

The Nature and Meaning of Insulin Pump Use in Emerging Adults With Type 1 Diabetes

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■ ABSTRACT

Objective. The purpose of this study is to investigate the meaning of living with an insulin pump for the management of type 1 diabetes during the period of emerging adulthood. Through a phenomenological narrative, this study contributes to the reflective understanding of the everyday life experiences of this population.

Methods. A hermeneutic phenomenological design was used for this study of nine emerging adults (aged 19–24 years). Data were generated through face-to-face interviews and analyzed using the phenomenological approach of Max van Manen.

Results. Four themes represent the essence of the day-to-day experiences of these emerging adults: seeking control, becoming responsible, staying connected, and accepting me.

Conclusions. An in-depth understanding of the meaning of daily experiences with insulin pump technology has the potential to promote a developmentally appropriate approach to this age-group. The human understanding gained through this study is essential to the development of evidence-based practice guidelines and resources for this vulnerable population.

Emerging adulthood has been identified in industrialized countries as a distinct developmental period between adolescence and adulthood (1). This period is crucial for diabetes control (2) and is significant for both emerging adults and their health care providers (HCPs), as they make the transition from their family home and their pediatric diabetes care team (3–5). For emerging adults with type 1 diabetes, this period has been identified as a time when glycemic control is at its worst (6–8). During these years, independent routines of self-care are established (9), and individuals typically face changes in living arrangements, HCPs, relationships, education, and employment.

Continuous subcutaneous insulin infusion, or insulin pump therapy, is used by ~ 25–41% of individuals with type 1 diabetes (7–10). A meta-analysis of insulin pump studies found improvements in glycemic control and reductions in severe hypoglycemia with insulin pump therapy (11). However, few studies have assessed psychosocial functioning in pump users, especially in the emerging adult population. Glycemic control continues to be an issue for this age-group (7,12,13).

The purpose of this study was to investigate the multidimensional meaning of living with an insulin pump while facing the challenges of life as an emerging adult. The human understanding gained through this study is essential to the develop-

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ment of evidence-based practice guidelines and resources for this vulnerable population.

This study used the hermeneutic phenomenological method described by van Manen (14). Arnett's developmental theory of emerging adulthood (1) and van Manen's life-world existential experiences were used to provide the contextual richness and depth of interpretation that produced an expanded understanding of what it is like to live with an insulin pump as an emerging adult. The research question was: What is the meaning and significance of insulin pump use for emerging adults with type 1 diabetes?

Study Methods

Study Sample

Participants were solicited in two southern states by the lead researcher (DGH) and through letters from the researcher distributed by area diabetes educators. A purposive sample of nine emerging adults (between the ages of 18 and 25 years) who reported having a diagnosis of type 1 diabetes for a minimum of 1 year and who had been using an insulin pump for diabetes self-management for at least 6 months was adequate to reach information redundancy.

The average age of participants was 20.9 years (range 19–24 years). They had lived with type 1 diabetes for an average of 12.5 years (range 4.5–21 years) and used insulin pumps at an average of 7 years (range 2.5–11 years). Six participants were female, three were male, and all were Caucasian. Six participants were college students at the time of data collection. Their last self-reported A1C ranged from 6.1 to 12%. This study was approved by the academic institutional review boards; all participants signed written informed consent, and caution was taken to minimize any risks of distress while participants were being interviewed.

Data Collection

An ongoing reflective journal was begun before initiating interviews

to facilitate recognition of personal presuppositions and biases that existed as a result of the lead researcher's roles as a pediatric nurse, a university faculty member, and a mother of an adolescent who uses an insulin pump. Audio-recorded interviews using participant-chosen pseudonyms were conducted in a location of the participants' choice. A semi-structured interview guide with probes was used to gain a deeper understanding about participants' experiences as insulin pump users in their university or work environments. Field notes were maintained to reflect nonverbal communication and contextual information.

Data Management and Analysis

Using van Manen (14) as a guide, individual transcripts and field notes were initially read to gain a sense of general holistic meaning from the interview. The transcripts were then analyzed line by line with key words and phrases highlighted and interpretive notes recorded on the transcripts. These meaning units were grouped until essential themes that reflected the meaning of insulin pump use for these participants were identified. Through an iterative process of writing and re-writing, four final themes were identified that expressed the meaning of insulin pump use to these emerging adults.

Trustworthiness was achieved through participant verification of transcripts and themes. An audit trail was conducted with verification of themes by an independent qualitative researcher. Reflexivity through the researcher's written reflections in a research journal provided a way to identify personal perspectives and compare them to the iterative process of interpretation of meaning.

