** Participants Characteristics.

Participants	Frequency (n=124)	Percentage	Mean	Standard Deviation
Male	60	43.7%	--	--
Female	64	55.3%	--	--
Age (47-89)	--	--	68.1	8.93
<b>Need to pay for consultation? (HK\$45 per consultation)</b>				
Need to pay	99	79.8%	--	--
No need to pay	25	20.2%	--	--
<b>Occupation</b>				
Not being employed	99	79.8%	--	--
Being employed	25	20.2%	--	--
<b>Education</b>				
Primary or below	83	66.9%	--	--
Middle school	23	18.5%	--	--
High school	12	9.7%	--	--
Tertiary or above	6	4.8%	--	--

Clinical history				
Body mass Index	[18.1-41.3]	--	25.8	4.28
Number of years since DM diagnosed	[4-55]	--	15.0	7.6
Latest HbA1c level	[7.5-11.4]%	--	8.4%	1.05
Number of kinds of oral DM drugs				
One type (biguanide only)	2	1.6%	--	--
Two types (biguanide and sulphonylurea)	96	77.4%	--	--
Three types (biguanide and sulphonylurea and other any other group)	26	21.0%	--	--
Other significant medical illness				
Hypertension	81	65.3%	--	--
DM complications (Microvascular only)	45	36.3%	--	--
DM complications (Macrovascular only)	5	4.0%	--	--
DM complications (Mixed)	6	4.8%	--	--

Note: DM = Diabetes Mellitus

\* Reasons of “no need to pay” includes being staffs or dependents of government or hospital authority, on social security scheme.

\*\*Not being employed includes being housewife, retired, or unemployed.

\*\*\*DM complications includes any microvascular or macrovascular complications related to DM.

124 participants (mean age= 68.1, M:F ratio = 0.94) were interviewed in 24 focus groups. Most participants (84.6%) were not in full time employment (i.e. housewife, unemployed or retired). Their educational level was relatively low: 66.9% attained primary school education or below, while only 5%

received tertiary education. Their mean latest HbA1c amounted 8.4% (68.3 mmol/mol) and that indicated poor glycaemic control. The majority (98.4%) were prescribed with two or more types of OAs.

**Table 2:** Characteristics of Participants in Different Focus Groups.

Group Number	Clinic	Number of Participants	Age	Male: Female Ratio	Educational Level*	Mean of Years of DM Diagnosed	Mean HbA1c (%)	Employed: Not Employed ratio	Group Characteristics
G1	A	6	66-89	2:4	1	20.7	8.7	0:6	Retired, old aged, lower education level
G2	A	4	55-70	1:3	1-2	11.25	8.2	2:2	Mixed
G3	B	5	66-81	2:3	1-4	13	7.7	0:5	Retired old aged
G4	B	6	57-64	1:5	1-3	15.8	8.4	0:6	Not employed
G5	C	7	68-81	3:4	1-4	17.9	8.7	0:7	Not employed
G6	D	6	56-87	1:5	1	18.2	8.4	2:4	Lower educational level
G7	C	4	52-64	2:2	1-2	11	9.5	4:0	Younger employed
G8	C	4	57-64	2:2	1-3	17.8	9.2	3:1	Younger
G9	E	6	71-86	1:5	1	21.8	7.8	0:6	Retired, old aged and lower education level
G10	D	7	57-77	3:4	1-2	14.3	8.5	0:7	Not employed
G11	D	4	53-83	2:2	1-4	15.5	9.0	0:5	Not employed
G12	F	5	63-77	5:0	1-2	16.4	7.9	1:4	All male
G13	F	5	61-71	0:5	1-2	10.2	8.9	0:5	All female housewife
G14	G	4	66-85	1:3	1-2	12.0	8.9	1:3	Old aged

G15	E	2**	71-77	0:2	1	11.5	8.2	0:2	All Female, Retired
			77						Lower educational level
G16	H	4	51-76	3:1	1-4	13.0	8.7	1:3	Mixed
G17	H	3	49-66	3:0	1-3	10.7	8.2	3:0	All male employed
G18	I	6	58-80	2:4	1	17.7	8.7	0:5	Not employed lower educational level
G19	I	4	62-86	3:1	1-2	14.8	8.4	0:5	Not employed
G20	J	5	54-77	1:4	1-2	12.0	8.7	0:5	Not employed
G21	K	6	63-82	4:2	1-4	14.7	8.6	0:6	Not employed

\* 1 = primary or below; 2= middle school; 3 = high school; 4 = university or above

**Major findings**

The characteristic of different groups were shown in Table 2. Misconception in this study refers to any inaccurate idea, belief, myth, presumption and conjecture that deviate from the proven

medical knowledge. The three main sources of misconception among the participants are: 1) lacking adequate knowledge 2) conflicting medical advice, and 3) hearsay from community. All participants' names were replaced by assigned number P1, P2, P3, etc. Group names were assigned as G1 (Group 1), G2, etc.

