

The Experience of Mexican-Americans Transitioning to Insulin Pump Technology

Emily F Piven^{1*} and Homer Nazeran²

¹Health Matters First of Florida Inc., USA

²Professor, Electrical and Computer Engineering, University of Texas at El Paso, USA

Abstract

Occupational therapists help people of all ages do the things they need or want to do through therapeutic activities that constitute everyday occupations. They are interested in how people adapt to disease or illness in performance of all activities of daily living in self-care, work, education, leisure, play, and social participation. This study was undertaken as there was a paucity of literature about how people make adjustments to living with, a biomedical device. The aim of this pilot study was to explore the life experience of Mexican-Americans with type 1 diabetes mellitus, who transitioned from multiple daily insulin injections to using continuous subcutaneous insulin-infusion therapy (also called the insulin pump) to manage their conditions. This exploratory, qualitative research study had a convenience sample of three females and three males from 28 to 55 years old. Themes were: 1) Easy for one yet hard for another; 2) Feels like starting over; 3) High expectations: The magical pump; and 4) Self-perception redefined. Conclusion: Insights about the cultural attitudes, beliefs and experience of Mexican-Americans transitioning to the insulin pump may assist health professionals to prioritize their initial concerns when helping patients deal with this technology. Referrals to occupational therapists should be considered to help Mexican-Americans deal with psychosocial issues that arise, for facilitation of problem-solving and coping skills, in order to manage self-care issues is recommended.

Keywords: Adaptation; Occupational performance; Qualitative; Continuous subcutaneous insulin infusion

Introduction

Management of type one diabetes mellitus (T1DM) requires consistent attention throughout the day to balance food intake with insulin, exercise, and monitor glucose levels, in order to avoid hypoglycemia and maintain homeostasis [1]. Landmark longitudinal studies established that tight control of glucose that is accomplished by continuous subcutaneous insulin infusion (CSII) therapy can delay or reduce the severity of long term micro-and macro-vascular complications, thereby extending the lives of people with T1DM about five years [2,3]. This form of therapy is recommended when an individual has wide glycemic excursions, recurrent severe hypoglycemia, when the insulin regimen compromises lifestyle, and/or when there are macro-vascular complications. The terms CSII therapy and the pump are used interchangeably throughout this paper.

CSII therapy delivers short-acting insulin from a reservoir by means of a subcutaneous cannula and a programmable external pump that replaces injections. Precise doses are delivered in increments of 0.025, 0.05, or 0.01 units, depending on calibration of the medical device, under a physician's individualized treatment plan. A basal rate can be tailored for 24 hours/day to provide background of insulin. Then, the user administers daily bolus doses to accommodate extra insulin needs that are based on the carbohydrate content of meals. The pump can be temporarily turned off during exercise, bathing and showering, if necessary [4].

Those who show that they have established good habits and routines, demonstrate diligence and dedication in their own care, and have health insurance are offered the device [5]. The recognized advantages of CSII therapy are flexible eating schedules, being able to vary meal sizes, and tighter control. Disadvantages are that there can be many technological issues with pumps such as discomfort, irritation, site infections excessive bleeding, bruising, tissue clogs, difficulties keeping the pump attached, ketoacidosis from pump malfunction, a visible sign of diabetes, and necessity to check blood glucose often

[6]. Wearing the pump can tax one's problem-solving capabilities and coping capacities. Some people discontinue the use of this life extending technology that optimizes control [7,8], so that CSII therapy may not be the best approach for everyone.

There is a paucity of research reporting how CSII therapy affects the lives of adults who use the technology and documents their experience while trying to adapt to the device [7,8]. There were no studies found about the transition from injections to CSII therapy in Mexican-American adults.

Problem

Mexican-Americans have higher uninsured rates than non-Hispanic whites and Asian/Pacific Islanders, which is linked to poorer health outcomes [9]. They may be less likely to be placed on CSII therapy, due to their underinsured status and health disparities [10]. There is a need to explore the lived experience and coping processes of Mexican-Americans because of the potential for cultural nuances to affect how one is able to adapt to CSII therapy.

