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Original research

The Barbados Insulin Matters (BIM) study: Barriers to insulin therapy among a population-based sample of people with type 2 diabetes in the Caribbean island of Barbados

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ABSTRACT

Aim: The purpose of this study was to document in people with type 2 diabetes (T2DM) in Barbados, attitudes and beliefs that may result in psychological insulin resistance.

Methods: A representative, population-based, sample of 175 eligible people with T2DM 25 years of age and over was surveyed by telephone. The 20-item insulin treatment appraisal scale (ITAS) was administered (score range 20 to 100 for positive to negative perceptions).

Results: 117 people participated (67% response rate, 32% male, mean age 66 years, 90% Black, 22% on insulin). Of non-responders, 52 were not contactable and 6 were difficult to communicate with.

Negative perceptions about insulin use included – meant a worsening of diabetes (68%), would worry family (63%), feared self-injection (58%), meant a failure in self-management (57%), injections were painful (54%), would be seen as being sicker (46%), increased hypoglycaemia risk (38%), required effort (34%), causes weight gain (27%), causes a deterioration in health (14%), and would have to give up enjoyable activities (10%). Positive perceptions were – helps good glycaemic control (78%), would prevent complications (61%) and improves health (58%).

Mean total ITAS score (61.6, SD = 7.7) was lower for those on insulin compared to those not on insulin (53.7 vs. 63.8, $p < 0.0001$). Sex, age and diabetes diagnosis duration were not significant predictors of ITAS score.

Conclusions: Multiple factors related to patient beliefs and attitudes need to be considered and addressed when initiating insulin in order to minimise psychological insulin resistance and delay. Patients using insulin had less negative perceptions than those not on insulin.

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Introduction

In people with type 2 diabetes mellitus (T2DM) good glycaemic control helps prevent the development of complications [1]. In many cases insulin is required to achieve good control and as T2DM is associated with a progressive decline in pancreatic beta cell function, the need for insulin increases with disease duration [1]. In Barbados 28% of private compared to 15% of public sector primary care patients with diabetes over 40 years of age are estimated to be using insulin [2].

Unfortunately despite the potential benefits and frequent need, insulin initiation is often challenging and delayed for reasons that may be related to the healthcare system [3], healthcare professional [3–7] or the patient [3,6–10]. Patient reluctance or psychological insulin resistance (PIR) has been reported to be a factor approximately a quarter of the time [10]. Reasons include the fear of hypoglycaemia [10,11] and painful injections [3,9,11–16], social stigma [11,15], belief that insulin initiation means failed self-management [8,10], their diabetes has gotten worse [3,8,10–13] and that insulin therapy is burdensome and complex [3]. A physician's assessment that insulin is needed does not mean that a patient will have the same opinion or be willing to use it. Physicians therefore need to determine if PIR is present and address the causes early during diabetes management.

Exploring PIR through the framework of the theory of planned behaviour (TPB) [17] could be potentially useful as this theory sug-

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gests that attitude towards a behaviour, subjective norms and perceived behavioural control together influence intention and ultimately behaviour. Factors related to PIR may be a proxy for behavioural intent, even though further research is needed to explore whether behavioural intent predicts actual behaviour at the time insulin is prescribed.

The first step to exploring this relationship would be to determine attitudes towards a behaviour in a particular context. The insulin treatment appraisal scale (ITAS) is one way to examine insulin-related attitudes and was created to quickly measure negative and positive beliefs regarding insulin [18]. ITAS was generated from the literature on patients' barriers to insulin use, discussions with health care providers and clinical encounters. It consists of 20 questions and has a two-factor structure with items pertaining to a positive and a negative appraisal of insulin. Snoek and colleagues in the United States tested its reliability and validity in a mainly Caucasian sample of both insulin naïve and insulin treated patients with T2DM [18].

The Caribbean diaspora, a population of primarily African-descent, extends across the world with many established communities in countries such as the USA, Canada and Europe [19]. There is little data on the causes of PIR in this population even though research on PIR has been focused on numerous countries and ethnicities [20]. A UK focus group study with 8 people of Caribbean and 5 of African origin found that people on oral hypoglycaemic agents felt insulin was a last resort and indicated death was imminent while those on insulin thought it was efficacious and prolonged life [21]. Previous studies on causes of PIR have not been conducted in Barbados or other Caribbean islands with similar health care systems. However, cultural issues regarding insulin have been identified among 'ethnic minorities' [11,13,22,23] suggesting that it is important to identify such issues in all ethnicities to allow for culturally-tailored interventions to improve insulin uptake, compliance and patient outcomes.