**Misconceptions from lacking adequate knowledge (Table 3)**

**Table 3:** Lacking Adequate Knowledge.

Themes	Focus Group Number	Participant Number	Sex	Age	Selected Verbatim Quotes
Necessity, effect and side effect of insulin therapy was not discussed	G4	P41	F	62	P42: When you go inside (the consultation room), the doctor has already printed out the prescription. We chat a little and then everything is ready.  P41: Then go to the dispenser  P42: Because the regimen is the same. It's fixed.
		P42	M	61	
	G17	P86	M	63	Oh ... I was just told to do injection (therapy), I don't know the details, such as frequency of injection daily, and the treatment duration. I heard that there will be no end to injection (therapy), but I'm not quite clear. ... But I've heard many opinions about injection (therapy). Some said it can instantly control the condition and you can stop taking oral drugs. Others said you'd still need to continue with oral drugs even if you do injection (therapy). It's so confusing.
	G6	P30	F	61	I don't see any difference. I work in an elderly home with two residents injecting insulin. The man ate without restriction, but the woman was on strict diet and won't eat anything with high sugar content. Yet her blood sugar level is still as high.
	G7	P34	F	81	Injection therapy is not necessarily good (for me). I had to take 6 tablets before starting injection. Now with injection, I still have to take 6 tablets. So why bother with injection therapy?
G6	P31	F	55	The doctor won't tell you that (insulin) injection will destroy the pancreas. ... I heard that (insulin) injection gives (your body) insulin directly, causing the pancreas to stop producing insulin on its own and thus be destroyed. Of course I'd be afraid. ... If there's a disease, you'd want to treat it instead of having organ failure. ... But those oral drugs will not affect the pancreas, there is no side-effect.	

Patients were not familiar with insulin pen and the injection process	G17	P86	M	63	You need to clearly spot the right blood vessels and know how deep to puncture. You can't simply inject, you can't. You need to learn and practice how to correctly puncture the vessel. ... If you puncture at a wrong angle, it'd be extremely painful. If the nurse injects for you, you'd not feel too much pain; s/he must learn to do it well, otherwise you'd suffer from much pain. You'd bleed profusely if you puncture incorrectly, right?
		P88	M	70	I don't know how to inject, right? Even the nurses had to learn it for several years, right? I'm an elderly patient, (if I inject myself) the needle might just break and I'd be dead. ... The broken needle will circulate inside my body.
	G15	P79	F	53	If you go out, or sometimes you want to go traveling overseas, you have to bring along the needles and injection medicine. Some medicine needs to be stored in the fridge. ... If I travel for 8 to 10 days, it'd be very inconvenient. ...
	G7	P34	F	81	(Describing the use of the syringe) You have to flick it, press it, inject it, hold it, sterilize it ... Wow! There are so many steps, don't bother me, I won't be able to remember.
	G9	P51	F	81	I can't do injection (therapy), I'm blind, I don't know how to inject, the words (on the syringe) are so small, how can I do it? ... You have to inject at the umbilicus, and then on the buttock, and then on the sole. ... (It's too difficult to learn.)
	G10	P52	M	78	I heard from my neighbors, that you'll die if you overdo the injection (therapy)!
	G19	P85	F	61	The needle is this long (using her fingers to show around 2.5 cm)! ... How do you know if it won't puncture your guts?
	G16	P88	M	70	... Injection is very dangerous. ... It can only be done by people who are knowledgeable. You might just inject wrongly if you do it yourself. ... You might become handicap (from the injections) like the drug addicts.
Concern on the cost of insulin therapy	G8	P41	F	62	There are lots of 'holes' (injection scars) on my son's (an insulin user) tummy. ...When I initially helped my mother to inject (insulin), her muscles were so tensed, it was very difficult to inject. ... Sometimes my mother appeared to be in so much pain. ...Someone eventually taught me to use a hot water patch to help relax the muscles.
	G10	P57	F	66	Taking the injections will cause the tummy (muscles) to become slack. I don't like that, I'd rather die!
	G18	P93	F	66	(Describing her husband, who uses insulin, having hypoglycemic attack) His speech became non-sense; he was very confused and didn't know what he was doing. He kept hitting me with a rod to the extent that I had to call 999 (the police). When the ambulance staff arrived, his blood sugar level was so low, he seemed to have transformed into a different person. Having experienced this, I'm worried that our house might turn into a mental asylum if both of us were to have hypoglycemia (attacks at the same time).
Concern on the cost of insulin therapy	G17	P86	M	63	(They say) the medication will be provided by the clinic, but I have to buy the needles myself. I heard it's going to cost several thousand dollars, and I don't know if that's for one month's supply or a few months'. ... I have to buy the needles at designated places. ... (I expect) It'll cost over HK\$40000 (USD5,000) per year.
	G13	P68	F	81	They (my family) won't be able to afford it (hiring a domestic helper) ...
	G7	P34	F	81	It's so expensive, 25 sticks cost \$250 (USD 32), I mean the glucometer stick. It's really not easy to be a DM patient. ...