Materials and Methods

The aim of this phenomenological study was to explore the lived experience of Mexican-Americans with type 1 diabetes mellitus, who transitioned from multiple insulin injections daily to using continuous subcutaneous insulin-infusion (CSII) therapy to manage their

***Corresponding author:** Emily F Piven, Health Matters First of Florida, Inc. P.O. Box 64, Oakland, Florida 34760, USA, Tel: (915) 203-0718; Fax: (407) 656-1081; E-mail: emilyh@utep.edu

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conditions. Six bilingual participants were interviewed, comprising a convenience sample of three females and three males of 18-55 years. Qualitative method may be the best method to illuminate the cultural viewpoint, free from preconceived notions of the researchers [11]. The personal perspectives gathered through interviews and discussions identify shared commonalities that may uniquely influence self-care habits of Mexican-American adult on CSII.

Procedures

The University of Texas at El Paso Investigative Review Board approved the study. Informed consent describing study benefits and risks, voluntary participation, withdrawal at any time without penalty, and confidentiality of identity was signed by the six participants. Referrals for participants came from health educators at a community diabetes association in a large city along the Texas-Mexico border. Participants attended three 2-hour focus group meetings in the association. Then, one individual interview was scheduled for each of the six participants, to confirm that the data had reached saturation. A fourth focus group met to allow for the member-checking process that validated that the emergent themes captured the true meanings of their words and the essence of being a Mexican-American using the biomedical device. Criterion for participation was based on being an adult bilingual Mexican-American, and having used CSII therapy for more than six months. The researcher initiated discussions with the approved open, broad semi-structured questions, and then probed further into details, drawn on the clinical experience of the lead researcher. The discussions were tape-recorded and the conversations of the focus groups and individual interviews were subsequently transcribed verbatim by the lead researcher and student. Atlas ti. software [12] provided ease of coding, mapping, and management of the data for extraction of themes. Participants asked the agency for their glycosylated hemoglobin (HbA1c) blood test records, to provide information about the average glucose reading during the last three months to identify their status before they began using CSII.

Confidentiality and trustworthiness of data

All procedures enhanced the trustworthiness of data collected. Pseudonyms (fake identities) were created to enable the reader to track individual responses in the paper. Audiotapes and documents were stored in a locked filing cabinet and were password protected on computer. All tapes were erased and transcripts were destroyed at the end of the study. Transcripts were read and coded by two Mexican-American diabetes lay educators to identify cultural nuances, two CSII users, and the lead researcher to exceed triangulation of data criteria.

To further confirmability and soundness of data, the investigator kept field notes to capture the emotion and non-verbal observations, and record any personal biases [11]. Data audit by reviewers controlled bias and distortion of data before asking for member-checking of themes.

Results

Detailed demographic information is presented in Table 1 to enable readers to determine similarities and differences between these participants and the Mexican-Americans in the context of their own setting for transferability of data. Duration of diabetes for participants ranged from 7 to 32 years. Duration of time using CSII therapy ranged from 6 months to 7.5 years. Education spread from 8th grade to master’s degree. Participants were single, married, divorced and widowed. All were gainfully employed and had insurance to assist with cost of supplies and purchase of the durable medical equipment. Reasons for approval of the pump by participant’s insurance companies were included.

Themes and integrated discussions

Themes were 1) Easy for one, yet hard for another. 2) Feels like starting over. 3) High Expectations: The magical pump! 4) Self-perception redefined. Each theme is presented with integrated discussion.