Understanding the causes of PIR among people with diabetes in Barbados, where this study was undertaken, may provide insight that is useful to populations in other parts of the Caribbean and in people of Caribbean descent in other parts of the world. We therefore sought to answer the following research questions: 1) In people with T2DM (insulin and non-insulin treated), what are attitudes and beliefs with regards to insulin use as determined by the ITAS? 2) What are the predictors of the total ITAS score in this population?

Material and methods

Setting

Barbados is a Caribbean island with a population of approximately 280,000 [24]. Primary care is provided by a public sector governed by the Ministry of Health, financed through taxation and available through 9 polyclinics located across the island, and a private sector funded by insurance and out-of-pocket financing by patients and available through numerous independently owned solo or small group practices [25]. Human insulin is readily available at no cost from polyclinics or for a small dispensing fee from private pharmacies. No public sector multidisciplinary clinics for ongoing primary care or access to routine structured education on diabetes are available.

Participants

Participants were taken from those of the Health of the Nation study (HotN), a population-based survey of people 25 years and over to determine the prevalence and distribution of diabetes, car-

diovascular disease and associated behavioural and biological risk factors by age, sex and socioeconomic status. The HotN sample was obtained by island-wide sampling of enumeration districts (EDs) with a probability proportional to their population size. From each ED, households were systematically selected [26]. HotN had 1234 participants, 192 (15.6%) with reported known DM [26].

Inclusion and exclusion criteria

Inclusion criteria were a history of T2DM in the HotN study, 25 years of age and over, and the use of any form of treatment for diabetes inclusive of lifestyle changes. Exclusion criteria included terminal illness, institutionalisation or cognitive impairment.

Procedure

A cross-sectional survey was conducted between July and August of 2015. People with T2DM from the HotN sampling frame were sent letters explaining the study and the possibility of future telephone contact. Potential participants were then contacted by telephone to facilitate assessment of eligibility, and once willing, verbal consent and the interview occurred either at that time or at the participants' convenience.

An interviewer-administered survey consisting of patient information (demographic data, disease duration, health sector attended, diabetes medication, and complications of diabetes) and the ITAS was conducted. The ITAS consists of 4 positive and 16 negative questions reflecting attitudes and beliefs towards insulin, with responses on a 5-point Likert scale from strongly disagree (a score of 1) to strongly agree (a score of 5). The scores for the positive items were reversed and added to the negative items generating a total score range of 20–100. Higher total scores indicate more negative attitudes [18].

Data analysis

Data were entered using EpiData® and imported into Stata v13 for analysis. Firstly, descriptive statistics were used to describe variables. Then, to accommodate non-normality of data, the Mann-Whitney test was used to compare total ITAS score and individual ITAS items between participant subgroups, defined by selected characteristics (sex, having complications or not, having up to secondary level education or not, and insulin use or not). Next, a total negative beliefs score for each participant was created— representing the number of items to which a participant had a negative response to an ITAS item. This number could range from 0 to 20 (number of items on the ITAS scale).

Ethical approval

The institutional review board of the University of the West Indies, Cave Hill, Barbados and the Barbados Ministry of Health approved this study.

Results

Of 192 people identified as having T2DM, 17 were ineligible to participate in this study (8 had died, 4 had mental illness, 3 had terminal illness, 1 was hospitalised and 1 was in a nursing home). The response rate was 67%, with 117 of 175 eligible persons participating. Reasons for nonresponse were that 40 had telephone numbers not in service, 12 were not contactable after 5 attempts and 6 were difficult to communicate with over the telephone because of hearing impairment or stroke. Non-responders had a mean age of

64 years (SD = 15; range 27 to 89 years) and 40% were male. These characteristics were not significantly different from those of responders ($p > 0.05$).

Of the 117 that participated, 80 (68%) were women, 37 (32%) were men. The mean age was 66 (SD = 13; range: 39 to 91) years, mean duration of T2DM was 13.5 (SD = 9; range: 1 to 34) years, 42 (36%) were married, 105 (90%) were Black, 76 (65%) completed year 5 at secondary school and 64 (55%) were retired. Regarding health sector attended for T2DM care, 63 (53%) received private sector care, 38 (33%) public sector care and 16 (14%) utilized both sectors. Regarding treatment regimen for T2DM, 13 (11%) were assigned lifestyle changes only; 35 (30%), 39 (33%), and 4 (4%) were on 1, 2 and 3 oral hypoglycaemic agents respectively; 15 (13%) on insulin only; and 11 (9%) taking insulin with 1 oral hypoglycaemic agent. Regarding complications of T2DM, 19 (16%) reported diabetic retinopathy, 9 (8%) neuropathy, 9 (8%) a cerebrovascular event, 5 (4%) a myocardial infarction, and 2 (2%) nephropathy.

