

ORIGINAL RESEARCH

The influence of an insulin pump experience on nursing students' understanding of the complexity of diabetes management and ways to help patients: A Qualitative Study

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Abstract

Background: Worldwide, 78,000 children develop type 1 diabetes annually with European cases increasing every year. In the United States, 215,000 children under 20 years of age have type 1 diabetes and over 6.5 million adults with either type 1 or type 2 diabetes need daily administration of insulin. Misunderstanding the complexity of diabetes management on the part of health care providers can affect their attitudes and negatively affect patient outcomes. The purpose of this descriptive qualitative study was to explore family nurse practitioner and undergraduate nursing students' perceptions of diabetes management while using an insulin pump in order to more effectively prepare them to understand the complexities of diabetes management faced by patients with diabetes and, therefore, provide better patient care.

Methods: Nurse practitioner and undergraduate students, who participated in a week long diabetes simulation experience, were asked to participate. Consents were obtained allowing analysis of journals detailing their experiences. The journals were analyzed for common themes according to qualitative methodology.

Results: Three themes emerged from the data: 1) handling self-management issues, 2) living with an insulin pump, and 3) gaining an appreciation for those who live with diabetes. Self-management subthemes included making dietary changes and monitoring blood glucose levels. Making dietary changes included carbohydrate counting, eating a balanced diet, and not snacking all day. Issues related to the monitoring of blood glucose levels included the pain of poking their fingers, difficulty getting enough blood, forgetting to check blood glucose, and not wanting to check blood glucose in front of people. Living with an insulin pump subthemes included learning where to wear the pump, having the pump get in the way, interfering with daily activities, including changing clothes or using the bathroom, interfering with intimacy, and having to change the needle site. Subthemes of gaining an appreciation for those who live with diabetes included having empathy for patients related to complying/not complying with treatment regimes, understanding the inconveniences of required lifestyle changes, and obtaining support from others having the same experience.

Conclusions: Diabetes requires many lifestyle changes. Study participants cited an increased understanding of the hassles and inconvenience of living with diabetes, particularly dietary changes, monitoring blood glucose, and living with an insulin pump. Undergraduate and graduate nursing students caring for patients with diabetes would benefit from a similar simulation experience in order to gain an understanding of the complexity of diabetes management and learn ways to help their patients. Nursing faculty should consider implementing a similar simulation experience in their curriculum.

Key words

Diabetes management, Insulin pumps, Nursing education

1 Introduction

Diabetes (type 1 and type 2) is a worldwide health concern affecting 366 million people in 2011 with 78,000 children developing type 1 diabetes annually^[1]. Statistics of European cases of type 1 diabetes (T1DM) show an overall increase of 3.9% per year, prompting the prediction of a 100% increase in the number of cases between 2005 and 2020, with the greatest increase among children between 0 and 4 years of age^[2,3]. North America has demonstrated an annual increase of 5.3% affecting 215,000 young people in the United States under 20 years of age who must receive insulin every day^[4,5]. Exogenous insulin administration compensates for the body's lack of insulin and when administered properly, reduces the risk of hyperglycemia and associated complications. However, exogenous insulin administration must be monitored carefully to maintain blood glucose levels within safe levels in order to prevent hyperglycemia or hypoglycemia. Further, the treatment demands of T1DM require significant lifestyle changes including not only insulin administration but also blood glucose and dietary monitoring^[6]. Adherence to these lifestyle changes creates challenges for patients, families, and health care practitioners^[7-10].

Understanding the challenges patients with diabetes experience is essential for nurse practitioners and registered nurses who will assist them in managing their disease. Simulation experiences are an effective way for health care practitioners and students to learn firsthand about various conditions and their challenges. For example, in a rehabilitation rotation, medical students were randomly assigned a disability such as paralysis, blindness, or deafness, and asked to perform activities designed to demonstrate practical issues faced by patients with these disabilities^[11]. The students gained new insight into what it was like to have the disability, improving rapport and communication with patients. Other health care professions have also used simulation experiences to learn about patient and caregiver experiences with a particular disease or condition. For example, pediatric residents participated in a role-play activity in which, as a low-income single parent raising two children with chronic conditions, they were required to contact community agencies to obtain needed resources for their children^[12]. In addition, third year medical students experienced geriatric conditions such as cataracts, presbycusis, decreased manual dexterity and sensation, and mobility impairments^[13], and via headphones, baccalaureate nursing students experienced auditory hallucinations that patients with psychiatric disorders have while attempting to complete specific tasks^[14,15]. Finally, pharmacy students participated in a "living with diabetes for a week" experience in which they counted carbohydrates and injected insulin^[16,17].

