Diabetic Medicine

Research: Care

Concerns and perceptions about necessity in relation to insulin therapy in Type 2 diabetes, in an ethnically diverse UK population: a qualitative study focusing mainly on South Asians

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Aim: To explore attitudes towards insulin acceptance in an ethnically diverse population of people with Type 2 diabetes.

Methods: We conducted semi-structured interviews using a topic guide based on a literature review and findings from our previous study which explored the perspectives of healthcare professionals about insulin initiation and management. Analysis of data involved undertaking an abductive approach in response to emerging themes.

Results: Participants discussed not only their concerns about insulin therapy, but also their views and beliefs about the necessity of insulin. Their attitudes to accepting insulin could be mapped into four main typologies. These fitted with an attitudinal scale based on the Necessity-Concerns Framework, described in the medication adherence literature, comprising four attitudes: accepting, sceptical, ambivalent and indifferent. Decisions about accepting insulin involved balancing concerns (such as needle-size) against perceived necessity of insulin (generally, inadequacy of oral medication). South Asian and White British participants had similar concerns, but these were sometimes enhanced in South Asians, due to the influence of negative views and experiences of other insulin users.

Conclusions: When discussing insulin with people with Type 2 diabetes, healthcare providers need to ensure that they explore and contribute to patients' understanding and interpretation of the necessity of insulin as well as discussing their concerns. Furthermore, they should be aware of how an individual's social context can influence their perceptions about the necessity of insulin as well as concerns, and that this influence may be more enhanced in some South Asian populations.

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What's new?

- This is the first time the Necessity and Concerns Framework drawn from the medical adherence literature has been used to explore decisions to commence insulin therapy in an ethnically diverse sample of people with Type 2 diabetes.
- This study offers a practical insight on why it is important to elicit beliefs about the *necessity* of insulin therapy as well as people's concerns to help address the reluctance of some people with Type 2 diabetes to commence insulin therapy in a timely way.

Introduction

Approximately 50% of people with Type 2 diabetes will at some point need to commence insulin therapy [1] in order to achieve or maintain good levels of blood glucose control. Good glycaemic control can help to reduce or prevent the development of diabetes associated complications as shown by the 10 year post-trial follow up data from the United Kingdom Prospective Diabetes Study [2]. This showed that good glycaemic control continued to confer benefits; in the sulfonylurea-insulin group, for example, there were relative reductions of 13% and 24% in the risk of diabetes-related death and microvascular complications respectively. Additionally, research modelling has shown that if insulin is commenced according to management guidelines there are benefits relating to life expectancy and quality-adjusted life expectancy [3]. However, the transition to this treatment can be challenging for some healthcare professionals and patients, often resulting in people with diabetes not accepting insulin therapy. In the UK, evidence indicates that some people with diabetes remain on oral hypoglycaemic agents for a median time of 7.7 years despite having poor glycaemic control [4, 5]. Furthermore, there is evidence [6, 7] of comparatively lower prescribing of insulin for people with Type 2 diabetes who are from South Asian populations than for the white British population. Whilst not much is known from a South Asian perspective about the reasons for lower levels of prescribing insulin, our previous study of healthcare professionals' views and experiences found that patient-related barriers to insulin prescribing are perceived to be accentuated in some South Asian patients [8]. The reasons cited included lower levels of understanding and knowledge about diabetes and insulin; language barriers; and the influence of 'other people' in decisions about commencing insulin therapy [8].

A useful concept to emerge from research into the reasons for delays and refusal to commence insulin therapy is 'psychological insulin resistance', which can apply to both healthcare professionals and patients [9, 10]. The concept encompasses issues such as fear of needles and feelings of personal failure in patients, and lack of confidence to initiate insulin [11] and concerns about hypoglycaemia in healthcare professionals [12]. It manifests in avoidance strategies by both patients and healthcare professionals and can lead to collusion to delay initiation of insulin therapy in spite of poor glycaemic control [13].