Most participants confirmed heavy psychological burden such as fear, anxious, shock, depressed if they had to commence insulin as most of literature description [4]. Almost all participants did not know or could not give accurate information about insulin pen or injection process.

**Necessity, effect and side effect of insulin therapy was not discussed:** The discussion between P41 (female, 62-year-old) and P42 (male, 61-year-old) in G4 described an extreme situation of the communication with doctors. Doctors would print out prescription sheet few minutes after consultation started. The patients therefore felt that there was no need to understand insulin therapy. Others participants reported that they would strongly challenge their doctors about the necessity of using insulin therapy. While they recognized that the effect of oral drug would be diminishing, they had no idea about

the effectiveness of insulin therapy, particularly what was its difference from oral drugs in controlling blood sugar.

Likewise, discussion of the side effects of insulin was insufficient. Three participants P31 (female, 55-year-old), P75 (male, 70-year-old) and P88 (male, 73-year-old), from 3 focus groups expressed a shared worry that exogenous insulin would take over remaining pancreatic function and thereby result in organ (pancreas) failure. They suspected direct injection of insulin was overly potent. It would therefore stop pancreatic cells from producing insulin. Other commonly exaggerated insulin side effects include chronic neuralgic pain, profuse bleeding, broken needle, punctured internal organ and consequential scars over body with many holes, and subsequent changes of skin texture and colour. Air bubbles might be injected into body that could result in death. Few participants described their observation

of hypoglycemic attack of their relatives. The victim became uncontrollable, insane and unable to handle. Collectively, insulin injection should be avoided at all cost for self-preservation.

**Patients were not familiar with insulin pen and the injection process:** On the contrary to the existing research finding that most insulin naïve DM patients were familiar with insulin pen [12], most participants in this study never saw an insulin pen, much less the injecting process. Consequently, some participants associated injection of insulin with what they saw and felt in their existing experience from their visits to clinics or hospitals. The needle is a much longer and bigger, 20 or 25 -gauges and 25 to 30 mm long. This explained why some participants were prompted into anxiety, fear of pain, phobia of blood, and other physiological responses (e.g., chills, rigor, sweating and palpitation).

Participants generally perceived that the injection of insulin was a complicated process requiring intensive professional knowledge and training. The storage of insulin, the sterilization of instruments, and the steps for injecting were all highly demanding and rigorous. Some participants illustrated the difficulty of injection by their clinicians' multiple attempts

before successful venepuncture even though they were professionally trained. Injection of insulin was definitely beyond their literacy, knowledge and ability to handle. Various sites for insulin injection were also aired amongst the participants such as buttock, cubital fossa, umbilicus, anus and even the sole. It bothered much more the older age group because of their illiteracy in English, some also in Chinese, and their decline in eyesight and hand functioning.

**Concern on the cost of insulin therapy:** Given that most participants came from the lower socio-economic class, they worried much about the cost of insulin therapy. Some participants thought that they had to buy the pen and injection medicine from their pocket. In fact, people on insulin therapy only need to buy the needles of insulin pen that costs HK\$200 (USD25) per month. The cost would be reimbursable if they were on the social security scheme. However, nearly none of the participants were clear about the policy. P86 (male, 63-year-old) even estimated the regular expenses for insulin therapy to be up to HK\$40,000 (USD 5,000) per year. In line with the drug cost, P68 (female, 81-year-old, lives alone) worried about the additional financial cost for employing a helper to perform injection for her.