Easy for one, yet hard for another

Some participants handled their frustrations better than others. Situations or challenges that seemed easy for one were more difficult or frustrating for others. Ricardo quipped, “I found the pump easy, but I am very mechanical. In two seconds, I take my shots. Can’t beat the convenience!” Ana said, “I’ve lost weight because I have less hypoglycemia on the pump.” Others were less positive. Manuela’s physician indicated she should wear her waterproof pump in the shower because her blood sugar levels drastically elevated 15 minutes after pump removal. She said, “How ridiculous is this? No one else has this kind of inconvenience! Then, I get a letter from the manufacturer saying the pump is no longer waterproof, so I am getting a new one. Until then, I take two minute showers.”

Manuela responded, “If I take a bath, I lay it on the tub and pray that it doesn’t fall in. That irritates me.” Roberto was frequently awakened, “The weird thing is when I sleep, I sense the pump poking me when I roll over. It awakens me a lot and I move it.”

Wearing a pump requires trial-and-error problem-solving. “Sometimes, I bruise badly and I have to change my tubing. It becomes

Reasons for CSII	Age	Marital status	Occupation	Duration T1DM	Education	Duration on pump	Sex
High glucose HbA1c 10.0 mg/dL	43 y/o	Married, 2 children	Fork-lift operator	17 years	8 th grade	2.11 years	M
Life threatening hypoglycemia, HbA1c 4.2 mg/dL Lost driver’s license Frequent cheating on sweets	28 y/o	Divorced	Social worker	10 years	Master’s degree	7 months	M
Wide glycemic excursions HbA1c 7.2 mg/dL	38 y/o	Single	Fireman	32 years	12 th grade	11 months	M
HbA1c 7.5 mg/dL 7 shots per day, insulin resistance	31 y/o	Married	Dietician	7 years	Baccalaureate degree	1.3 years	F
5 shots per day, HbAc 7.3 mg/dL	48 y/o	Married, 3 young children	Realtor	26 years	High school	7.5 years	F
Overweight Neuropathy, HbA1c 7.0 mg/dL. Took daily weight loss injections	45 y/o	Widow, 2 adult children	Nurse-aide for hospital	27 years	10 th grade	6.4 years	F

Table 1: Participant Demographic Characteristics.

very expensive when I get tissue clogs and my sugar goes sky high. Until I figured it out, I was miserable.” [Ana] New users seemed to take things literally and were limited in problem-solving abilities. “It gets in the way. I bump it at work.” [Marisela]; “I was forced to wear suits every day to work.” [Manuela]; “I kept looking at the beach and the water. Damn, I was sure I wanted to swim, but I kept looking at the pump...I just kept looking at the water”. [Ricardo]; “I always get hypoglycemic when I exercise, so I don’t exercise.” [Manuela].

Transitioning to the pump was complicated, inconvenient and frustrating for all. It was experienced as bothersome, intrusive, adding unwanted attention to themselves with diabetes, as evident by their comments, “I like my pump, but hate this constant appendage!” [Marisela]; “Sleeping with the pump interferes with nudity!” [Ana]; “Sex is more difficult with a pump, but it beats the alternative.” [Ricardo]; “When I take my pump off during intimacy, I forget it is off and fall asleep, then I wake up with a 400+ blood sugar. How embarrassing!” [Roberto]; “My pump comes off when I sweat.” [Marisela]

“Who gets tissue clogs like me here? I get so disappointed when I think I have done everything right, and I cannot explain high blood sugars. I quiz myself, am I getting sick? Did I miscalculate? Did I overeat? You know the routine. I didn’t want to use the pump, ever. I was ungrateful and avoidant. The first few months were awful adjusting basal rates. My doctor kept encouraging me to stick with it. I almost quit five times!” [Ana]

“Diabetes is a pain in the butt. I had problems finding a site to place my pump after 26 years of scar tissue from shots. I didn’t rotate properly. Now I have to put the catheter in my butt. Picture that! My little pump helps me, still have to take shots. How ironic is that? I don’t have it easy.” [Manuela]

There was positivity and sharing stimulated by the discussion. Marisela summarized, “Diabetes is a 24/7 job. The pump is just another life challenge that can be conquered with self-discipline and persistence. I love my pump now.” Roberto passionately said, “Without it I’m gonna croak! I was afraid to start too; I didn’t want to have a machine stuck inside my body, but I got used to it and it beats taking four shots every day.”