Research into psychological insulin resistance from the patient perspective has tended to focus on individuals' concerns [14-16] about insulin, with less emphasis on their views and beliefs about the *necessity* of this treatment. The present paper draws on medication adherence literature, and more specifically the Necessity-Concerns Framework [17-19] where the relationship between concerns and necessity is critical; individuals' decisions about starting and/or continuing with medication are argued to be driven by a process that involves weighing up perceptions about necessity against concerns regarding potential adverse effects [19]. The framework highlights key factors that may interact to influence individuals' decisions, including beliefs and practical issues such as the capacity to take medication as prescribed [20]. The framework has been extended by identifying four attitudinal categories: sceptical (high concerns, low necessity), accepting (low concerns, high necessity), ambivalent (high concerns, high necessity) and indifferent (low concerns, low necessity). These categories were developed to make the framework more clinically relevant [21].

In this paper, we explore attitudes to accepting insulin therapy in people with Type 2 diabetes in an ethnically diverse community, with particular emphasis on people of South Asian (mainly Indian) origin. We draw upon the Necessity-Concerns Framework, and the four attitudinal categories, to inform our analysis.

Participants and methods

Approvals and recruitment of general practices

Ethical approval was obtained from Leicestershire, Northamptonshire and Rutland Research Ethics Committee, UK (09/H0406/40). A sample of general practices in the city of Leicester was purposively selected to facilitate recruitment of people from both South Asian and white British backgrounds. A letter explaining the study was sent to these practices, followed by meetings with practices that expressed an interest. Four general practices agreed to participate; all were located in an urban setting with high levels of deprivation. The proportion of registered patients of South Asian origin was over 60% in three practices and approximately 10% in the fourth.

Recruitment and selection

We used purposive sampling to recruit a sample that was diverse in terms of gender, ethnicity, duration of diabetes and current treatment. In line with the principal focus of our study, we aimed to include mainly South Asian patients, but it was also considered that it would be useful to include a small sample of white British living in the same geographical area, so that we could consider whether findings were different in this group. Formal comparison of the two groups was not, however, within the proposed scope of our study. People with Type 2 diabetes were eligible to participate if they were over the age of 18 years, were either South Asian or white British and were able to give informed consent. Eligible individuals were initially approached by practice staff when attending appointments and those who indicated an interest were directed to discuss the study further with the bilingual researcher (NP) who was present at the practice. After this discussion, individuals who were interested in participating were asked to complete an initial consent form, giving permission for the researcher to contact them to arrange a time for the interview.

Data collection

Prior to holding the face-to-face in-depth interviews, full written informed consent was undertaken. Interviews were semi-structured and were informed by a topic guide (Table 1). The interviews were conducted from November 2009 to April 2010; one was conducted on University premises and the remainder in participants' homes. All interviews were audio-recorded and transcribed verbatim. Six of the interviews were conducted wholly or partly in Gujarati; the audio recordings of these interviews were translated into English at the time of transcribing by the researcher (NP). The accuracy and conceptual equivalence of a random sample of translated transcripts was assessed by an independent professional translator.

Analysis

Analysis was informed by grounded theory, particularly the constant comparison approach [22], whereby we allowed key themes to emerge from participants' accounts and **regularly moved between the transcripts, emerging themes, coding framework, and topic guide.** Data collection and analysis was iterative; preliminary analysis of early transcripts led to changes to the topic guide to facilitate exploration of emergent themes in subsequent interviews. After conducting 19 interviews, it was determined that no new themes were emerging. One participant was on GLP 1 agonist treatment; although this is an injectable therapy, additional issues associated with insulin may not be applicable. This interview was therefore excluded from the analysis presented in this paper

Analysis involved two stages. The initial approach was inductive and involved reading and re-reading of transcripts by two researchers (NP, CM) who independently open coded all transcripts. Two additional researchers (MS, HE) open coded a random sample of transcripts. Discussions about the open codes identified a prominent theme regarding participants' concerns about insulin; an equally prominent theme emerged regarding beliefs about the necessity of insulin and other medication for diabetes. This stimulated discussions (MS, NP, HE, CM) about the Necessity-Concerns Framework [23] and associated attitudinal categories [21], which together appeared to provide a useful framework for further exploration of the data.

