

Mismatch between health-care professionals' and patients' views on a diabetes patient decision aid: a qualitative study

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Abstract

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Background Malaysia is an Asian country with population of diverse culture and health perceptions. Patient decision aid (PDA) is a new tool in Malaysia. Patients' and health-care professionals' (HCPs) expectation of a PDA is unknown.

Aim We aimed to explore patients' and health-care professionals' (HCPs) views on the information needed in a patient decision aid (PDA) on insulin initiation developed for patients with type 2 diabetes mellitus (T2DM).

Design We used a qualitative design and thematic approach.

Setting Three main primary health-care settings in Malaysia: public university-based primary care clinics, public health-care clinics and private general practices.

Method We conducted focus groups and one-to-one interviews with a purposive sample of health professionals and patients with type 2 diabetes.

Results We interviewed 18 patients and 13 HCPs. Patients viewed the content of the PDA as simple and clear. However, HCPs felt the PDA might be difficult for patients with low literacy to understand. HCPs thought the PDA was too lengthy. Nevertheless, patients would prefer more information. HCPs tended to focus on benefits of insulin, while patients wanted to know the impact of insulin on their quality of life and practical issues regarding insulin and its side-effects. Patients preferred numbers to weigh the risks and benefits of treatment options. HCPs' views that presenting numbers in a PDA would be too complex for patients to understand.

Conclusion It is important to consider including issues related to psycho-social impact of treatment to patients when developing a patient decision aid.

Introduction

Studies worldwide have reported poor achievement of glycaemic control in patients with type 2 diabetes mellitus.¹⁻⁴ The majority of these patients end up requiring insulin for optimal glycaemic control.^{5,6} Patients often have many concerns and misconceptions about insulin, and they need discussion and support from health-care professionals to aid treatment decision.⁷ In primary care settings, due to short consultation time, physicians are often limited by time constraint to discuss and share decision making on insulin initiation with the patients.⁸

The use of a patient decision aids may aid health-care professionals in supporting type 2 diabetes mellitus patients during the phase of treatment decision for insulin initiation.⁹⁻¹¹ Many patient decision aids are available on diabetes care and treatment.⁹⁻¹² However, these patient decision aids were developed in the Western countries and hence may not meet the needs of patients from a different culture and country. Malaysia is a country with multi-ethnicities of diverse culture and social composition, perceptions of illness and health.¹³ These differing factors and the low health literacy rate may influence their ability to understand the content of a patient decision aid developed in a Western country.¹⁴

A patient decision aid was thus developed based on literature reviews and input from all stakeholders involved in diabetes care. These included patients, doctors, nurses, pharmacists and policymakers in the country. However, as the concept of shared decision making and the use of a patient decision aid is new in the country, the acceptability and the expectation of the patient decision aid among patients' and health-care professionals' views were unknown. Therefore, this study aimed to explore patients' and health-care professionals' views on the content and format of a patient decision aid on insulin initiation developed for patients with type 2 diabetes mellitus.

Methods

Design

This study used qualitative approach where in-depth interviews and focus group discussions were conducted to collect participants' opinions towards the content and format of a patient decision aid for insulin initiation.

Setting

The study was part of the pilot testing of a larger project. We developed a patient decision aid for insulin initiation in four languages. The content of the patient decision aid is described in Table 1. The study was conducted in three main primary health-care settings in Malaysia: public university-based primary care clinics, public health-care clinics and private general practices between 2012 and 2013.

Health-care professionals who participated in the study were trained in a workshop on the use of patient decision aid for patients with type 2 diabetes who needed insulin initiation.

Topic guide

A topic guide was used in the interviews with the participants. The feasibility of the patient decision aid usage, and the acceptability of the format and content of the patient decision aid was assessed. The feasibility is reported elsewhere, and this study focuses on the acceptability about the content and format of the patient decision aid.

