

The meaning of insulin to Hispanic immigrants with type 2 diabetes and their families.

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Abstract:

Purpose

The purpose of this study was to explore the meaning of insulin among a sample of Hispanic immigrants with type 2 diabetes and their family members/significant others.

Method

Forty-three Hispanics with type 2 diabetes and their family members/significant others were recruited in the southeastern United States for a family-based intervention study on diabetes self-management. Focus groups were conducted in which participants with diabetes and family members were asked to describe their perceptions of insulin. The sessions were audiotaped and transcribed, translated from Spanish into English, and analyzed using standard content analysis. This article reports the findings as well as demographic information and hemoglobin A1C levels of participants.

Results

The meaning of insulin was described by both Hispanic immigrants with type 2 diabetes and their family members/significant others. Participants' perceptions were categorized into three major themes: (1) negative perceptions of insulin therapy, (2) perceived barriers to insulin therapy, and (3) positive experiences with insulin emerged from qualitative data.

Conclusions

The Hispanic immigrants with diabetes and their family members/significant others in this study described perceptions and fears of insulin indicating a lack of understanding of the diabetes disease process and the progressive nature of diabetes. Strategies and further research are necessary to dispel negative perceptions and facilitate positive experiences with insulin for patients and family members/significant others.

Keywords: diabetes | nursing | diabetes education | insulin | Hispanic immigrants | type 2 diabetes

Article:

Type 2 diabetes is a progressive disease resulting in a decline in β -cell pancreatic function and a decrease in insulin secretion.¹ Consequently, insulin therapy may be required to achieve and maintain glycemic control and prevent microvascular and neuropathic complications associated with type 2 diabetes.² Current diabetes therapy guidelines recommend early initiation and intensive adjustment of insulin, in addition to oral hypoglycemic agents, to maintain a hemoglobin A1C (A1C) level less than 7% in adults.^{3,4} However, many people with diabetes are not effective in their self-care management and they suffer from daily symptoms and long-term complications.⁵⁻⁷ This is especially true for Hispanics with diabetes; many of them do not achieve glycemic control⁸ and must be hospitalized for hyperglycemia.⁹ Kuo et al.¹⁰ for example, reported that inconsistent use of insulin was associated with an increase in diabetes-related deaths and all-cause mortality among Mexican American seniors (N = 908) over a 7-year period.

Psychological insulin resistance is the term used for refusing insulin or delaying the initiation of insulin therapy.^{11,12} Factors associated with psychological insulin resistance are poorly understood, though a number of studies have examined the phenomenon. A multistate study of 1267 persons with type 2 diabetes found that commonly reported negative beliefs about insulin included restrictiveness of lifestyle (45.2%), permanence (once you begin insulin, you can never quit; 45%), fear of hypoglycemia (43.3%), personal failure (43.3%), and low self-efficacy (43.3%).¹² In that sample, ethnic minorities were significantly less willing to use insulin than non-Hispanic Whites (35% vs. 22.4%; $P < .01$). Larkin et al.¹¹ found similar negative attitudes toward insulin in a study of insulin-naïve persons with type 2 diabetes who were predominantly non-Hispanic White. Reported negative attitudes toward insulin included fear of hypoglycemia (59%), permanence (56%), feelings of failure (49%), and fear of self-injection (< 40%). In addition, 61% reported that using insulin would worry their family or friends, and 77% believed that using insulin meant their diabetes was worse.

Prior research with predominate non-Hispanic populations has shown that unwillingness to use insulin is common among persons with type 2 diabetes, with as many as 20% to 53% refusing insulin therapy despite recommendations by their health care provider¹¹⁻¹⁴ or delaying the initiation of insulin therapy because of negative attitudes and fears about insulin.¹⁴ However, little research has been conducted on the perspectives of Hispanics in regard to insulin, and no research has looked at the views of family members of Hispanics with diabetes. Understanding the meaning of insulin as perceived by Hispanic immigrants with diabetes and their family members can help health providers deliver culturally competent care and overcome barriers to diabetes self-management.

Study Purpose

The purpose of the study therefore was to explore the meaning of insulin in a sample of Hispanic immigrants with type 2 diabetes and their family members/significant others living in the southeastern United States.