The second stage of analysis therefore involved an abductive [24] approach based on our speculations about the relevance of the Necessity-Concerns Framework to our dataset. A randomly selected sample of transcripts was coded (NP, CM) using a revised coding frame informed by the Necessity-Concerns Framework. This was found to provide a good conceptual fit with the data. All transcripts were therefore recoded (NP) using the revised coding frame, facilitated using NVivo software. As part of the analysis, participants who were not currently on insulin were categorised according to their attitudes to accepting insulin at the time of the interview, using the four attitudinal categories. Those who were already taking insulin were, logically, all currently in the accepting category, but these participants were additionally categorised according to their previous attitudes to taking insulin. This enabled us to identify and consider the factors that had helped them to make the transition to an attitude of acceptance or that had contributed to the fact that they had always held views that placed them in this category. In order to illustrate the ways in which concerns and perceptions about necessity that emerged from the data enabled us to allocate categories, a series of case studies was prepared.

Results

Of the 18 participants included in the analysis, 5 were white British and 13 South Asian; eight were currently being treated with insulin (Table 2). We will briefly describe some key overall findings regarding concerns and perceptions about necessity and we will then present our observations based on allocating participants to attitudinal categories, including a selection of illustrative case studies.

Concerns and perceptions about necessity

Across the sample, participants reported concerns (Table 3) including: fear of hypoglycaemic episodes ('hypos') (Int. 13); maintaining privacy when injecting insulin in public (Int. 11); insulin being made from animals (Int. 03); and a perception that diabetes is getting worse if insulin is required (Int. 03).

Participants' talk about necessity (of insulin or other medication) was as dominant as their talk about concerns. A typical way of describing insulin was as a 'last resort' (Table 3), but beliefs about what constituted the 'last resort' differed. Some participants felt that this stage had been reached when their regular HBA1c test result provided objective evidence that they could no longer achieve optimal blood glucose control with oral medication (Int. 18), whilst others described feeling that they would not be ready to accept insulin until they had reached the stage of life-threatening complications (Int. 11).

Interviews revealed key influences behind participants' beliefs about concerns and necessity. Some participants recalled being informed at diagnosis or soon after about the progressive nature of diabetes and the fact that insulin might eventually be needed (Table 3). This had generally helped to alert them to the potential necessity of insulin treatment in the future and provided an opportunity, over a period of time for their healthcare professionals to identify and discuss concerns. Hence, applying the Necessity-Concerns Framework, advance warning and preparation appeared to have reduced concerns whilst heightening perceptions about necessity. Furthermore, for a minority of participants, this had motivated them to address their concerns by seeking information from books, personal observations and the internet, which appeared to have helped them to make a self-empowered decision to accept insulin as necessary when advised by their healthcare professional (Int. 21). On the other hand, observations of, and conversations with family and community members appeared to have generally worked in the opposite direction, by lowering participants' perceptions of necessity and heightening their concerns (Table 3, Int 16). In a minority of cases, however, observations had moved participants to an accepting attitude to insulin therapy, for example, if family members were already on insulin (Table 3, Int 02).

Categorisation of participants

We categorised participants according to their attitudes to accepting insulin: sceptical (n=2), accepting (n=3 not on insulin, n=10 on insulin), ambivalent (n=2) and indifferent (n=1) (Figure 1). The four case studies selected to illustrate this categorisation (Table 4) include one participant categorised as indifferent and one sceptical (both on oral medication only) (Case studies 1 and 2) and two participants on insulin categorised as accepting, including one who was previously ambivalent (Case studies 3 and 4).