Sampling and data collection

Health-care professionals in the primary care settings were invited to participate in the pilot testing of the patient decision aid. Training workshops were conducted at three main primary health-care setting. Interested health-care professionals would then choose patients with type 2 diabetes who had been advised to start insulin from their own practice for the pilot

Table 1 Description of the PDA content

PDA sections	Description
What are your concerns?	<ul style="list-style-type: none"> • Highlights common concerns and misconceptions about type 2 diabetes mellitus and insulin. • This also includes short answers to address the concerns.
Information about diabetes and treatment	<ul style="list-style-type: none"> • Explains what is insulin and the reasons for starting insulin.
About insulin therapy	<ul style="list-style-type: none"> • Explains how one starts insulin and its side-effects.
Knowing your blood sugar	<ul style="list-style-type: none"> • Explains how blood glucose control can be assessed by using HbA1c, fasting blood glucose and glucometers. • The target blood glucose readings are also presented.
What are your choices?	<p>List of treatment options:</p> <ul style="list-style-type: none"> • do nothing • following stricter diet and exercise • start insulin injection • add another oral diabetes medication • a new non-insulin injection (GLP agonist) • using complementary and alternative medicine.
Advantages and disadvantages of the treatment options	<ul style="list-style-type: none"> • Advantages and disadvantages of the treatment options based on the latest research evidence.
Knowing the facts	<ul style="list-style-type: none"> • Assess whether the patient has understood the information on the advantages and disadvantages of the treatment options presented in the PDA.
Knowing what is important to you	<ul style="list-style-type: none"> • Explores the preferences and concerns of the patient with regard to starting insulin.
Do you need more support?	<ul style="list-style-type: none"> • Explores whether the patient needs more information about the treatment options. • Finds out whether he has received enough support from the clinicians and family members.
What is your decision?	<ul style="list-style-type: none"> • Deals with the patient's readiness in making a decision about starting insulin and the option chosen.
Blank space	<ul style="list-style-type: none"> • The patient also has a chance to write down his queries in the space provided

testing. The patient decision aid was given to patients in advance, and it was used during the consultations to facilitate decision making. Both health-care professionals and patients were interviewed at the end of a consultation using the patient decision aid. All participants were given participant's information sheet and signed a consent form prior to the interview. The consultation and interview were audio-recorded. The participants include general practitioners ($n = 2$), medical officers ($n = 7$), diabetes nurses ($n = 3$), pharmacists ($n = 1$) and patients ($n = 18$). Fifteen consultations were done in urban setting and three consultations were in suburban setting. Twenty-six in-depth interviews and two focus group ($n = 2$ each group) discussions were conducted.

Data analysis

The interviews were transcribed verbatim, and the data were managed using Nvivo 9 software. Analysis of data was performed using a thematic approach. Two team of researchers analysed data on patients and health-care professionals, respectively. Four researchers (CJN, PYL, KLA, AAS) from one team analysed health-care professionals' interviews and three researchers (YKL, EMK, WYL) from the other team analysed patients interviews. Interviews were coded individually, and consensus on the list of themes (codes) and coding framework was done. This thematic framework was pilot-tested on one other interview, and any discrepancies were resolved by discussion. Any new

codes that emerged from the data were added to the coding tree after agreement among the researchers. The quotes were chosen based on their representativeness of the themes that emerged from the transcripts.

Researchers involved in the analysis were primary care physicians (PYL, EMK, CJN), psychologists (WYL, YKL), Nursing lecturer (KLA) and a master student (AAS). All researchers were conscious of their personal views and biases about patient decision aid content and format. The team had constant reflection and open discussion throughout the analysis. The quotes that best captured the essence of the themes were extracted for presentation in the results.

Ethics approval

This study received ethics approval from the University of Malaya Medical Centre Medical Ethics Committee and the Medical Research and Ethics Committee of the Ministry of Health, Malaysia.

Results

Four themes emerged on the content of the patient decision aid: readability; adequacy of information; balance of information; and information needs. For the patient decision aid format, participants commented on six themes: mode of delivery of patient decision aid, flow and sequence, size, space, font size and layout. The details of the setting of the consultations, participants' demographic profiles and languages used are summarized in Table 2.

Content

Readability

Most of the patients viewed the patient decision aid content as readable, simple, clear and systematic. However, health-care professionals felt that the patient decision aid might not be understood by patients with low literacy who would benefit from a simpler patient decision aid with fewer words and more illustration or diagram.