Method

Design, Sample, and Setting

The data reported here were gathered as a part of a family-based study of diabetes self-management intervention for mainly Mexican immigrants with type 2 diabetes. Participants were recruited from a community-supported clinic in central North Carolina that provides health services to low-income Hispanics and uses sliding scale payment. Flyers were posted in the clinic. The Hispanic clinic coordinator introduced the study to clients, and a bilingual and bicultural research team member recruited participants. Eligibility criteria included self-identification as Hispanic, age 18 years or older, a medical diagnosis of type 2 diabetes on the clinic record, a family member/significant other willing to participate, and ability to speak Spanish or English. Participants who were pregnant or who had type 1 diabetes or cognitive impairment were excluded. The study was approved by the clinic director and by the Institutional Review Board of the University.

Participants attended an 8-week diabetes education intervention that was culturally tailored to Hispanics with type 2 diabetes and their family members/significant others. The study also included three focus group sessions with the Hispanics with type 2 diabetes and family members or significant others. Focus groups were chosen because they offer an efficient and reliable design for exploratory research questions.¹⁵ Specifically, the focus groups allowed the participants to express their perceptions, beliefs, and attitudes toward insulin in relations to diabetes self-management. A total of 43 Hispanics with type 2 diabetes ($n = 21$) and their family members/significant others ($n = 22$) participated in the focus groups. This article reports the focus group findings.

Data Collection and Analysis

Each focus group consisted of 10 to 16 participants. A structured interview guide that included one open-ended question exploring perceptions of insulin was used. Morgan¹⁵ suggests questions flow from very general to more specific. The focus group interviews began by asking "Please tell us what you think about insulin." Two follow-up questions were "What worries you

about insulin?” and “What has been your experience with insulin?” The focus groups were facilitated in Spanish by the second author, a bilingual family nurse practitioner with training in qualitative research methods, who has worked with the Hispanic community for more than 25 years, and a bicultural and bilingual native Spanish interpreter. Each session lasted 20 to 30 minutes. The focus group discussions were audiotaped and transcribed verbatim in Spanish. The Spanish transcriptions were then translated into English by a bicultural and bilingual research team member. To assure accuracy, all Spanish transcriptions were checked against the audiotapes by two bilingual research assistants. Finally, each English translation was reviewed and verified by two bilingual persons for congruence.

The focus group transcripts were analyzed utilizing the strategies described by Morgan¹⁵ for qualitative data analysis. After first reading through each transcript, significant text segments pertaining to perceptions and barriers of insulin use were identified. Word codes were then assigned to each text segment. The codes were examined by the research team for discrepancies in interpretation, and significance and discrepancies were discussed until consensus on interpretation was achieved. Similar codes were clustered to categories and then assigned into major themes. A qualitative expert reviewed and confirmed the findings for the final level of data analysis. Credibility was met by allowing focus group participants to fully share their experiences and by using bilingual and bicultural interviewers.¹⁶ Sharing transcripts and reading consensus on data interpretation established the confirmability of study findings.

Results

Characteristics of Participants

The average age of participants was 47 (SD = 12.31) years. The average age of those with diabetes was 51 (SD = 9.95) years, and the average for family members/significant others was 42 years (SD = 12.98). The majority of participants were female (72.1%). The average hemoglobin A1C for participants with diabetes was 8.56% (SD = 2.42), and for family members/significant others it was 6.35% (SD = 1.87). More than half of the participants with type 2 diabetes took oral hypoglycemic agents (68.4 %), and a third (31.6%) used insulin injections. All participants were immigrants; most were from Mexico (83.3%). The average length of time living in the United States was 15.5 years (SD = 7.68). Demographic information is presented in Table 1.

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Perceptions of insulin were identified in the focus group interviews with Hispanic immigrants with type 2 diabetes and their family members/significant others. The data were analyzed, coded, and categorized into themes derived from participants’ discussions and responses to the open-ended questions. These perceptions were categorized into three major themes: (1) negative perceptions of insulin therapy, (2) perceived barriers to insulin treatment, and (3) positive experiences with insulin.

Negative Perceptions of Insulin Therapy

Both participants with diabetes and their family members/significant others expressed negative perceptions of insulin therapy and fear that using insulin would result in organ damage and even death. The negative perceptions about insulin included the idea that insulin kills, insulin scares, insulin is the last resort possible, and insulin itself causes problems and damages the body.