The mean total ITAS score was 61.6 (SD 7.7) out of a possible range of 20 to 100. Negative attitudes and beliefs held by the majority were that taking insulin meant their diabetes had become much worse (68%), concerns by family and friends would increase (63%), self-management had failed (57%), and a belief that insulin injections were painful (54%). Other negative attitudes and beliefs included – being seen as sicker (46%), increased hypoglycaemia risk (38%), makes you more dependent on your doctor (38%), requires effort (34%), it is difficult to inject the right amount of insulin (32%), causes weight gain (27%), makes life less flexible (24%), causes a deterioration in health (14%), and would have to give up enjoyable activities (10%). Positive attitudes and beliefs held by the majority included that taking insulin helps maintain good glycaemic control (78%), would prevent complications (61%) and improves health (58%). Participants on average had 6 negative beliefs related to insulin (SD 3.3; range 0 to 17).

The mean total ITAS score of participants currently taking insulin (53.7, 95% CI 51.1 to 56.4) was 10.1 points lower than those not taking insulin (63.8, 95% CI 62.5 to 65.2) ($p < 0.0001$). Table 1 shows the responses to the 20 ITAS questions by insulin treatment status. Participants not taking insulin were statistically significantly more likely than those taking insulin to have the following negative beliefs and fears about insulin – taking insulin meant that their diabetes had become much worse [(77%, 95% CI 66 to 85) vs (35%, 95% CI 17 to 56)] ($p = 0.001$), they were fearful of injecting them self [(71%, 95% CI 59 to 79) vs (12%, 95% CI 0.02 to 30)] ($p < 0.0001$), managing injections would require a lot of time and energy [(40%, 95% CI 29 to 50) vs (15%, 95% CI 0.04 to 35)] ($p = 0.02$), and taking insulin is painful [(63%, 95% CI 51 to 73) vs (19%, 95% CI 0.07 to 39)] ($p = 0.001$). No other demographical factors (sex, age, sector of healthcare and duration of diabetes) significantly influenced total ITAS scores in this sample.

Discussion

This study identified the factors on the ITAS that are most likely to contribute to psychological insulin resistance in a predominantly Black Caribbean population; a population with a high prevalence of T2DM but little published information on the subject. Most participants believed that insulin would increase their risk of hypoglycaemia, and meant their diabetes had gotten worse and they had failed to self-manage their condition. In a North American study which included few African Americans, the negative factor that most strongly separated people willing to use insulin from those unwilling was the belief that beginning insulin therapy indicates a failure to perform proper diabetes self-management [10]. In an eight-nations European study, patients who were unwilling to start insulin were more likely than willing patients to hold the neg-

ative belief that starting insulin meant the disease is getting worse, were fearful of injections and had a feeling of personal failure [8]. It has been suggested that physicians who threaten patients with insulin may be contributing to the belief that patients had personally failed unless they make greater efforts with self-management [27]. Many were concerned about the perceptions of important others – family and friends would worry about them and people would see them as sicker. All of these concerns could to some extent be true. Most believed injecting insulin is painful, many were afraid of injecting themselves and a third felt that managing insulin required a lot of time and energy, and that it was difficult to inject the right amount of insulin at the right time every day suggesting a lack of perceived behavioural control (perceived ease or difficulty in performing the required behaviour). Even with a positive attitude and intention of performing an activity a lack of perceived behavioural control would be expected to decrease the chance of the activity being performed.

Many also simultaneously held positive beliefs. Therefore, while most felt that needing insulin meant their diabetes had gotten worse and others would see them as sicker, the majority also felt that insulin helped prevent the complications of diabetes, improved health and helped maintain good blood glucose control. Physicians counselling patients can use motivational interviewing techniques to identify and help patients work through the opposing attitudes and beliefs for and against using insulin.

People already on insulin had a lower ITAS score than those not on insulin, indicating that they had less negative attitudes and beliefs. Those using insulin were less likely to feel that their diabetes had become much worse, that injections were painful, to be afraid of injecting themselves and feel that managing insulin injections took a lot of time and energy. This is in keeping with the findings of the ITAS validation study [18] where, like this study, the most marked difference was for people on insulin to be less fearful of injections compared to those not on insulin. There is some evidence that negative attitudes may decrease after insulin initiation [20,28] and it is therefore possible that education and experience may reduce negative attitudes and beliefs and improve perceived behavioural control. However, while counselling, exposure and desensitisation have been proposed as strategies to reduce PIR there is a lack of studies to validate these strategies [20].

Strengths and limitations

The study design cannot determine whether experience and education are the reasons why people already on insulin have a lower ITAS score than those not on insulin. Reasons for refusing insulin may have been missed by the survey instrument. Self-reported information e.g. on disease duration, medication history and complications may be subject to recall bias. A strength of this study is that the HotN study [26] in which it is nested identified a population-based sample of people with diabetes, although it is acknowledged that as in all population based surveys of this type, there may be unknown differences between responders and non-responders. In the HotN Study, 55% of those eligible participated in the study. It is not known if people with known diabetes were more or less likely to respond. A chart audit of patients 40 years of age and over with T2DM attending public and private clinics in Barbados estimated that the patients had a mean age of 64 years and 61% were female [2]. These proportions are in keeping with this study.