Key Findings

The journey through life with type 1 diabetes is much like the process of learning the art of tightrope walking. Like learning to live with diabetes, learning to walk on a tightrope unfolds over time and requires the

walker to return to the wire after inevitable falls. Participants' experiences of trying to maintain balance in life during the years spanning adolescence through young adulthood fell into four broad themes: seeking control, becoming responsible, staying connected, and accepting me.

Seeking Control

Initial transitioning to an insulin pump meant hope for control as the emerging adults began using this tool to gain control of their blood glucose and to regain control of their life. Participants found themselves battling new variables in the university environment. They encountered vulnerability when they lost control of their blood glucose and recognized that multiple factors must be considered to regain control.

Some participants who initially resisted the pump found that, in gaining control of their blood glucose, they also gained more control of their life overall. One reported, "I did not want a pump. I hated the sound of a pump . . . to have anything attached to me 24/7 scared me to death."

However, using a pump enabled them to regain control of their lives and to have the freedom to eat when their friends were eating and to enjoy the spontaneous lifestyle of typical university students.

Transitioning to the university environment with type 1 diabetes required a daily balancing act of dealing with changing schedules, stressful exams, frustrating roommates, late-night studying, and evolving new relationships, all of which continually challenged their efforts to maintain glycemic control. As one participant noted, "If I'm stressed out, it'll skyrocket . . . my menstrual cycle, it'll jump." Participants repeatedly described their experience as one in which "every day is different." Despite the lack of stability, using a pump brought a sense of hope in battling the variables of daily life.

Scary episodes of severe low and high blood glucose brought the emerging adults face to face with their vulnerability. “Hannah” described through her tears a severely low blood glucose episode that occurred during her first year in college:

“I kept getting lower and lower, and my pod [pump] just automatically gives me [basal insulin]. My boyfriend called me, and I don’t even remember talking to him. I didn’t know where I was or what time of day it was . . . My roommate . . . asked me if I was drunk. I was like, ‘No, . . . I was so scared when I actually came to . . . the chair in my room was knocked over, and a picture frame was broken . . . a bowl was completely shattered . . . It was real scary.”

Although Hannah notified her physician so changes could be made to her pump settings, her fear instigated a new routine for her. “[I would] usually go to bed with my blood sugar like almost to the 200s just because I was scared that it’d get so low,” she said. The challenge of maintaining tight blood glucose control was, at times, at odds with the need to be in control.

The fear participants experienced with extremely high blood glucose values that were not responsive to insulin boluses and infusion set changes brought heightened concern for “What next?” High blood glucose could occur rapidly with insulin pump troubles and could also result in participants’ blood glucose then plummeting to dangerously low levels as they faced vulnerability from both extremes. “Burt” reflected this concern when describing being hospitalized for diabetic ketoacidosis (DKA) and feeling his blood glucose dropping to a scary level:

“I had to get my dad to go get me something to eat. They [nurses] wouldn’t listen to me . . . It’s dangerous, you know?”

You can die from this. They [nurses] didn’t know about it as much as I did.”

Controlling pump placement and the frequency of infusion set changes was also an issue. Physical restrictions, such as having limited subcutaneous tissue or scar tissue that can result from years of pump use with limited site rotation, were frustrating. Practical restrictions, such as difficulty reaching potential sites or discomfort from constant bumps of the infusion set from backpacks, were challenges, as were social concerns, such as visible bulges or exposed tubing from the pump. Time constraints, economic concerns, comfort issues, and a general sense of dread came into play as primary motivators for delaying site changes until the insulin reservoir was empty or blood glucose readings were high.

Becoming Responsible

Just as tightrope walkers learn their art through a series of progressive steps, accepting responsibility for diabetes self-care began for these participants as a gradual shift, with major markers occurring during the high school years, such as getting a driver’s license and gaining increased independence. With some, the epiphany of “being on my own” came when they faced the reality of complications and the realization that “it was all me now.”

Enjoying the freedom that is possible with insulin pump technology required accepting responsibility for planning ahead to be sure there was enough insulin in the reservoir, enough battery power life in the pump, a cool place to store insulin in the heat of the summer, and enough back-up supplies in case they were needed. “Anne” described how she learned the hard way when she transitioned from college classes to work and realized she could not “just go home” for batteries, insulin, or a new infusion set. Stuck at work and unable to contact anyone for help, she described how her blood glucose

steadily increased until she got “sick as a dog.”