**Misconceptions from conflicting medical advice (Table 4)**

**Table 4:** Conflicting medical advice.

Themes	Focus Group Number	Participant Number	Sex	Age	Selected Verbatim Quotes
Newer and more expensive oral drugs is equally effective as insulin	G8	P42	M	61	If the Hospital Authority has yet to offer this (new) drug, we can buy it outside. If we can afford the new drugs, we can choose not to start insulin therapy, right?
	G13	P70	M	71	...Actually, private doctors provide more drug choice (than government doctors). If my children are willing to pay the medical costs, I will try to get other oral drugs (from the private doctors). If they can't afford it, I can only come back and do whatever the doctor tells me to do (i.e., start injection therapy).
	G15	P81	M	70	The doctor did not ask me to start insulin. ... Taking oral drugs works best for me. ... I went to XXX Hospital (private) and they changed my drugs. The doctors there told me, "Your condition is much better now!" I'm really happy. ... The (oral) drugs are really very effective.
Different clinicians gave different treatment recommendation	G6	P31	F	55	At one point, the doctor asked me to start injection therapy. During the next visit, she asked me again, but I still preferred not to. Then she said, "You probably won't need that yet." So what does she mean? How can I trust her when she is so inconsistent? As a patient, I don't understand the doctor's intention. ...
	G9	P49	F	68	I was sent to the hospital (Emergency Department) because of high glucometer readings. Doctors from the public hospital advised me to continue with oral drugs instead of starting insulin therapy, and then he sent me home. Afterwards I consulted a private doctor, and he asked me to start insulin therapy.
	G12	P65	M	64	He (the doctor) said I'm already so old, and I should just continue taking oral drugs rather than starting injection therapy. Every doctor gave different advices. ...I asked if it'd be better for me to start insulin injection, but he (the doctor) said it was too risky... A few doctors said the same thing. ... I just saw a new doctor. This time he suggested that I should start insulin therapy.
	G16	P86	M	63	I want to know for sure whether I'd need to take oral drugs if I start insulin injection. Because some doctors said I need to continue with oral drugs even if I started insulin injection, but others said I could stop the oral drugs. I'm so confused now.
	G9	P48	M	75	Traditional Chinese Medicine can treat DM by acupuncture. After trying acupuncture for 1 month, my DM is well controlled, (now) it's usually 4-5 (mmol/l), no more than 6 (mmol/l). ... It's less than 8 (mmol/l) after food, it's rather good. (His latest HbA1c was 7.7%, he graded his DM control as mild.)

Most participants reported that the continuity of care from public and private doctors for their chronic illnesses was generally poor and the consultation time was short and erratic. If different clinicians gave different opinions, it confused patients of which DM treatment was the best in their condition. As a result, most participants simply chose the advice that supported their intention to delay or avoid insulin therapy.

**Newer and more expensive oral drugs is equally effective as insulin:** Many participants believed newer generation of OAs that was ever effective and potent in controlling their blood sugar. The switch to insulin therapy was therefore deferrable if one could afford the expensive newer generation of OAs. P58 (female, 55-year-old) claimed that she regularly attended both public clinics and a private doctor. While her latest HbA1c had been already up to 10.7% (93.4mmol/mol), she appreciated her private doctor who reassured and prescribed her with “drugs not available in public clinics”. She adhered to oral therapy and

had no intention to start insulin therapy. Such form of personal presumption gives rise to a myth in real life: the deferability of insulin therapy depended on money.

**Different clinicians gave different treatment recommendation:** The most common advices from clinicians were “you should be more careful about what you eat”, “you should get out and move about” when the participants’ blood sugar was high. They have an impression that one’s success or failure in maintaining the optimal blood sugar level was solely a matter of diet and lifestyle control. Other advices from clinicians suggest the patients to the contrary that is to make no change. P65 (64-year-old) knew that his blood sugar was always high, which was harmful to his health. He was hesitated whether he should start insulin therapy or not. Some doctors encouraged him, but one of them told him that he was too old, and therefore too risky to start insulin therapy. Overall, our participants commonly perceived clinician’s negative attitude towards insulin.