The case studies also draw attention to factors that helped participants to move to the accepting category or that explain their current attitude to taking insulin, for example, indifferent in the case of the participant in case study 1. His perception is that oral medication can prevent the need to go onto insulin; he indicated a general acceptance of oral medication but was reluctant to consider more specifically the use of insulin because of concern about its perceived association with seriousness of the condition. We speculated that education might help this participant to understand the progressive nature of diabetes and its treatments, as well as encouraging him to articulate concerns, in order to prepare him to accept the necessity of insulin therapy should it be required in the future.

A need for education was also strongly indicated by the participant in case study 2, whose views about insulin being a treatment of last resort suggest a lack of awareness that damage may already have occurred at least 10 years before the diabetes is diagnosed and that this damage may be asymptomatic. These perceptions led to a lack of acceptance about the necessity of insulin, even though her blood glucose levels indicated that it was needed.

The participant in case study 3 had accepted the necessity of insulin at some future stage, but delayed his decision to commence it when required, because of concerns about using needles; these concerns outweighed his views about necessity. This observation highlights the fact that the concepts of 'low' and 'high' concerns or perceptions about necessity were identified as relative rather than absolute in participants' accounts of their decisions regarding insulin treatment. In preparing this case study, we reflected that the decision to commence insulin might have been reached earlier had his concerns about needles been addressed soon after diagnosis through demonstrations of newer pen injection devices and discussions about the role of insulin in helping to prevent or delay complications.

Case study 4 illustrates a participant who delayed his move to insulin therapy for several years, because his concerns outweighed his perceptions of necessity; this attitude was modified when a doctor's caring approach made him receptive to considering the possibility that he might need to start insulin. This approach enabled him to be in an accepting frame of mind, tipping the balance between necessity and concerns, by increasing his recognition of necessity and enabling him to acknowledge and overcome his concerns.

Discussion

Summary

This qualitative study based on the views of an ethnically diverse sample of people with Type 2 diabetes has demonstrated that participants' perceptions about insulin involve balancing concerns and necessity. Using the Necessity-Concerns Framework and attitudinal categories helped us to identify factors that contributed to acceptance of insulin (low concerns and high necessity) and to consider ways of helping individuals to move to this status. Beliefs about the need for medication *in general* to control diabetes did not always translate to insulin *specifically*.

Comparison with other literature

In our study, participants' beliefs and concerns were sometimes derived from their observations of people who were on insulin, although, for the South Asian participants, the influence of other people seemed to be enhanced. This may be because the high prevalence of Type 2 diabetes in this population [25] offers greater exposure to negative experiences and views of using insulin. This finding, based on participants' accounts, fits with findings from our previous study, conducted in a similar setting, in which healthcare professionals perceived the influence of 'other people' as being accentuated amongst their South Asian patients [8]. Other authors have also highlighted the importance of contextual influences such as families and community networks [26].

The observation that insulin was perceived as a 'last resort' treatment presents a major challenge in the clinical management and treatment of Type 2 diabetes; poor glycaemic control may not immediately manifest symptoms of complications, thereby reducing individuals' perceptions of the necessity [19] of starting insulin therapy in a timely manner. Our findings thus concur with findings from research in other conditions such as asthma [19], and depression [27], where the experience of concrete symptoms has been found to influence individuals' decisions about commencing medication.

Our finding that perceptions about medication in general often differ from those about specific medication supports previously reported observations [28]. In our study, this distinction was linked to balancing beliefs about the necessity of medication for controlling Type 2 diabetes against the relative strength of concerns about insulin; oral medication was regarded as adequate for glycaemic control, while less harmful than insulin. The possibility of an effective alternative to insulin (oral medication and increased lifestyle modification strategies) reduced the influence of perceptions about the necessity of insulin (see case study 2, Table 4).