She and the other emerging adults recognized that, in not accepting this responsibility, they would put themselves at risk. Forgetting such pump management essentials as counting carbohydrates, entering the data, and giving insulin boluses with food was a common and irritating occurrence. As “Lily” said, “How do you forget to bolus? It’s right there on your hip!” The reality is that life gets busy, and distractions mount. However, the forgetting is interrupted by the body’s alarm system as a response to hyperglycemia or “feeling horrible.”

Self-monitoring of blood glucose (SMBG) before meals was also forgotten or just skipped (as one participant said, “It gets so old”), and it was not uncommon for the emerging adults to say they relied on “feeling” rather than on SMBG results, especially when they were around other people. As one said, “I can usually tell what range my blood sugar is in.” Forgetting to perform SMBG was a struggle for those transitioning away from home without, as one put it, “constantly having Dad breathing down my neck and making you.” Accepting sole responsibility for the ongoing daily tasks necessary for intensive self-management was challenging.

The reality of the risks associated with diabetes had an influence on participants’ acceptance of responsibility for their self-care. “Michelle” felt aggravated by her parents telling her about complications they see in people with diabetes. “I don’t want to hear about how I could lose my foot,” she said. “But sometimes it’s . . . part of life . . . makes you think . . . wouldn’t want that to happen to me.” Burt reflected on his history of not accepting responsibility, which resulted in numerous hospitalizations for DKA. “It feels like you’re dying, literally,” he said. “I tried to stand up, and I couldn’t even move.” Being told that he would be blind in 10 years “. . . kind of woke me up,” he said.

Lily shared her reality check, which occurred during her first solo visit to her adult HCP. “It’s starting to hit me now . . . I don’t realize that the diabetes is damaging [my body] . . . It was just kind of a wake-up call . . . is my responsibility . . . not my mom’s.”

Participants typically used the basic pump features they had learned with their initial pump training. Fine-tuning insulin delivery through the use of square-wave and dual-wave boluses and temporary basal rates was uncommon. “Greg” did not make changes independently unless “it’s high just continually,” he said. “I’ll lower the basal a little bit because they told me to, but mostly I leave it up to the doctor.” The paradox was that this was a frequent source of tension with participants who felt that their HCPs made pump changes without taking into consideration other variables in their busy, nonroutine lives. “I don’t want my blood sugars to be high all the time or low all the time,” one said. “But when [the HCP] adjusts stuff without looking at what’s actually going on or listening, it’s just kind of pointless.”

Staying Connected

These emerging adults reported often feeling that they were walking the tightrope alone and without the safety net of family, friends, and the pediatric endocrinology team. The daily sense of aloneness while living with an insulin pump was common and was compounded as participants, in their quest to be “normal,” tried to hide their insulin pump from the view of others. Since starting college, Hannah was pleased to meet two other students with insulin pumps through her church. “We’re like, ‘How’s your blood sugar?’” she said. “We’ll joke about it. It’s . . . reassuring, that other people are going through it too, you know. So you don’t feel as weird . . . You feel kind of normal.”

One young woman who was feeling the stress of being on her own in college without knowing anyone

else with a pump was recently able to connect to other pump users through blogs. She still longed for face-to-face support from others her age with pumps. In contrast, Greg stated that he did not really need the support because, “I got it under control. I can do it myself.”

Transitioning from home to college typically occurred at roughly the same time these emerging adults were making the shift from their pediatric endocrinology team with whom they had close bonds to an adult HCP. This shift often resulted in frustration because they were accustomed to someone making them feel “upbeat,” accepted, and cared about. Some participants expressed feelings of disconnectedness with the other patients in the waiting areas, who were typically older patients with type 2 diabetes and more debilitated. “Fran” offered insight into this type of situation that reflected wisdom in her young age, saying, “Even adult people need that encouragement and that uplift and stuff. It’s hard to come by, I think, in an adult clinic.”

In addition to the challenge of transitioning to adult HCPs, these emerging adults often faced their first clinic visit alone, without the benefit of a familiar person present on their behalf. Lily cried as she described that experience, explaining that, although the nurse practitioner was very friendly, she felt a sense of panic when told she was going to have an ultrasound of her thyroid. “She didn’t tell me why we were going to do one . . . I’m just laying there . . . thinking ‘Do I have cancer? Am I gonna die?’ . . . I didn’t know what was happening.”

Not all experiences were negative. The need to connect to an HCP was important, and that involved finding a good fit. Anne eagerly shared, “I love my doctor that I’m with now. . . . Her nurse gave me her e-mail and said, ‘If you ever need anything and you can’t reach me, . . . feel free to e-mail me for anything.’” Some participants found reassurance and comfort from connecting with an

HCP who displayed an understanding approach and caring availability.