**Misconception from Hearsay from Community (Table 5)**

**Table 5:** Hearsays from Community.

Themes	Focus Group Number	Participant Number	Sex	AGE	Selected Verbatim Quotes
Preference of avoiding “invasive” therapy, keep peace in mind	G18	P96	M	75	(In response to question: Do you think you would develop the DM complications as mentioned previously because of high blood sugar level?) No. ... I can’t say for sure (if I’d develop complications), but I’m happy as long as my condition remains as it is now. Even if complications were to develop, there’s nothing I can do. It doesn’t help even if I’m afraid. You know, one will eventually die anyway.
	G15	P81	M	70	You might still die even if you start insulin injection. ... I’m already in my 70s, why would I do injection (therapy)? I’ll rather have peace of mind. I’m definitely not starting injection therapy!
Focusing on current body functioning rather than future unpredictable risk of complications	G8	P44	F	64	I fear injection, I refused injection therapy when the doctor suggested it. For me it’s ok, I can just control my diet and take things as they come. ... No, I don’t know there’d be complications.
	G18	P93	F	66	Each time they (clinicians) found my blood sugar level to be high, they’d ask me to do a urine test (for ketones). ... After the test they always told me things were ok. ... (If they said it’s ok) I take it as I’m ok. ... (In response to question: Do you think you would develop the DM complications as mentioned previously because of high blood sugar level?) No, I think I’ll be ok.
	G18	P94	F	85	(In response to question: Do you think you would develop the DM complications as mentioned previously because of high blood sugar level?) That’s not related (to my condition) I’ll be fine as long as I watch my diet. ... It’s like DM doesn’t affect me, but (if I start injection therapy) I’ll be inviting trouble by injecting myself. What if anything happens to me as a result? What if I fainted? Right?
	G19	P103	M	49	(In response to question: Do you know what will happen if your HbA1c level keeps remaining at 7-8%?) Yes. ... It can affect the brain and eyes. ... But even if the blood sugar level is lowered, there will still be other kinds of complication
	G8	P41	F	62	You can’t recover (from DM), there is no way to prevent (DM complications). ... My mother still developed complications after 15 years of insulin therapy. ... She died so suddenly.

5.5.3 It's stigma to use insulin, but not to use oral tablet	G14	P75	M	73	I feel really depressed. ... I keep thinking about the doctors forcing me to inject insulin, that means I am terminally ill and beyond treatment. I can no longer control it with hiking (more exercise).
	G8	P44	F	64	It's just like being given a death sentence, when you have to inject (insulin) every day. It's unacceptable to me.
	G18	P95	F	66	I need to take (DM oral) drugs, and people often ask what medication I'm taking. I just tell them they are vitamin supplements. I won't tell them I have DM. ... Sometimes others might wonder if they should keep a distance from you. ... Actually, is DM contagious?
	G18	P94	F	85	You know the Cantonese, if they know you have a certain illness, they might think you will spread the disease. I don't dare to tell other (about my DM). ... I don't have much knowledge. ... So I only tell my close relatives (about having DM). ... I feel that others will discriminate against me because of my DM.
	G19	P100	M	76	(Describing other people's respond to own DM condition) Wow, you are always injecting insulin! If you are eating with us, will you spread any serious illness to us? ... People think your condition must be very severe, and worry if it's safe to eat with you. Human mind is very complicated. ... People tend to have many considerations.
	G6	P33	M	58	(Other people may think) You are not restricting your diet, you are not exercising. They will view you negatively. ... If you have to inject insulin during work, it will also affect your work. ... I think I will try my best to keep it a secret.
	G6	P30	F	61	You have to inject in private. It's impossible to do it at a Chinese restaurant with thousands of people around. If you lift up your clothes (to inject insulin) there, people would think you are behaving inappropriately. ... People will stigmatize you.
	G11	P61	M	52	If you have to inject insulin in private and others think you look suspicious, they might mistake you for a drug addict.

Discussions from focus groups showed that most participants were haunted by the rumours and myths from one's social circle and from the media such as newspaper and online discussions.

**Preference of avoiding "invasive" therapy, keep peace in mind:** The older participants often expressed their will of keeping peace in their remaining life because their age is approaching the end. Any procedure or treatment that would increase physical suffering should be avoided. They preferred minimal use of drugs in any form. They believe that self-injection could not improve their health but only add suffering. Some of the participants even regarded daily injection as "torturing their remaining life."

**Focusing on current body functioning rather than future unpredictable risk of complications:** In order to justify their resistance to insulin injection, many older participants cited the hearsay from community that the rise of DM complications was independent of the blood sugar control. Most of them at the same time denied their risk of having complications because they had been well-disciplined in diet control and regular exercising. They did not experience any disabilities or ill-health sensation at the moment. They would emphasize current situation and would not bother "future risks".