However, none of these simulation experiences used insulin pumps. Use of insulin pumps by individuals with T1DM has increased dramatically over the past decade and contributed to improved glycemic control^[18]. With the increased use of insulin pumps among patients with T1DM, it is important for nurses and nurse practitioners to understand the experiences of patients using insulin pumps. Therefore, the purpose of this descriptive qualitative study was to explore family nurse practitioner and undergraduate nursing students' perceptions of diabetes management while using an insulin pump in order to more effectively prepare nursing students to understand the complexities of diabetes management faced by patients with diabetes and, therefore, provide better patient care.

2 Methods

2.1 Design

A descriptive qualitative design was used to gain in-depth information related to students' experiences of using an insulin pump and carrying out diabetes self-management activities.

2.2 Participants

Twenty-one students, 2 male and 19 female, enrolled in a Family Nurse Practitioner (FNP) graduate program (n=16) or a baccalaureate nursing program (n=5) participated. All graduate students enrolled in a course on chronic conditions participated in the experiences as part of their coursework, and five baccalaureate nursing students serving as research assistants in another research project requested the opportunity to participate in the insulin pump experience. Student ages ranged from 21 to 59 years with a mean of 29.3 years (SD = 11.64). For the FNP students, experience as an RN ranged from 0 to 32 years with a mean of 6.15 years (SD = 6.8). Graduate students had worked as RNs in a variety of medical surgical areas, as well as in the emergency department, labor and delivery, pediatrics, critical care, and as a care manager. The baccalaureate students had completed a basic medical surgical nursing class and were halfway through their program. None of the students was diagnosed with T1DM.

Students were neither required to participate in the study nor penalized for non-participation, and were given the option to participate in the activity by just wearing the insulin pump but not inserting the cannula. However, all students inserted the cannula. There were minimal risks for participation other than time and discomfort due to blood glucose monitoring or insulin pump cannula insertion.

2.3 Setting

Participants were all full-time students in a western state and participated in the insulin pump experience while maintaining their normal activities and routines.

2.4 Procedures

The 7-day insulin pump experience is a standard part of a second-year graduate family nurse practitioner (FNP) course in the diagnosis and management of chronic conditions. As a part of the assignment, students were required to keep a daily journal on using the pump. After study approval by the University Institutional Review Board (IRB) students signed an informed consent granting permission to use their daily journals. This study was considered to have minimal risk to the students participating.

In preparation for the insulin pump experience, participants attended a class on carbohydrate counting, the importance of eating a balanced diet, and the mechanics of insulin pump management. During this class, students were instructed by a certified diabetes educator on how to estimate carbohydrate intake, test blood glucose, and program the insulin pump to deliver a bolus of insulin. Participants also received handouts, were directed to internet sites that could be accessed for more information, and instructed on filling the pump, inserting the cannula, attaching the tubing, and changing the insertion site after 3 ½ days. For this experience, normal saline was used. The diabetes educator assisted participants insert the cannula and program the pump and provided contact information in the event students had questions during their experience. Each student was provided with a glucometer, monitor strips, insulin pump, normal saline, and replacement cannula and tubing. After demonstrating they were able to insert the cannula and manage the insulin pump, students were instructed to carry out diabetes management activities during the next seven days including: 1) check and record blood glucose levels prior to eating, 2) estimate number of carbohydrates consumed, 3) bolus appropriate "insulin", 4) wear the insulin pump day and night, 5) incorporate diabetes management activities into normal activities, and 6) keep a daily journal. Students were instructed that the daily journal should record blood glucose levels prior to eating, challenges, unexpected experiences, and the ways they thought the experience would affect their future practice.

2.5 Data analysis

Participant journals were analyzed line by line for codes which revealed major and minor themes following Denzin and Lincoln's guidelines^[19]. As major themes emerged, they were identified and coded by the first author and verified by other members of the research team. Themes and subthemes were discussed until consensus was reached. Repetition of themes was noted both within and across all student journals^[20]. Exemplars were then chosen to illustrate the themes and subthemes.