Insulin kills

Participants linked the use of insulin to impending death. Some voiced the belief that insulin kills people with diabetes:

There was a lady with diabetes and she would inject herself with insulin and she died. My mom who has diabetes would take a pill that she would put in water in order to take it. So far, my mom has lived many happy years. (Female, age 49)

Because of a lack of information in my family, we thought that when you inject insulin in your body, it is as if you are already dead. It kills you. (Female, age 40)

Insulin scares

Participants expressed fears about insulin therapy and described insulin treatment as scary and associated with advanced diabetes:

Well, what I've heard about insulin is that when you have to use insulin it means that your diabetes is very advanced and that you also can lose your sight. (Female, age 68)

I have heard people say that using insulin is the worst thing possible. I tell you this because in Mexico, when I talk with my mom, she says that my sister-in-law became diabetic while pregnant. A year later she now has diabetes permanently. She doesn't take care of herself. Now, they tell me that I should take care of myself. My mom says that my sister-in-law is in a bad way and she must give herself insulin injections . . . I tell my mom that my sister-in-law is not going to last much longer. And it scares me because the doctor says that he might have to switch me over to insulin. (Female, age 35)

Insulin is a "last resort."

Several participants believed that using insulin injections was the worst treatment to be used for diabetes and should only be used as a last resort:

A lot of people think that using insulin is the last resort. It is the worst. I think that many people think like this. (Female, age 34)

Insulin causes problems and damages

Many participants described perceptions that insulin caused health problems and damaged their bodies. For example, some participants associated insulin with increased hunger and being forced to inject themselves. Other persons believed that insulin resulted in blindness and renal failure.

I have used insulin for four years. I feel like the insulin makes me eat a lot and makes me very hungry. I feel like it doesn't help me because at times it affects my appetite and then I eat more. (Female, age 52)

I think that insulin is a big problem because you have to stick yourself and stick yourself. (Female, age 35)

From using insulin you get swollen. It damages your kidneys and your blood changes every three days. I have a neighbor in Mexico who is going blind. (Female, age 46)

They say that insulin cures some areas, but affects other areas as insulin supposedly is controlling sugar. But it damages the kidneys also. That is what the doctor told me. It heals the one and affects the other. (Male, age 47)

Perceived Barriers to Insulin Therapy

The second major theme was perceived barriers to insulin therapy. Perceived barriers to insulin therapy reported by participants include insulin inconvenience and a lack of family support for using insulin.

Insulin is inconvenient

Many participants identified inconvenience as a barrier to using insulin therapy. Participants who had used insulin experienced difficulties when they were away from home because they needed to carry a cooler. Also, they reported difficulties in accessing syringes for insulin therapy:

The problem is when someone goes out, you always have to take a cooler. (Female, age 40)

Before, I was never able to get the syringes, because here they won't sell you the syringes because you can use them for bad things, like drugs. (Female, age 40)

One participant thought that insulin pens were easier to use, therefore more convenient:

Those insulin things that look like pencils that they have now, so that you do not have to have syringes. With those things like pencils you can give yourself a shot. You just push down like you would on a pencil. My niece has those and only uses the pencils. However, you still need a cooler. (Female, age 40)

Lack of family support for using insulin

A lack of family support and knowledge was also identified as a barrier to insulin therapy. Family members' misconceptions about the disease process sometimes influenced participants with diabetes not to use insulin because the families did not see the effectiveness of insulin therapy. One family member said:

I saw my mom thin, starving. . . . When she [her mom who had diabetes] asks questions about using insulin, I would tell her "don't take it," "don't take it," because my mom does not drink sodas, does not drink juices, does not eat bread, no chili, nothing, not rice, not tortillas, but the disease continues. (Female, age 40)

Positive Experiences With Insulin

The final theme was positive experiences with insulin. Despite negative perceptions of insulin and barriers to insulin therapy, a few participants reported positive experiences with insulin treatment. They indicated that insulin made them feel better and they perceived insulin as more helpful than oral hypoglycemic agents:

I have used insulin for five years. I don't feel bad. I inject myself every day. (Female, age 58)

From what I have seen and heard, I think that insulin is better than pills. (Female, age 42)