Trial-and-error problem-solving was reported to be a daily experience and necessary coping skill for Mexican-Americans with T2DM [12-14]. People with T1DM must also learn to problem-solve, because diabetes poses challenges to all aspects of occupational performance [15]. Ana described the experience that everyone had best.

“If my sugar is high, I start the inquisition all over again with the questions, is my pump clogged? Am I getting sick? Did I eat too much? Did I exercise too little? Is my pump malfunctioning again? Did I insert the tube too slowly? Am I out of insulin? The list is exhausting. Sometimes I just don’t have a clue why my sugar is high.”

Feels like starting over

Everyone, except Roberto, had difficulty transitioning to the pump initially. He wore it from the beginning because his work was dangerous and exhausting and he thought the pump protected him. The other men voiced that they were less concerned about their appearance because they saw beepers as a symbol of importance. Men were most practical about avoiding hypoglycemia and wanted to extend their longevity. Everyone eventually showed better adherence with self-care, perhaps due to the trial-and-error problem-solving process.

Ana viewed her transition to the pump as “failure” because she was unsuccessful with all other attempts to balance her blood sugars.

“I hung onto my 7 shots/day. I really don’t know why I did not acknowledge the pump box. I procrastinated opening it. I freaked when I actually put the pump on! Reality hit me. Intellectually, I knew the pump was better than shots. Finally, I sat down, read the book and just started.”

Although participants thought that the health benefits outweighed any negative feelings towards the pump, Manuela also resisted change. She felt ill prepared for the psychological issues that arose when using the pump.

“It’s extremely frustrating not to be able to do anything the way I use to do it...Nobody told me how I’d feel transitioning into it... I wish people told me everything! The good, the bad, the ugly... not just that your sugars are going to be better. Nobody told you the games that it plays with your mind. I wish I knew other people felt like me. I did the pump because I knew that the way I was living was not going to guarantee my health. Diabetes is a gamble every day.”

Marisela felt overwhelmed. “I had to change everything I did before! It was like being diagnosed with diabetes all over again.” Manuela talked about the way she would try to hide having diabetes at work, wearing a pump was like wearing a sign...“Everyone would question me about my beeper. At first, I let them think it was a beeper. My hose was always showing”. We will return to Manuela’s comment when we discuss the Mexican-American concept of “weakness”.

Ricardo had modified his viewpoint, following his car accident, “You know, Latinos have it worse than anybody. Most of us get the sugar. Most of us die with complications. I don’t have time to get complications. I have a long life ahead of me! I watch myself better now.”

Ritholz et al. [16] also confirmed that transitioning to a pump reminded participants in the study of the kind of emotional reactions that they had when first diagnosed. Her participants focused on the convenience aspects. In this case, initially some of these participants engaged in risky behaviors, operating on their high expectations that got them into trouble with hypoglycemia and weight gain described below.

High expectations: The magical pump!

Like everyone in the group, Manuela had high expectations about the pump.

“I wish everything magically had a carbohydrate number on it. Like something that is not packaged...You have to guess-ti-mate it [approximate the carbohydrates]... I did have the book and I’d have to sit there for a good 5 minutes before I could figure out how much I have to factor in before I can start enjoying my meal. It’s just, ugh, the constant calculating...Even then it’s just hit or miss because sometimes you eat with your eyes and you put the insulin on thinking you are going to finish all that food and half way through the meal you are like ‘I have to eat it now’ because I put the insulin in my body.”