Trustworthiness of the data was established by having another investigator read the journals to confirm initial findings. Peer debriefings were also used to evaluate the trustworthiness of the data by exposing the investigator's thinking to the research team^[19].

3 Results

Three themes emerged from the data: (a) handling self-management issues, (b) living with an insulin pump, and (c) gaining an appreciation for those who live with diabetes. Although the undergraduate students were younger than the graduate students and had no RN experience, no differences were found between journal entries of the undergraduate and graduate students.

3.1 Self-management issues

Self-management subthemes included challenges making dietary changes and monitoring blood glucose levels. The dietary challenges included counting carbohydrates, eating a balanced diet, and not snacking all day. Issues related to monitoring of blood glucose levels included the pain of poking their fingers, difficulty getting enough blood, forgetting to check blood glucose, and not wanting to check blood glucose in front of people.

Dietary changes proved to be more difficult for participants than they had expected. For example, a 57-year-old with 11 years of experience as an RN experience stated, "I was not as compliant as I thought I would be." A 21-year-old baccalaureate student who had learned about carbohydrate counting in class wrote about her difficulties in identifying how many carbs were in her food:

Counting carbs is so much more annoying than I thought it would be! Although the class was helpful, it did not tell me how many carbs were in my sandwich from Subway or my soup from Zuppas. It was more confusing and difficult than I thought it would be.

A 26-year-old RN with three years of experience explained how she handled not knowing her carbohydrate intake: "Then I went to a crock-pot party with all sorts of good food that I had no idea how many carbs it had. So I played a large guessing game as to how much I was eating."

Eating a balanced diet was also a challenge. A 40-year-old RN with 14 years of experience reported, "With my work schedule it is hard to plan ahead for meals. I ended up skipping one meal today rather than eating fast food. I got a banana at the gas station." A 29-year-old with four years of experience as an RN wrote, "I thought I ate worse this week. My food was less varied, and I ate more processed food because it was easier—the package has the carb counts." The difficulty of planning a balanced diet in addition to counting carbohydrates was described by a 30-year-old with five years of experience as an RN: "Counting carbs isn't too bad but then figuring in fiber and fat gets confusing. I didn't really grasp that concept."

Finally, most participants were challenged by their snacking habits. The following comments were typical, and they underscore the difficulty of making the lifestyle changes necessary for good diabetes management: "I never realized how much I snack through the day," "I am a snacker by nature and found it very challenging to have to think about everything

that went in my mouth,” “I unconsciously ate some grapes on the counter; no! I didn’t even realize I ate them!” and “Mindless munching. So easy not to keep track of each nibble. I ought to eat an actual meal.”

All participants either had had experience in monitoring patients’ blood glucose as RNs or had learned the process as student nurses. However, they were challenged when monitoring their own blood glucose. A 40-year-old participant with 14 years of experience as an RN, tried to use alternate sites to avoid the pain of poking her fingers. She wrote:

I am finding that only after approximately 24 hours of finger sticks I am already dreading each experience. I have attempted several times to obtain blood from my forearm, but after repeated attempts am unable to get enough blood to sample and end up poking a finger anyway. The fingers certainly hurt more, but I can’t seem to get enough blood from other sites.

Developing a routine for checking blood glucose was another challenge. For example, a 29-year-old participant with four years of experience as an RN explained, “I still can’t seem to remember to check my blood sugar and program my breakfast carbs into the pump. My mornings are so rushed that I can’t remember to add in this new step to my morning routine.”

Finally, checking blood glucose in front of others was intimidating for many participants. A 21-year-old baccalaureate student said, “I actually felt somewhat embarrassed and so I went to the bathroom and didn’t tell anyone that I was checking my blood sugar.” Checking blood glucose in restrooms was typical of most participants.