Implications

These results can inform structured diabetes educational design and counselling in Barbados. They also provide insight for healthcare professionals providing care internationally to people from

Table 1
Categorical Insulin Treatment Appraisal Scale responses of persons with diabetes in Barbados by insulin treatment status.

Item	Insulin treatment	Strongly disagree and disagree n (%)	Neutral n (%)	Strongly agree and agree n (%)
1. Taking insulin means you have failed to manage your diabetes with diet and tablet	No insulin Insulin	22(24) 11(42)	14(15) 3(12)	55(61) 12(46)
2. Taking insulin means your diabetes has become much worse (p = 0.001)*	No insulin Insulin	10(11) 14(53)	11(12) 3(12)	70(77) 9(35)
3. Taking insulin helps to prevent complications of diabetes	No insulin Insulin	11(12) 1(4)	28(31) 6(23)	52(57) 19(73)
4. Taking insulin means other people see you as a sicker person	No insulin Insulin	25(27) 14(54)	20(22) 4(15)	46(51) 8(31)
5. Taking insulin makes life less flexible	No insulin Insulin	40(44) 18(70)	27(30) 4(15)	24(26) 4(15)
6. You're afraid of injecting yourself with a needle. (p < 0.0001)	No insulin Insulin	24(27) 21(81)	2(2) 2(7)	65(71) 3(12)
7. Taking insulin increases the risk of low blood glucose levels (hypoglycaemia).	No insulin Insulin	13(14) 15(58)	39(43) 5(19)	39(43) 6(23)
8. Taking insulin helps to improve your health.	No insulin Insulin	14(16) 2(8)	27(30) 6(23)	49(54) 18(69)
9. Insulin causes weight gain.	No insulin Insulin	15(16) 10(39)	56(62) 4(15)	20(22) 12(46)
10. Managing insulin injections takes a lot of time and energy (p = 0.02)	No insulin Insulin	26(28) 21(81)	29(32) 1(4)	36(40) 4(15)
11. Taking insulin means you have to give up activities you enjoy	No insulin Insulin	63(69) 23(88)	18(20) 1(4)	10(11) 2(8)
12. Taking insulin means your health will deteriorate	No insulin Insulin	51(56) 21(81)	25(27) 4(15)	15(17) 1(4)
13. Injecting insulin is embarrassing.	No insulin Insulin	11(12) 1(4)	28(31) 6(23)	52(57) 19(73)
14. Injecting insulin is painful (p = 0.001)	No insulin Insulin	15(17) 19(73)	18(20) 2(8)	57(63) 5(19)
15. It is difficult to inject the right amount of insulin correctly at the right time every day.	No insulin Insulin	35(38) 19(73)	25(27) 1(4)	31(34) 6(23)
16. Taking insulin makes it more difficult to fulfil my responsibilities (at work or home).	No insulin Insulin	55(60) 23(88)	27(30) 1(4)	9(10) 2(8)
17. Taking insulin helps to maintain good control of blood glucose.	No insulin Insulin	4(4) 0(0)	19(21) 2(8)	67(75) 23(92)
18. Being on insulin causes family and friends to be more concerned about you.	No insulin Insulin	12(13) 8(31)	19(21) 4(15)	60(66) 14(54)
19. Taking insulin helps to improve your energy level	No insulin Insulin	8(9) 4(15)	53(58) 13(50)	30(33) 9(35)
20. Taking insulin makes you more dependent on your doctor	No insulin Insulin	22(24) 13(50)	30(33) 7(27)	39(43) 6(23)

* Bold text indicates a statistically significant difference between those taking insulin and those not taking insulin.

the Caribbean region. Multiple factors related to beliefs and attitudes, perceived behavioural control (perceived personal control over a behaviour and the frequency at which barriers are experienced), and subjective norms (perceived social pressure to behave in a certain way) need to be identified and addressed by health care practitioners when insulin initiation is indicated, in order to minimise psychological insulin resistance and delay. The intention to use or not to use insulin in many cases does not depend on a single factor.

Interventions can involve providing correct information, helping patients weigh up the pros and cons of using insulin, and helping them improve confidence when perceived behavioural control is low. A trial of insulin under medical supervision and for a short period with the possibility of opting out has been suggested as a way of decreasing PIR [20]. Further research is required on the effectiveness of interventions to change not only insulin-related beliefs and attitudes but also actual behaviour.

Conflict of interest

All authors disclose that there are no financial or personal conflicts of interest that can inappropriately influence the contents of this article.

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