I think it's very easy to understand, everything's clear. The English is easy. (Patient, 69 years old, male, Degree-level education)

Make it like more readable... A diagram is better because it is all words you see. When you go through it, it is very difficult for those who are not used to reading a book, you know. May be can put it as a diagram, simple, simple words ok. So that it will be easier. (Medical Officer, 31 years old, female, Degree-level education)

Adequacy of information

Patients and health-care professionals had different opinions on the adequacy of information in the patient decision aid. Some patients thought it was too long; they felt that some information, such as assessment of needs of support and patients' value assessment, could be omitted. On the other hand, a number of patients felt the information was inadequate; they wanted more information addressing their concern, for example side-effects

It's (the patient decision aid) long...I think it should be shorter...'do you need support section'...No need because this is all clearly shown...'Knowing what is important' are things about your concerns, like what will my friends think about me...no need. (Patient, 70 years old, female, secondary school education level)

Ok, I like it very much... It is informative. It could have been a little bit more detailed. If you want to highlight something you highlight it, more detail for example... it is better than oral tablets, then tell me how it is better. You say it's the side effects, say it clear to me and more detail of the side effects. (Patient, 57 years old, male, Diploma-level education)

Most health-care professionals thought that it might take too long to use the patient decision aid in one consultation. They proposed patient to take home to read.

If you have to go through the patient decision aid during consultation, I think it is too long. If they have read the book at home and we only discuss the salient features or address the doubts which the patient has, then it is quite all right. (Medical Officer, 38 years old, male, Degree-level education)

Table 2 The setting of the consultations, participants' demographic profiles and languages used

No.	Location	Health-care professionals	Patient	Consultation language	Interviews language	PDA language
A1	Urban	Indian, Doctor (Private GP)	Indian, 51 years old, No formal education	Malay mixed with little English	Malay	Malay
A2	Urban	Malay, Doctor (Private GP)	Malay, 61 years old, Secondary School education	Malay mixed with lot of English	Patient declined to be interviewed	Malay
A3	Urban	Malay, Doctor (Private GP)	Malay, 69 years old, Degree-level education	English	English	English
A4	Urban	Malay, Doctor (Private GP)	Indian, 73 years old, Primary School education	English	English	Tamil
B5	Suburban	Malay, Doctor (Public clinic medical officer)	Indian, 37 years old Diploma-level education	Malay	Malay	Malay
B6	Suburban	Malay, Nurse (public clinic)	Indian, 74 years old, Primary School education	Malay	Malay	Malay
B7	Suburban	Malay, Doctor (Public clinic medical officer)	Chinese, 68 years old, Primary School education	Malay	Patient declined to be interviewed	Chinese
B8	Urban	Malay, Doctor (Public clinic medical officer)	Indian, 70 years old, Secondary School education	English	English	English
B9	Urban	Malay, Nurse (Public clinic)	Malay, 53 years old, Secondary School education	Malay	Malay	Malay
B10	Urban	Malay, Pharmacist (Public clinic)	Indian, 65 years old, Secondary School education	Malay mixed with little English	Malay	Tamil
C11	Urban	Chinese, Doctor (Public teaching hospital primary care clinic)	Indian, 54 years old, Postgraduate education	English	English	English
C12	Urban	Indian, Doctor (Public teaching hospital primary care clinic)	Chinese, 69 years old, Secondary School Education	English	English	English
C13	Urban	Malay, Nurse (Public teaching hospital primary care clinic)	Malay, 57 years old, Secondary School Education	Malay mixed with a lot of English	Malay mixed English	English
C14	Urban	Chinese, Doctor (Public teaching hospital primary care clinic)	Chinese, 57 years old, Diploma-level Education	English	English	English
C15	Urban	Chinese, Doctor (Public teaching hospital primary care clinic)	Chinese, 72 years old, Diploma-level Education	English	English	English
D16	Urban	Indian, Doctor (Public clinic medical officer)	Indian, 50 years old, Secondary School Education	English	English	Tamil
D17	Urban	Chinese, Nurse (Private clinic)	Chinese, 35 years old, Degree-level Education	English	English	English
D18	Urban	Chinese, Doctor (Private GP)	Chinese, 62, Secondary School Education	Chinese	Patient declined to be interviewed	Chinese

GP, general practitioner.

Balance of information

Most patients and health-care professionals thought the patient decision aid is well balanced on information regarding treatment options. However, some felt the patient decision aid favoured insulin.