3.2 Living with the insulin pump

Participants were challenged by the insulin pump itself. However, only one participant mentioned a challenge with programming the pump. Major challenges were the pump itself: attaching the pump to clothing, having the pump interfere with daily activities and intimacy, and needing to change the cannula site. These challenges prompted some participants to remove the pump early, before the end of the 7 days. A 29-year-old RN with four years of experience wrote, “My big issue—THE PUMP! What do I do with it???? It’s very annoying.” A 40-year-old RN with 14 years of experience described these challenges with the pump:

I don’t mind the pump, other than I’m not sure how to handle it when changing clothes and I almost pulled it out when using the bathroom. I ended up just letting my pump dangle when I changed my clothes, hoping that the adhesive held and I didn’t have to replace it. I also hate sleeping with it. I am a restless sleeper and woke up several times with the pump beneath me.

Although neither male participant mentioned clothing difficulties, almost all female participants mentioned challenges, especially when wearing dresses, skirts, or pajamas, since waistbands were not available or strong enough to hold the pump.

Intimacy was also a challenge. A married 21-year-old baccalaureate student explained, “One thing that never dawned on me was the challenges I might face with intimacy. My husband actually was a little nervous because he didn’t want to displace it or get injured by it!”

Reinserting the cannula after 3.5 days was painful for some participants and many discovered their cannula had been kinked. A 26-year-old RN with three years of experience wrote:

Today I had to change out my catheter site. Apparently I have abs of steel. Or no subcutaneous tissue. Or the catheter just has a problem. Because I took out the old catheter to discover it completely bent at a 90 degree angle. Was I even getting ‘insulin’ this entire time? The pump had never indicated to me that it was blocked or kinked, but I can’t imagine much liquid was able to squeeze through the kink. So in choosing a new site, I chose

what seemed to be the fattiest part of my abdomen. The insertion was still quite painful, and stung much of the rest of the day. I am starting to get more annoyed with it.

Participants who found kinked cannulas were also concerned that the insulin pump never registered a problem regarding insulin delivery.

3.3 Gaining an appreciation for those who live with diabetes

All participants wrote about their increased respect and appreciation for children and adults who live with diabetes every day, not just for one week. A 59-year-old RN with six years of experience wrote:

I have more empathy for patients with diabetes in several ways. One of the big ones is for the amount of time it takes to be compliant. Initially, it was no big deal to check my blood glucose. I had the curiosity factor going. But as the days went by, it got in the way of my daily activities and work. I found myself not checking it as often as I should have. I found myself not taking the time to read labels and figure out carbs. I would try and remember the carbs on another food item and 'guesstimate' what I had actually eaten. And at other times, I would cop out and think, 'well, I'm not really diabetic so I don't have to give myself a bolus.' I don't think it would be much of a stretch to have diabetes and do the same thing. And I KNOW what diabetes does. It's amazing just how much people can rationalize, and I can do it with the best of them.

This new perspective on the realities of living with diabetes full-time led many participants to reflect back on their interactions with patients with diabetes. For example, a 29-year-old RN with four years of experience gained an enhanced understanding of the difficulties of managing diabetes during an illness. She explained:

Typically when a diabetic comes in with DKA (diabetes ketoacidosis), it started with a simple illness. I would secretly roll my eyes and think "How could they not know that they still have to check their sugars and give themselves insulin even if they are sick and not eating?" Now I realize how easy it is to not care and not want to deal with diabetic management when you don't feel well.

Finally, participants found support from others with diabetes or fellow students engaged in the same experience. A 33-year-old with ~~ten~~ 10 years of experience as an RN wrote:

I felt as though I had lost freedom, and it was depressing and discouraging. I can't even imagine how I would feel if I knew I had to do this for the rest of my life. I wanted to call one of my classmates and talk because I knew they would understand. It helped me to realize how important support groups are for people with chronic disease.

A 40-year-old with 14 years of experience as an RN wrote that he would prepare his newly diagnosed patients better for living with diabetes. He would share his experience and acknowledge the challenges he faced. He also stated that because of his new level of empathy for patients with diabetes, he would listen to them, respect them, and work with them to improve their health outcomes.

4 Discussion

The study participants were enrolled in either undergraduate or graduate nursing courses. Most graduate students had significant experience as RNs, and all understood the physiology and self-management behaviors required of T1DM. Participants, therefore, may have had preconceived ideas of the challenges they would encounter during the week they wore an insulin pump, such as carbohydrate counting and blood glucose monitoring. Consequently, their daily journals may have focused more on aspects they did not anticipate to be challenging, such as dealing with the insulin pump. Indeed, health care practitioners who have not experienced living with T1DM may have knowledge about the pump but may be

unaware of the daily challenges patients encounter. By experiencing some of the daily challenges faced by those with T1DM, participants gained a greater empathy for their patients with diabetes. They anticipated their interactions with patients with diabetes would reflect this empathy.