I felt very bad before insulin. But since I started using insulin I feel well because I've had diabetes for seven years and I have never gone to a hospital. (Female, age 32)

Discussion

We explored the meanings of insulin of both the individual and family levels among Hispanics with diabetes and their family members. Participants reported negative perceptions about insulin therapy, perceived barriers to insulin therapy, and positive experiences with insulin. These negative perceptions and barriers to insulin use can be major challenges to successful diabetes self-management. Although some of the negative perceptions and perceived barriers to insulin identified in this study have been previously described in the literature among non-Hispanic populations,^{11,14,17} the study findings provide unique perspectives on insulin from both individual and family that extended beyond fear and negative attitudes toward insulin treatment. Thus, family support and family members' understanding of diabetes, diabetes management, and cultural beliefs about insulin need to be included in diabetes education for Hispanics with diabetes.

Negative perceptions about insulin in the current study with predominantly Mexican immigrants might be related to the fear that the start of insulin therapy could be a sign of advanced stage of disease or impending death. These negative perceptions and fears may be related to prior practices of initiating insulin late in the treatment plan, which was more common before the development and use of long-acting insulin analogs.¹⁸ Cultural beliefs that insulin is toxic and

patients' and families' perceptions that insulin is associated with diabetes complications may contribute to refusal of insulin therapy.¹⁹ Lack of knowledge about insulin and its side effects was reported to be associated with fears of insulin.²⁰ Knowledge deficits in diabetes and its associated risk factors have also been found among Hispanic populations.²¹ Many Hispanics may lack knowledge on the pen device for the administration of insulin due to the fact that they may not be able to access the health care system, receive education of this delivery system, or afford this treatment option. This was particularly common in this sample and may have been due to the fact that many Hispanic immigrants in the United States are socially and economically disadvantaged, have limited access to health care services, and have cultural and language barriers.²² Findings of the study are consistent with a previous research showing that many Hispanic patients with diabetes have negative perceptions of insulin²³ and many patients with diabetes delay or refuse to use insulin. This lack of adherence to the treatment of diabetes is primarily related to hassles related to insulin, uncertainty about self-administration of insulin, or fears of their disease having progressed into a serious stage.^{22,24} Caballero and colleagues,²⁵ for example, reported that 43% of Hispanics with diabetes believed that insulin can cause blindness. Jezewski and Poss²⁶ reported that Mexican Americans expressed fear of using insulin thought insulin might lead to addiction and cause blindness and they believe an association between insulin use and serious stage of the diabetes.

Participants in this study also said that inconvenience, inaccessibility of syringes, and a lack of family support are major barriers to insulin therapy. A previous study reported that most patients with diabetes worried about the inconvenience of insulin and its consequences resulting in restrictiveness of lifestyle.²⁷ Accessing syringes was a great concern, perhaps because of low income and lack of health insurance. Also, all participants were immigrants, and difficulties in accessing syringes may have been related to their lack of familiarity with the health care system of the United States. These findings are consistent with reports by Campos²⁸ that socioeconomic factors, language and health literacy issues, cultural issues, and patient-provider relationship are barriers to the successful use of insulin in Hispanics with type 2 diabetes.

Another major barrier to insulin therapy was a lack of family support. Participants reported that family members discouraged the use of insulin because of their misconceptions about the disease process. Cultural concepts of maintaining family support and cohesiveness as well as smooth social relationships are important factors in diabetes self-management in Hispanic culture.^{29,30} Other researchers have noted that family support and religious faith are key facilitators of diabetes self-management among Hispanic patients.³¹ While in Hispanic cultures there is a high expectation of receiving support from family members or friends, with decreased family size and increased responsibilities outside the home, family members may not be available to provide support to the individual who has diabetes.³² A recent study of Hispanics with diabetes reported that participants with diabetes perceived they received less support from their children because the children were busy. Also, family members provided them with high-fat and high-calorie foods despite their diabetes conditions.³³ Further, Mexican women with diabetes have reported a

lack of general family support.³⁴ Several studies have suggested that diabetes education for Hispanic populations be provided within a family context.^{35,36} Also, promoting and facilitating family support can be significant in overcoming barriers to insulin therapy in this population.