Roberto and Marisela tended to run higher HbA1c tests than others because of their dietary indiscretions. “When I started the pump, I thought I could eat anything. After nearly getting killed, I had to get more realistic about my limitations, fast!” [Roberto]. Marisela said, “I gained weight too because I could just take more insulin, but now I cannot seem to lose it.” Ricardo added, “Still, I can’t seem to give up the forbidden Hispanic foods. I binge in cycles. The pump allows me to do that. Then, I feel guilty and get back on track. I have to remind myself of my need to be healthy.”

Roberto was grateful for the pump and was more realistic. He said, "The diabetes killed my mom. My brother lost his leg, then he died. To me, my pump is a miracle. It's magical. This is my lifeline, I depend on it."

"I thought this is a super cure! I was just going to be better. I would be able to do anything I wanted to do. No one told me how tough it would be to get used to. Over time, it got easier, but it was so hard in the beginning. It was just as bad as getting my diagnosis. I was tired of shots, but the pump seemed much worse at first." [Ana]

Low sugars were more threatening to the participants because hypoglycemic behavior can be noticeable by others. "When I get low, I am afraid I cannot control myself and I stuff sugar in." [Ana], "When I have a low sugar, I don't want people to see me weak. Men are supposed to be strong!" [Roberto]. Marisela said, "When I get low, I raid the stash of sweets that I save for my children." There was social discomfort about people noticing their pump and seeing them as weak during hypoglycemia [14].

Our research dovetails with previous research [16] where new pump users initially experience misconceptions about their new found freedoms with the pump. Those who began with high HbA1cs tended to fear the technology initially. Likewise, in the previous study, authors found that participants either lost weight because of less hypoglycemia or gained weight on the pump [16]. Mexican-Americans in this study sought freedom from diabetes before they stopped eating forbidden sweets and extra food. They either lost weight because of polydipsia or gained it because of the extra insulin they took.

Self-perception redefined

The women had concerns about wearing a conspicuous device that altered their appearance and body image. Manuela had challenges to her role as a woman.

"I dress like a man! I always feel like some kind of robotic creature or something. I hate feeling this way. My sales are down because I am not self-confident any more. It affects what clothes I look at on the racks now; I exclude everything that doesn't have a pocket. Not that I was ever very fashionable, but I feel less feminine. I need to hide the pump!" [Manuela]

"I get frustrated sometimes, especially if I am going to church on Sunday and I am wearing something nice, I am like I have this "stupid thing on me". "It looks like a bump under my clothing and makes me feel sloppy." [Ana]

"I had a tough wake-up call with my car accident. I was lucky. I had to take better care of myself and stop acting irresponsible like an adolescent. Still, I resisted change, until I matured. I slacked off of my glucose monitoring. I did not gain weight because I was losing everything in my urine." [Ricardo]

"I take it off to swim and when I am doing yard work. I will take it off so I won't get it wet or dirty. Maybe I am self-conscious too because it is not macho." [Ricardo]

"I felt like a bionic woman or something like a robot." [Ana]

Unlike the findings of a previous study [16], Mexican-Americans did not think that the pump reduced the stigma of diabetes. They had a reduction of social acceptance with a visible demonstration of having diabetes. This has been seen in other studies of Mexican-Americans with type 2 diabetes mellitus in what the authors called the "social cost of diabetes" [14] and feeling cursed with diabetes [13]. Some people with diabetes viewed their diagnosis as a punishment, curse or susto

(imposed by a great fear that they experienced) [13,17]. Some use a curandera (folk healer) to bestow folk cures [18]. Marisela explained, "If you display a pump, you share that you have diabetes, which people think is a curse." Marisela shared, "When I went on shots, I believed God had punished me with the curse of diabetes. On the pump, I believed now he was doing it to me again!" Somewhere in the adaptation process, Marisela overcame her fatalistic belief and began to take more responsibility for her health. Fatalism, common among Mexican-Americans [19], could interfere with development of good problem-solving skills. Familiasmo, meaning dedication to family's well-being above one's own well-being, is another cultural attitude that is common among both sexes [20]. Manuela stated, "It's cultural. The needs of my spouse and children are more important than mine." This turns the focus away from the self, and as a person using CSII, one must pay close attention to their own needs first, or they may not be available to help others. Familiasmo was seen as interference by the extended family, reflected in comments by Ana, "I laugh about the whole cultural thing. Everybody has a remedy for something. Instead of accepting it, they try to cure you. Do this herb, see this curandera, do this and do that. After the 500th remedy, you are just like "Shut up, ok! I just have to live with diabetes!"