By saying it is our decision, whether we take the insulin or not. It not forcing us to take, it's our own decision. To know how valuable is our body. See. So that, I have lot of concerns for it. So, but it not forcing you to follow the book. They are not forcing us. It giving us the ideas, what will happen to us if we don't follow that. It depends on us whether to take the insulin or not. (Patient, 70 years old, female, secondary school education level)

Because the certain area of contents like comparative to other medications and the side effect and there is also the comparison on the cost of using insulin with including the glucometer and the injection. So, that is indirectly says that for a better control of disease probably insulin and initiating insulin is a much better option than initiating other drugs so there is an indirect hidden agenda for that, I think. (Medical Officer, 38 years old, Female, Degree-level education)

Some health-care professionals felt that 'do nothing' was not an option for patients who required to start insulin and it should not be included as an option.

Oh, like the options (suggestion for changes to the patient decision aid). Whether you can ask the patient to say ok you 'do nothing', just wait and see. Normally we won't encourage that, but in that booklet actually written that you can choose not to do anything. (38 years old, male, Degree-level education)

Information needs

The health-care professionals tended to favour insulin as the treatment option and focused on information related to benefits of insulin.

Need to include more details on the benefits. Sometimes when we explain to the patient, they are not sure of the advantages of starting insulin. When we explain to them in just one sitting, they won't, they won't really understand... (Medical Officer, 38 years old, female, Degree-level education)

Patients, on the other hand, wanted to know the impact of insulin on their quality of life, and practical issues such as insulin storage during travel, side-effects and sources of insulin.

See, that booklet, to me, it should have more information on... the side effects. The side effects are not much, written there (Patient, 69 years old, male, Degree-level education)

Some patients preferred the patient decision aid to use statistics (numbers) to compare the risks and benefits of the treatment options.

Maybe, I prefer to have some statistics... Yeah, like err Dr. X have shown me statistics umm. I mean maybe research towards people who are taking insulin and compared to oral drugs, so with the statistics I think, it's more convincing to me. (Patient, 35 years old, female, Degree-level education)

This is in contrast to the health-care professionals' views that presenting numbers in a patient decision aid would be too complex for patients to understand. During the development of the patient decision aid, health-care professionals had suggested to remove the numbers in the patient decision aid as it was difficult for patients to understand.

The pros and cons table is rather confusing... suggest replacing it with simple text. (Endocrinologist, 44 years old, postgraduate degree education level)

*Format**Mode of delivery of patient decision aid*

Different modes of delivery such as multimedia, video and CDs have been suggested to cater for different age groups. However, most patients and health-care professionals agree that the booklet form is the most useful.

Because we read, VCD means like pictures only we see. If book means we can read and understand. (Patient, 54 years old, female, secondary school education level)

Again I think is the patients' type, so maybe the better educated ones will probably go through

webpages, iPad, they also be very responsive to booklets. The ones who are not so well educated, maybe in electronic form like DVD, CD played in the clinic and also by doctors explaining to them. Depends on the patients. (Medical Officer, female, 34 years old, Degree-level education)

Flow of sections in the patient decision aid

Most patients were happy with the arrangement of different sections in the patient decision aid. However, health-care professionals varied in their opinion on the flow of the patient decision aid. Some felt it was fine, while others felt the sequence of the sections need rearranging. Some experienced health-care professionals found the patient decision aid disrupts their usual way of consultation. They suggested not to follow the flow of the patient decision aid, but used each section as seen fit for discussion with patients.

Clear. I mean, the information flow, from one to another. So, I can find the relationship, between topics to topics and also clear cut between these topics and another topics. So, it won't mess up or everything jumble together. (Patient, 35 years old, female, Degree-level education)

Yes (the patient decision aid distracts conversation with patients) because seem like, like the flow... I already 12 years in this field and with asking patient to start on insulin because I have my own flow. I find that when I start on this booklet I was a bit kind of like disrupted, oh I have to address that concern first. Second, what is diabetes and then what is insulin. Actually what I do is, I explain about diabetes first to them, okay and then at this point why do they need the insulin, it's different, my, my approach is different. So maybe if I use this a few more times, I will get the flow.(laugh)... I think for me maybe we can follow our own flow but we don't have to follow how it goes about (Medical Officers, 38 & 31 years old, female, Degree-level education)

It did (help in the consultation), because at least I have a certain flow on how to go through educating patients on insulin. Normally when I explained to the patients, I think I do cover most of it, but is like all over the place la (laughing) This one has a certain flow. (Medical Officer, 34 years old, female, Degree-level education)

Size, Space, layout and font size

Some Patients suggested smaller size patient decision aid for ease to carry around. In addition, patients and health-care professionals suggested using more attractive colour. Some patients were fine with the font size, while health-care professionals found the font size too small.