Strengths and limitations

To our knowledge this is the first time that the Necessity-Concerns Framework developed from the medical adherence literature has been applied to explore and understand attitudes to commencing insulin initiation in an ethnically diverse sample in the UK. Our study demonstrates the transferability of the framework to this context, enabling a theoretically informed approach to understanding of the way in which concerns and beliefs about necessity are balanced in making decisions about a change in therapy. Although our sample included only small numbers of participants in some attitudinal categories, the attitudinal analysis suggested a good fit between this model and our data. It is also acknowledged that comparisons between white British and South Asian participants'

accounts are limited by the relatively small sample of the former, which reflected our specific interest in people of South Asian origin; additional research would be needed in order to more formally make detailed between-group comparisons. It should also be noted that the South Asians in our study sample were mainly of Indian origin and their experiences and views may not reflect those of other South Asian populations in the UK. We believe, nevertheless, that this study adds to the previous literature both in terms of understanding the process of decision making regarding insulin therapy and also in relation to the ethnically diverse population studied.

Implications for clinical practice

Our findings highlight the need for healthcare professionals to be vigilant about eliciting beliefs and meanings [29] about medication. The Necessity-Concerns Framework and the attitudinal scale could provide a conceptual framework that can be practically applied by clinicians to systematically identify and address concerns and beliefs about necessity, as well as the way in which they interact in relation to decisions about commencing insulin treatment. This study suggests that the attitudinal scale could assist clinicians in deciding where to practically focus their efforts for the individual patient: by addressing concerns, convincing them about necessity, or both. For example, concerns about injections and large needles can be addressed by showing a 'dummy injection' or arranging for a patient peer to discuss insulin therapy to allay concerns. It may also be useful to elicit and explore patients' beliefs about the necessity of insulin including perceptions of this therapy as a treatment of last resort. There may be scope for developing resources that could help healthcare professionals to determine the attitudinal category in which an individual patient fits.

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Competing interests

Professor Melanie Davies has acted as consultant, advisory board member and speaker for Novartis, Novo Nordisk, Sanofi-Aventis, Lilly, Merck Sharp & Dohme, Boehringer Ingelheim and Roche. She has received grants in support of investigator and investigator initiated trials from Novartis, Novo Nordisk, Sanofi-Aventis, Lilly, Pfizer, Merck Sharp & Dohme and GlaxoSmithKline.

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Table 1: Main areas for discussion in interviews

- Background information:
 - Demographic information
 - Reflection on diagnosis
 - Beliefs about causes
- Reflections on treatment throughout duration of having diabetes:
 - Discussions with healthcare professionals about treatment options and insulin specifically
 - Views and beliefs about taking insulin
 - (Where appropriate) experiences of insulin (including impact on lifestyle)
 - Sources of information and beliefs about insulin (e.g. family, community, etc.)
 - Consideration of alternative/complementary therapies

Table 2: Participant Characteristics

Participant Characteristics (N=18)	
Ethnicity	
South Asians	13
White British	5
Gender	
Male	9
Female	9
Duration of diabetes	
Under 10 years	12
Over 10 years	3
More than 20 years	3
Treatment	
On insulin	7
Not on insulin	11

Table 3: Concerns and perceptions about the necessity of insulin therapy

Beliefs about concerns about insulin

Fear of Hypos

“I know I’ve got a brother-in-law who gets the shakes and things like that – hypo they call it. I’d be a bit bothered about that I think, that’s all I know about it really. [...] It stopped him driving and things like that, so it’s a nuisance sounds like.” (Int 13 WB Female, not on insulin therapy)

Maintaining Privacy

“Where would you take it? It’s the same as breast feeding isn’t it? Where would you do your breast feeding? It’s the same as that it’s like you have to lift everything up and do you know what I mean?” (Int 11 SA Female, not on insulin therapy)

Insulin from Animal Sources

“Well it’s another move towards the progression of the disease, it’s not a good thing; secondly is injections itself, needles and that’s not pleasant I wouldn’t like to have it done. Thirdly as I’m discovering more that insulin itself comes from either an animal, I’m not sure it’s artificial or not.” (Int 03 SA Male, not on insulin therapy)

Beliefs about necessity of insulin

Treatment of “Last Resort”

“They started me on tablets. They weren’t making no difference. They upped the tablets. They still didn’t make no difference, so for a start they started me on a night injection, just have it at night, nothing through the day, carry on with the tablets. But it still weren’t going down as it should have done, so they started me on insulin.” (Int 18 WB Female, not on insulin therapy)