Accepting Me

Becoming a well-balanced tightrope walker takes place over time and after much practice and determination. Likewise, the process of “becoming” within a context of social vulnerability was an issue for some, but not all participants. As “Amy” said:

“You think people can see right through you and tell that you have one (insulin pump) or tell that you have diabetes . . . You expect everybody to see you as ‘not normal’ . . . For me, with my pump, I’ve learned to hide it very well, so nobody ever asks me anything.”

Amy shared the tension she felt about keeping her pump hidden because, although others might “think I am weird,” she also realized that it is “better that people knew.” While transitioning to college, Anne said she was “always terrified” that her pump would alarm, vibrate, and light up during class or when she was talking with someone who was unaware of her pump. However, she acknowledged that having the pump actually made it much easier to “pull out my machine and check real quick instead of making a big scene.”

The quest for normalcy was evident in the lives of these emerging adults, although some expressed that they have achieved a sense of comfort. An insulin pump provided the ability to have a flexible lifestyle like others their age. “[Having the pump] made me feel normal again. I’m like everybody else,” said “Jim.” Having the pump visible to others was difficult for some participants but was not an issue for others. As Burt shared:

“I was self-conscious about [the pump] at first . . . I was like, ‘Ugh, people will see it’ . . . But [going to diabetes camp] really got me out of my shell . . . It’s like telling someone I got

a new tattoo It's just a part of me."

This personal transition from feeling the need to keep the insulin pump and diabetes hidden to accepting both as a part of who they are was a process that most participants experienced during their emerging adult years.

Several participants had progressed from being unable to talk to people about diabetes and their pump to being eager to share, teach, and encourage others. "I can use it [pump experience] to help other people rather than being bitter about it," one said. "It's part of my life." As some participants nearing graduation looked back over their experiences with diabetes, they were able to see how their openness about the pump and diabetes may be helpful to others they may encounter in the future. One young student teacher incorporated teaching plans that dealt with potential health emergencies in the classroom. Looking for purpose was a way of validating meaning.

Discussion

The four themes identified in this study illustrate the learning-while-living process that is experienced during the often unsteady tightrope walk between adolescence and adulthood for people who use an insulin pump. Seeking control, becoming responsible, staying connected, and accepting who they are reflected the essence of living with an insulin pump and type 1 diabetes as an emerging adult. For participants, this developmental period also included the normal challenges of this time in life. These emerging adults often begin to live away from their family for the first time, had multiple changes in living arrangements, and switched from their familiar pediatric health care teams to a new adult care service. This study found insulin pump technology to be particularly suited for the lifestyle and competing demands of emerging adults as they

faced what are typically the years of poorest glycemic control (6,7).

The first theme, seeking control, points to the challenge, as well as the possibilities. Living with an insulin pump as an emerging adult brought the possibility of improved blood glucose control, as well as the freedom and flexibility that allowed these participants to regain some control of their everyday lives. Encouraging emerging adults to embrace a sense of control over their diabetes has the potential to positively affect their metabolic control. Aberle et al. (15) found high internal locus of control to be associated with better glycemic control in adults with type 1 diabetes who use insulin pump technology.

The frustration these participants experienced when dealing with the negative impact of physical and psychosocial demands on glucose control mirrored similar findings regarding diabetes self-management in university students in the northeast United States and the United Kingdom (16,17). Having blood glucose out of control brought concern and even fear. Although Peters and Laffel (4) reported feelings of invulnerability in the early years of emerging adulthood, these participants came face to face with physical, social, and emotional vulnerability, especially in times of drastically abnormal blood glucose levels. This is a more vulnerable group because it has been shown that people between the ages of 20 and 29 years living with type 1 diabetes are four times more likely to die than their peers without diabetes (18). The vulnerable state of life without glucose control placed them on shaky ground and left them feeling the need to regain a sense of balance.

Controlling who knew about their diabetes was a choice of these emerging adults. Deciding where to place their insulin infusion set was another area of control they could claim. It was their decision whether to expose or hide their insulin pump. Although not specific to insulin pump users, an earlier study (19) also found it import-

ant for young people to have control over disclosure of their diabetes to others. Participants who attempted to keep the pump invisible to others and in a comfortable location reported struggling with the difficulty of "finding a good spot." Finding a pump site that balanced their need for comfort and their desire for concealment was often challenging.