Discussion

Most patients and health-care professionals viewed patient decision aid positively. They felt more information on side-effects, and complications are important to be included. Some health-care professionals also felt that 'do nothing' was not an option for patients who required to start insulin and it should not be included as an option. Although sometimes the scientific evidence about some options may be limited, the International Patient decision aid Standards Collaboration (IPDAS) criteria for patient decision aid recommend that the option of 'do nothing' should be included because some patients may decide to continue with the current treatment plan despite the doctors' advice.^{15,16} Most health-care professionals in Malaysia are not familiar with the concept of shared decision making where the best choice depends on the importance patients place on the benefits, harms and scientific uncertainties.¹⁷ A wider dissemination and education of the concept of shared decision making are needed for health-care professionals and patients, to improve understanding of shared decision making in the country.¹⁷

The findings suggest that there are discrepancies between patients' needs and health-care professionals' perceptions of patients' needs. Patients wanted more practical information on insulin initiation and how insulin might affect them physically, psychologically and socially. Health-care professionals on the other hand tended to favour insulin as the treatment option and focused on information related to benefits of insulin. It is important for health-care professionals to start with patient's agenda. Therefore, the sequence of information in a patient decision

aid is important. Most patient decision aids begin with the disease and treatment information. It may be more appropriate to start with patient identifying their concerns and addressing these in the discussion of treatment options. Indeed, clarification of the patient's objectives at the initial stages of the consultation is seen to be a key strategy in improving communication with patients in order to avoid unreconciled agendas and expectations.^{18,19}

The presentation of information in the patient decision aid affects its readability and usability. Some health-care professionals suggested using illustration or diagram to present information. However, literacy and age may affect patients' ability to understand information presented as illustration. Some studies have reported older adults tend to have difficulty integrating illustrations with textual information.^{20,21} In terms of balance and amount of information in the patient decision aid, it is meant to provide sufficient information for patients to make an informed health-care decision, and this is different from an education material. A review has reported patient decision aids with more detailed information generally resulted in slightly higher knowledge and lower 'feeling uninformed' scores than those with simpler information, but the differences are small and can be reversed under some circumstances.²² Therefore, a website might be better as it addresses more individualized needs as patient can choose the amount of info they wanted.

Patient wanted to know the weightage of each treatment options with numbers or statistics for ease of comparison. On the other hand, health-care professionals in an expert panel meeting before the patient decision aid was implemented, suggested removing the risk communication table as it was difficult for patient to understand. However, we are uncertain whether the patient's preference for statistical information is a minority view. In the process of patient decision aid development, the balance of opinion from health-care professional and patients need to be considered. In a country where the doctor-patient relationships are more towards paternalistic,¹⁷ it will be a chal-

lenge to ensure patient's voice are heard during expert panel meeting as doctors would most probably be dominating.

Strength and limitation

The strength of this paper is that this is done in a country where the concept of shared decision making is not widely known and the use of patient decision aids is rare. Thus, the study captures the range of responses from health-care professionals and patients to shared decision making as a novel concept.

This study included views of health-care professionals and patients from a dual-sector health system, that is both the private and government sectors. It highlighted the issues of discrepancies among health-care professionals' and patients' expectation of health information to be given in making a treatment decision.

Implications for further research or clinical practice

Future research may need to be done to improve the understanding of the concept of shared decision making and implementation of patient-centred care and patient empowerment in Asian countries like Malaysia. It is important to consider including issues related to psycho-social impact of treatment to patients when developing a patient decision aid.

Conclusion

Patients and health-care professionals have different expectations of a patient decision aid. Patients wanted more practical information on insulin initiation and how insulin might affect them physically, psychologically and socially. It is important to consider these issues when developing and implementing a patient decision aid.

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Conflict of interest

The author(s) declare that they have no conflict of interests.

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