**It's a stigma to use insulin, but not to use oral tablet:** Most participants favoured the oral therapy largely due to their concern on self-dignity and social status. Some of them would like to cover up their condition of having DM. Others

did not mind being known the need of regular oral drug-taking always because it was generally acceptable in the community. Even when others saw them taking oral tablets, P95 (female, 66-year-old) said that she could simply lie that she was taking vitamin supplement when she was questioned. Similar to other research finding, the use of insulin in the Chinese peoples' view represented a person to be really sick [13], P44 (female, 64-year-old) expressed that she would feel like "being given a death sentence" if she had to inject insulin every day. P75 (male, 73-year-old) from G14 claimed that he would be depressed if he had to commence insulin. He used to reduce his blood sugar by increasing the amount of physical activities. Failure to reduce blood sugar by his own effort meant that he lost control of his own body. Other participants also associated insulin users with some negative images such as the drug addict. The association was not only their personal imagination but also a common sense in the community. They thus found it egregiously stigmatizing if others knew that their body functions relied on daily injections. The comment from P100 (male, 76-year-old) was illustrative: "people would look down on you if they know you are using needles. ... They probably think that you have a contagious disease!" This was particularly troubling to participants who were employed, such as P62 (male, 58-year-old). Their main concern was that if their colleagues saw their daily insulin injection, they might be viewed as a "weak," a "handicapped," or a "criminal." Consequently, they might lose their job.

### Discussion

This is the first study in Hong Kong that adopts a qualitative approach to investigate insulin naïve T2DM patients' misconception on insulin therapy. The participants' socioeconomic background were characterised mostly by not being employed, with lower educational level and lower income. They were comparable with patients generally found in government funded primary care clinics in Hong Kong [14]. The analysis confirms with the existing research insights to the prevalence of PIR, particularly the lack of adequate knowledge on necessity [15], expected effect and unintended side effect of insulin therapy as profuse bleeding, severe skin reactions, injection process, patients' concern on treatment cost, stigmatization associated, patients' attitude of preference to oral tablet [16], and the concerning quality of health at the moment, but not future risk of complications [17] from most of the participants.

This study advances several new insights into patients' lived experience of how and why they became poorly informed about the treatment options. There were multiple sources from daily knowledge to social network. First of all, the DM patients in this study were not familiar with the insulin pen as the DM patients from other countries [12]. Many patients in Hong Kong primary care setting have never seen the insulin pen, much less understanding of the injection process. Under consultation time constraint, there were few opportunities for discussion about insulin therapy in either causal or structural manner. The result of poor patient-clinician communication was that many patients would favour and accept hearsays. Some would even believe that exogenous insulin was toxic to pancreatic cells, and speeded up organ failure.

This study also found that the presence of conflicting medical advice opened the rooms for patients to run upon their preference for treatment. Without a consistent medical advice for the switch to insulin therapy, patients occurred to distort what the clinicians suggested them to do for their health in various manners. For instance, when doctors suggested newer generations of OAs and insulin as options of managing hyperglycemia, patients might interpret the newer drugs as replacement of insulin therapy. While clinicians advised patients to maintain a proper diet and lifestyle, patients might believe that the blood sugar can be largely controlled by that alone. Clinicians should be alert to such over-interpretations and the like by clarifying the details and giving the sufficient information for patients. Another important finding from this study appears to be the presence of a remarkable difference between the Western and the Chinese DM patients. Namely, the Chinese patients concerns less on fear of weight gain and hypoglycaemia as the Western patients did [18]. In line with their negative evaluation of insulin therapy, the Chinese patients instead concern more on keeping peace in mind. They avoid being stigmatized as a sick person while they consider insulin commencement [19].

They also appealed to hearsays from community to justify their indifference to DM complications and resistance to insulin therapy. Clinicians should be aware of patients' attitude on stepping up drugs, especially in relatively older patient in order to arrive shared understanding of disease management [20].

### Conclusion

This qualitative study demonstrates how the prevalence of PIR involves misconceptions on insulin therapy among people with T2DM and in the general public. The three major sources of misconception include the lack of adequate knowledge, conflicting medical advice, and hearsay from community. When T2DM patients failed to rectify the misconceptions, their self-efficacy in starting insulin therapy will be undermined as what the research subjects in this study indicated. The possible improvement of the acceptance rate of insulin therapy from the improvement of insulin delivery devices will be equally upset due to the continuation of a large gap of the T2DM patients from what are the proper medical understanding and doings. Clinicians should be therefore sensitive to the rise of such misconceptions in part of their actions to ensure the offering of proper insulin therapy for T2DM patients.

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