Finally, despite negative attitudes and perceptions of insulin, some of these participants reported positive experiences with insulin, perhaps because they received positive information about insulin from their health care providers. Thus, diabetes education for this population should include the positive effects of insulin.

Several limitations of this study must be noted. The convenience sample of Hispanic immigrants with type 2 diabetes and their family members/significant others was drawn from one clinic that in particular serves Mexican immigrants, and they might not represent populations who live in other communities with large populations of Hispanics or Hispanics who have immigrated from Latin America areas.

Implications

Overcoming factors associated with psychological insulin resistance among Hispanic immigrants with type 2 diabetes is critical for improving their acceptance of insulin therapy and preventing delays in initiating or continuing this essential treatment option. The findings reported indicate that participants with diabetes and family members/significant others have misperceptions and fears of insulin, which may originate in part from a lack of diabetes knowledge of the comprehensive impact and progressive nature of the disease.

Diabetes education directed for patients and family members is essential. Including family members in educational interventions and emphasizing the role of family in the disease process are important for successful adherence to a diabetes self-care regimen.³⁷ Family members need to learn about diabetes, strategies to develop healthy behaviors, and psychological supports to the family member with diabetes. Education provided to family members should integrate cultural values and beliefs about diabetes, dispel their negative perceptions about insulin, and facilitate positive experiences. Discussing insulin therapy early in care, not as a threat or personal failure, but as an essential hormone necessary for achieving glycemic control and preventing complications, is one method to overcome psychological insulin resistance.³⁸ Encouraging patients and their family members/significant others to ask questions and voice concerns about insulin promotes rapport and provides a basis from which to begin to negotiate treatment options. Incorporating family members/significant others in these discussions is an important culturally competent strategy when working with Hispanic patients.²² Careful consideration is needed of socioeconomic barriers such as lack of health insurance and affordability of glucose testing supplies and insulin, syringes, or pen delivery systems.^{39,40} Other identified considerations

include assessment of visual acuity, manual dexterity, confidence in ability to self-inject, and receptiveness toward a simplified versus complex insulin regimen.^{22,38,39}

Primary care physicians, nurse practitioners, physician assistants, and certified diabetes educators must be familiar with various insulin regimens and be willing to initiate insulin early in the treatment plan as recommended by current guidelines and algorithms.^{3,4} Delaying the use of insulin has been reported to be significantly more common among US physicians and nurses than those from other countries according to a multinational investigation of more than 3700 physicians and nurses.²⁷ Currently, basal insulins, such as insulin detemir and insulin glargine, are recommended as step 2 therapy if lifestyle and the maximal tolerated dose of metformin fail to achieve glycemic goals.⁴ The addition of basal insulins may be an appropriate method for introducing insulin to Hispanic patients as these insulin analogs have a long duration of action, flat action time, usually require only once daily dosing, and have a lower incidence of hypoglycemia.³⁸

Providing quality care for Hispanics with diabetes requires cultural competence and interpersonal communication skills incorporating personalismo (warm, personal relationships), respeto (respect), and simpatía (kind, courteous interactions) in order to build trust and respect and promote honest dialogue and rapport between Hispanic patients, family members, and health care providers.^{22,41} Prior research findings indicate that when there is a perceived lack of these social amenities with health care providers, then Hispanic patients are less likely to disclose pertinent information, comply with treatment recommendations, and are less satisfied with the care they receive.^{42,43} Finally, non-English-speaking Hispanic patients with type 2 diabetes and their family members require access to appropriate and timely care as well as diabetes education in a language they can understand and that incorporates cultural values and beliefs that are meaningful and able to dispel negative perceptions of insulin.

Hispanics with diabetes and their family members in this sample described the major negative perceptions related to regular and appropriate insulin usage. Diabetes education programs tailored for this population should include information pertaining to the negative perceptions that Hispanics have about insulin and diabetes. Strategies to address barriers associated with psychological insulin resistance at both the patient and family/significant other level, as well as at the health care provider level, are required to meet national health objectives to alleviate this health disparity. Future research exploring barriers to insulin with regards to diabetes knowledge, communication/language barriers, and health care provider factors that may be associated with Hispanic clients' psychological insulin resistance will provide additional knowledge that can be translated to providers, policy, and delivery systems.

Article Notes

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