“If it’s something really drastic, really drastic if it’s like life and death then you have to take it then you have to take it, like, but I don’t think I want to go there yet. (Laughs).” (Int 11 SA Female, not on insulin therapy)

Influences on beliefs

Awareness of progressive nature of diabetes

“I think I was told it was in the gradual stages. These are the type of tablets that you need to take. If you control your diet, you know, cut down on your sugars and fatty food that you’d be eating, it will take a long while, but eventually you will need to go on to insulin but we will talk about that as we go through. So each time I went there was a bit more progress on there so they said ‘Alright, okay this is what will happen. This will happen. This is the type of insulin you may have to take but not yet.’ So it was all gradual. It wasn’t all blunt and straightforward saying ‘Right tablets for three years, insulin next year.’ It wasn’t like that. They said it will build up gradually. Eventually in the later years in your life you will be going on to insulin as all diabetics do.” (Int 09 SA Male, not on insulin therapy)

“Well I was quite happy to have as much information as I possibly could about the diabetes and the treatments there with, you know. It’s something that I think any illness you want to know as much about as you can and that, you know, sort of thing..... After I was diagnosed we bought a book on diabetes which my husband’s read thoroughly and I’ve read bits and pieces and it’s very interesting this book, very helpful. And that’s really where I know more about insulin.” (Int 21 WB, not on insulin therapy)

Negative Views from Community

“Yes everybody says insulin should not be taken and all of this and that, so we get a little scared.” (Int 16 SA Female, on insulin therapy)

Acceptance based on observations

“I thought it may happen in the future if it’s not controlled, then may have to take it cos my brother in law takes it.” (Int 02 SA, not on insulin therapy)

Key: SA: South Asian, WB: White British

Table 4: Case Studies

Case study 1. Int. 08:

Demographics and T2DM history: SA; male; aged 68; T2DM duration: 5 years; medication: oral medication for the last three years and no suggestion of requiring insulin to date.

Beliefs about the necessity of insulin therapy

When given a hypothetical scenario in which he was told by the doctor he needed to go onto insulin, he felt if he had no choice he would commence treatment to help control his blood glucose.

"I think if I have to go, I have to go. There is no way you can go back to tablets, I don't think. Because if tablets can't control you so good then we have to go to the insulin, it's as simple as that."

Although he is not, in theory, against the idea of insulin, his comments suggest that he has not actively thought about the necessity of this therapy or accepted that he may personally need it in the future. He is not convinced about the necessity of insulin, preferring to take tablets, as he believes that, if they are taken regularly, they can control diabetes:

"I think you are better off with the tablets and if you continue taking regularly ... if you're taking normally I think you are better off than anything else, that's what I believe."

Concerns about insulin therapy

He has not really thought much about insulin, but he thinks it would be worrying for him if he reached the stage of needing it:

"I don't know. You'd think it's I got something wrong, something like that, you know what I mean?"

He feels that if he needed insulin it would mean that his diabetes would have become serious. This is illustrated by his description of a case that he has observed:

"....he doesn't know he got the diabetes. And for a week he started going for a pee every half-an-hour. Then he went to see the GP and the GP checked his blood and he had diabetes at a very high level so he has to start with the insulin instead of tablets, which I'm thinking I'm better than him actually but that's what has happened to him."

He also mentioned that he had would have concerns about needles and injections but when asked to elaborate it was clear from his response that he was not really thinking about these concerns at this stage:

"To be honest I can't tell you anything about it [insulin treatment] until I had it. So, it's impossible to say anything about it."

Although this participant was willing to talk about insulin during the interview, it was clear that it is something that he does not feel the need to think about at the present time, as he does not currently need this therapy to control his diabetes.

Current status: Low necessity, low concerns- Indifferent

What might make this participant move to an 'accepting status'?