People with T1DM are required to make challenging lifestyle changes, including dietary changes, insulin administration, and blood glucose monitoring ^[5, 7, 9]. These participants also identified major challenges such as dietary changes, living with an insulin pump, and monitoring blood glucose. The participants noted pain due to needles ^[21] and loss of spontaneity due to the need for meal planning, glucose monitoring, and insulin administration, which required every outing to include snacks and proper equipment ^[8]. Participants focused on the daily challenges of self-management; in contrast, the literature has identified stressors that are more long-term, such as relationship issues, independence, and feeling normal ^[22, 23]. The differences were probably due to the short-term nature of the insulin pump experience.

Dietary changes required of patients with T1DM include estimating carbohydrate intake and administering an appropriate dose of insulin. Participants found carbohydrate counting difficult, and several limited their food varieties or skipped meals in order to simplify their life. Neither option is healthy or appropriate ^[24]. Other studies have also reported dietary challenges for individuals with diabetes, including peer pressure, emotional distress, restaurants, social gatherings, time pressure, and planning ^[25, 26].

Self-management issues were challenging. They included eating habits since most ate all day and did not have distinct meals; therefore, participants were tempted to not check blood glucose or administer insulin every time they snacked. This is not an uncommon situation since children and adolescents with T1DM also eat at times other than mealtimes ^[27]. In addition, dietary adherence can be influenced by a child's developmental stage, social fear, and confidence in carbohydrate counting ^[28].

Even though the insulin pump was lauded by many participants for its ease of use in determining the appropriate insulin bolus, they were overwhelmed by the constant challenge of being attached to the pump. Unlike many children who keep their pump in a case attached to their waist or in a pocket, these participants found it difficult to know where to put the pump. Routine daily activities such as using the bathroom, changing clothes, and sleeping became daily stressors. In addition, living with the pump became a major annoyance and many participants counted the days until the pump was removed; a few even removed it early. However, for patients with T1DM, choices are limited to using an insulin pump or administering insulin by injection several times a day ^[29].

T1DM requires a number of lifestyle changes. Study participants already had both clinical and didactic knowledge about the disease, but they gained an increased understanding of the problems and inconvenience of living with diabetes, particularly changing diet, monitoring blood glucose, and living with an insulin pump. This experience was thus beneficial in helping participants improve their attitude toward patients struggling with the challenges of living with T1DM and understand the importance of a support system.

There are limitations to this study. Qualitative studies are not necessarily generalizable to other populations. Students included in the study were volunteers which may have affected their perceptions. Study results came from student self-reports and were part of a class assignment, which may have influenced reporting; however, students were instructed to omit their names and, again, participation was voluntary with no penalty for non-participation.

5 Conclusion

This study demonstrates benefits of an experiential activity requiring participants to wear an insulin pump for 7 days. All nurses caring for patients with T1DM would benefit from such an experience, and gain a better understanding of the complexity of diabetes management and learn ways to help patients. Consequently, nursing faculty should consider

implementing an insulin pump experience and related activities such as carbohydrate counting and self-care in their curriculum

6 Implications

Learning self-management skills requires gaining knowledge and practicing the skills. Attaining comfort and expertise takes time. Health care practitioners should help patients with T1DM eat a healthy balanced diet while learning to anticipate carbohydrate intake. Adjusting to regular meal-times and snacks is challenging. Exploring meal-time and snack options in relation to blood glucose monitoring may improve compliance with a diabetes management regimen. Because blood glucose monitoring is also challenging, addressing the importance of this with patients with T1DM is crucial. Health care practitioners should also understand that knowledge about the importance of glucose monitoring does not necessarily make the process easier. Patients should be asked about their challenges with blood glucose monitoring, and practitioners should explore strategies to minimize these challenges. Finally, health care practitioners must also understand that the pump itself can be a stressor and discuss this with patients.

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Conflict of interests

The authors declare that they have no competing interests or conflict of interests.

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