Macho/machismo, synonymous with dominance and virility as well as assertiveness as the head of the family, has been found to affect one's sense of masculinity and adequacy [21], which may be challenged when a male wears an insulin pump. Ricardo, the youngest participant, referred to this issue on two occasions. "Maybe I am self-conscious because it isn't macho." Mexican-American men may experience challenges to their macho role on the pump.

The Mexican-American females in our study population seemed upset by their need to adapt clothing more than the males. In addition, Manuela dealt with emotional issues relating to intimacy and the roles she played as a female and worker. She reacted with a need to hide her pump, change her clothing, and avoid bathing suits. Her tears expressed how hard the transition had been.

"There is so much social interference. What's annoying to me is when I serve myself something to eat and everyone is like, "Uh, is that ok for you? How many carbs is this?" Let me enjoy myself! I am a dietician. Don't question my choices." [Ana]

There has been scanty information about discontinuance of insulin pumps in adults and children since 2003. One author found that women may be more at risk for discontinuation of this life-extending technology [7]. Mexican-American women in this study had difficulty with the transition from injections to CSII therapy. Numbers of females who have stopped using CSII therapy are not published, except in marketing research, but this poses the question whether women may need extra help to cope better with CSII.

Limitations

Phenomenology method draws meanings from the common experiences of a group or state of being, but by the time it is captured it can be transformed and cannot be generalized.

Implications for occupational therapists and allied health professionals

Occupational therapists help people of all ages do the things they need or want to do through therapeutic activities that constitute everyday occupations. They are interested in how people adapt to disease or illness in performance of all activities of daily living in self-care, work, education, leisure, play, and social participation.

Occupational therapists are accustomed to helping people deal with psychosocial challenges surrounding self-care issues.

Physicians, physician-assistants, nurses, health educators, and physical therapists who work with people using CSII therapy may provide referrals to occupational therapists. Occupational therapists are skilled at facilitating problem-solving and coping skills, which may prevent discontinuation of such a valuable resource for those Mexican-Americans, who have the blessing of being able to afford CSII therapy through insurance. Occupational therapists will need to engage in research to demonstrate that they play a role in prevention of the discontinuation of CSII therapy.

Conclusion

The authors did not find any research about the responsiveness of Mexican-Americans to continuous subcutaneous insulin infusion therapy (the insulin pump). Our data suggested that cultural attitudes seemed to have an impact as six Mexican-American adults in this study transitioned from multiple daily injections to an insulin pump. Participants revisited their initial feelings about coping with diabetes a second time. They had to modify their initial high expectations about achievable freedoms with the insulin pump, get more realistic, modify their attitudes, deal with psychosocial issues and social discomforts, and improve their problem-solving skills in order to adapt. Cultural beliefs about “the curse of diabetes”, fatalistic viewpoints, the “diabetes as a weakness” and “machismo” seemed to delay their initial adjustment to the technology. Females perceived the pump as an external appendage that drew unwanted attention toward them, interfered with body image, and made them more self-conscious than when they were taking insulin injections. Females seemed to be more bothered by clothing adaptations than men and are at greater risk for discontinuation [7]. Eventually, each participant came to the realization that the pump was beneficial as long as they used it properly. Participants went through a trial-and-error process to adapt, and became more active in their search for well-being over time. The insulin pump provides opportunity for secondary prevention that can delay or prevent the complications in people with T1DM.

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