Education could prepare him for the potential need for insulin in the future, so that he would be ready to accept this therapy if needed. His education would need to address the question of necessity by informing him of the progressive nature of diabetes and prevention of complications. It could also assist in helping him to think about and articulate his concerns so that they could be addressed.

Table 4 (continued)

Case study 2. Int. 17:

Demographics and T2DM history: SA; female; aged 58; T2DM duration: approximately 10 years ago; medication: oral medication for five years.

Beliefs about the necessity of insulin therapy

She does not view insulin as necessary at this stage because she doesn't believe her diabetes has advanced to the stage where her pancreas has stopped producing insulin. She believes that insulin therapy is a treatment of last resort, only to be taken when the pancreas stops producing insulin:

"Last option because other parts get damaged because of the diabetes then it's better to take it isn't it? ... but if there is no option and the pancreas has stopped working then you have to take insulin.... its better otherwise other parts will get damaged such as the kidneys and this and that."

Although she does not perceive that she is personally at this stage, she believes that insulin is necessary when there is no other option. This belief about insulin being a treatment of last resort is also linked with views about personal failure to manage diabetes through oral medication and lifestyle changes. This belief was evident when she recounted what she had said during a conversation with a relative, who had been told by the doctor he needs insulin:

"But you are not controlling that so there is a need for you take insulin because you are damaging your body. So you will need to take it and there is no need to be scared, that's what I said."

Concerns about insulin therapy

Her concerns were about insulin being a restrictive form of treatment requiring her to be vigilant about maintaining regularity with meal and injection times and thereby interfering with her social life. These beliefs are derived from her observations of friends and family who are on insulin.

"If we take insulin then we have eat food immediately you know or our sugar goes down and you have to take insulin on time extremely regularly, with the tablets, if our timing is misplaced by either a hour lost or gained, it is not a source of worry for us..... it's only that it's hard to manage when going out and doing things."

Current status: High concerns, low necessity- Sceptical

What might make this participant move to an 'accepting status'?

It may help her to have education about the role of insulin in preventing or delaying complications, in particular the benefits of introducing this therapy sooner rather than at an advanced stage of deteriorating blood glucose control. This might help her to be ready to accept insulin at an optimal stage rather than as a last resort in order to sustain life. Eliciting and discussing concerns, particularly about problems of self-managing insulin therapy on a day-to-day basis, could help to ensure that she reaches a stage where her beliefs about necessity outweigh her concerns.

Table 4 (continued)

Case study 3.

Demographics and T2DM history: Int 20: WB male aged 43, diagnosed approximately 9 years ago and on insulin therapy for about two and half years along with Exenatide.

Background

He was diagnosed when he was admitted to hospital for another condition and initially asked to undertake lifestyle changes and treated with tablets. He has a strong family history of diabetes with some family members with type 2 diabetes on insulin therapy. He delayed the decision to accept insulin.

Perceptions and beliefs about necessity of insulin treatment

His family experiences informed his understanding of the necessity of insulin therapy at some point in the treatment of type 2 diabetes:

“... from my experience of diabetes, it’s just an inevitable part of it that you’re going to end up being on insulin anyway... I was expecting it it was suggested a few times that I took insulin as my tablets were going up”

Concerns

His delay in deciding to accept insulin was influenced by his concern about using needles:

“And to be honest with you I don’t like needles. I don’t like them and I didn’t want to do it and that’s and that’s what kept putting me off”

At this stage, his beliefs about necessity and his concerns were fairly equally balanced, so he did not feel ready to make an active decision to accept insulin, however, over time he knew from observing his family treatment of diabetes that he would have to accept insulin therapy as his blood glucose control deteriorated:

“I think from my point of view what I’ve said and from my experience with my sister, my mum and my dad as well, they’ve all started Metformin slow and all that and they’re all on insulin.”

Previous status: High necessity, high concerns- Ambivalent

Current status: High necessity, low concerns- Accepting

What made the participant move to ‘accepting’ status?

He eventually accepted insulin therapy as oral medication was not working and he had poor glucose control. This meant that his beliefs about the necessity of taking insulin now outweighed any concerns and he felt that he had reached the point where he needed the treatment of last resort.

“It wasn’t under control so she suggested I went on to insulin. She started me low and gradually built up, up .”

What would have made this participant move to acceptance sooner?

Concerns about needles might have been addressed by discussions and demonstrations; discussions about potential complications might have helped to convince this participant about the necessity of insulin. Identifying and addressing both necessity beliefs and concerns early in the diagnosis might have led to necessity beliefs outweighing concerns at an earlier stage.

Table 4 (continued)

Case study 4.

Demographics and T2DM history: Int 07: SA male aged 57 diagnosed approximately 20 years and has been on insulin for the past five years. He refused to take insulin therapy when diagnosed even though his blood glucose levels were extremely high, preferring instead to take oral medication.

Beliefs about necessity of insulin treatment

He had not considered the necessity of insulin as he was focused on concerns about injections, even though his blood glucose levels were very high. He continued to take his oral medication despite the efforts of his doctor to persuade him to go onto insulin therapy. He believed that increasing his oral medication would bring his blood glucose levels down without the need for insulin.

"When they gave tablets it began to go low and I thought but then it started going up and the doctor said you will have to come onto injections, four years on. I said do not say the name injections. I will take as many tablets I as I need to. I don't have any problems with that...."

Concerns about insulin

He had many concerns about insulin, some originated from what people in his caste (Samaj) community had said about the frequency of injection and increasing dosage:

"People that were taking them said you have to them all the time, first of all you take 5cc, 10 cc, then 20cc, he said you will get up to 50cc and its this size bottle all of it will have to go in. I said oh! I was scared that out of one will happen another."

He also had a fear of injections and used to think that injecting insulin into the stomach every day would damage the stomach. He also worried about the size of the needles to inject insulin:

"I used to say that, one lady said I take 50ml. I used to think that is too much. All that medicine goes into your stomach every day and I said our stomach will increase and it will damage things inside and you will come into problems. I used to be scared."

"Yes, at first, the needle we used to take in the arm, long and is a little bit fat when they take blood it's a fat one. And it's because of that fear, I thought if I took a big needle like that for ever, it will swell up and be painful."

As his blood glucose control deteriorated and healthcare professionals communicated their concerns about his health, it prompted him to consider the necessity of insulin:

"That nurse explained to me so well with sweetness that if you begin, we are worried about you, you don't worry, we are worried about things in your body. So do this, do this. I began to do that."

"I spent five years deciding. Five years to decide tablets. The Dr.XXXXX before and now its Dr.XXXX he helped to me understand. He said please take injections, it is for your benefit because your tablet dosage, they used to give 850mgs and he said there is no effect from the tablets. He said please can you do this. He asked by requesting me so I thought if the doctor is saying in a way which is a request, why shouldn't we be able to do it?"

Previous status: High concerns low necessity- Sceptical

Current status: High necessity, low concerns- Accepting

What made this participant move to 'accepting status?

A range of factors prompted him to move to an acceptance of insulin. Firstly, the way in his healthcare professionals helped him to understand that it was necessary for him to take insulin because his health was deteriorating contributed to his decision to accept insulin. It was also because it reminded him of the negative consequences of poor blood glucose control experienced by his mother and helped him to change his beliefs about the necessity of insulin. It was at this at this juncture he was willing to accept the necessity of insulin therapy because his beliefs about necessity now outweighed his concerns.

What would have made this participant move to acceptance sooner?

Since this participant had a high level of concerns, it might have been useful to elicit and fully discuss these at an early stage, when he was first diagnosed with diabetes. A discussion similar to the one that had convinced him about necessity might also have been useful at an earlier stage. These two approaches at an early stage might have led to a shift in the emphasis placed on beliefs about necessity and concerns, by raising necessity beliefs and lowering concerns.

Key: SA: South Asian, WB: White British

Figure 1: Plotting of participants status on the Necessity and Concerns Framework and Attitudinal Scale