The second theme, becoming responsible, resonates with the findings of Arnett (20), which indicate that accepting responsibility is a process that occurs over time for emerging adults. Despite sudden wake-up calls that they are now "on their own," emerging adults with an insulin pump must learn to plan ahead, have back-up supplies available, remember to check their blood glucose, count carbohydrates, and administer bolus insulin doses as they learn to adjust to the irregular routines of college or work life (17). This shift in responsibility for self-management is also a struggle for many parents who must learn to step back from their own routines (2).

The third theme, staying connected, points to the importance of having a support network in the face of the continuous demands of diabetes self-management (21). The role of peer support has been found to increase during the adolescent years (2,22). However, several participants faced the loss of the important support network of family. Although parents were often considered to be nagging during these years, participants reported having times when they relied on the "safe base" of the family.

Markowitz and Laffel (23) identified the need for emerging adults to discuss issues of daily living with others who are facing similar demands. Such support group connections have a positive impact on self-management and metabolic control. Only one participant in this study had regular, face-to-face encounters with other pump users. Not knowing others their age with type 1 diabetes and insulin

pumps and thus having a perceived lack of social support networks has been a finding in other studies (24,25).

As these emerging adults lost immediate family support with a move from home, they typically also faced an abrupt switch from their familiar pediatric endocrinology team to a new adult HCP. Garvey et al. (26), in the first study of the transition care experience for emerging adults with type 1 diabetes in the United States, found the mean age of transition to adult care was 19.5 years, and fewer than half of those were given contact information for an adult HCP before their transition. Gaps in care of >6 months after leaving a pediatric care team have been identified in up to 40% of emerging adults (3,27,28). Several participants in this study felt frustrated by the change to an adult HCP practice after losing their connection to a holistic pediatric care team. Attention to the need for connection is an important aspect of care.

The final theme, accepting me, is also consistent with the developmental challenges of emerging adulthood. The emerging adult years are a time for identification of who one is as an individual, as well as who one is as part of a community (23,29,30). The experiences of emerging adults with type 1 diabetes and insulin pumps in this study suggest the quest for a sense of normalcy. Consistent with findings of Kay et al. (24), most participants expressed concerns about being viewed as different or “weird” and often tried to keep their insulin pump hidden from the view of others. Although Dovey-Pearce et al. (19) reported a shift in personal identity that seemed to take place before those newly diagnosed with diabetes left the hospital, participants experienced a self-acceptance of life with type 1 diabetes and a pump that takes place over time. Most participants gained a sense of acceptance as the pump eventually became a part of who they are, just like, as one young man described, “a new tattoo.”

Study Limitations

Several limitations to the study must be acknowledged. First, all participants were non-Hispanic white. Although type 1 diabetes disproportionately affects non-Hispanic white youths, this study included no participants from other races or ethnicities. Participants’ most recent A1C values were self-reported. Third, although this study has implications for emerging adults with type 1 diabetes who have an insulin pump, the sample was derived from the southern region of the United States; it is not known whether this population has different experiences from those who live in other parts of the United States or elsewhere in the world.

Implications for Practice

The everyday experience of living with type 1 diabetes and an insulin pump was described in terms of four themes reflecting emerging adults’ challenging tightrope walk bridging adolescence and adulthood. The goal of HCPs to support a “seamless, comprehensive, and developmentally appropriate” period of transition to adult care (3) requires that they have an understanding of what is developmentally appropriate for their patients. The findings of this study support Arnett’s model of emerging adulthood (1) and provide empirical support for the design and implementation of transition services for emerging adults with type 1 diabetes. Understanding the challenges and frustrations of desiring control over both their life and their blood glucose amid multiple competing demands is essential and comes through attentive listening to these patients, who are much more than the blood glucose numbers on their pump. Encouraging emerging adults to embrace a sense of control over their diabetes has the potential to affect their metabolic control.

It is important for HCPs to recognize that accepting responsibility for the endless demands of diabetes self-management is a process

that occurs over time and involves ongoing negotiations and open communication among emerging adults, their parents and/or significant others, and their adult health care team as the bulk of responsibility shifts to the emerging adults. Recognizing this shift is important for the entire health care team. It is also vital to understand emerging adults’ need to connect with others during this period when there is often a sense of going through the diabetes journey alone. Attention to the availability of support networks is an important aspect of care.

Understanding the everyday experience of those using insulin pumps opens the possibility of developing assessment tools and resources with the input of emerging adults. Patient-centered resources should address specific needs such as glycemic control issues encountered with routine changes at the start of a new college semester or during final exams, relationship changes, or a change in residence. Attention to the life concerns of this developmental period, such as career preparation and intimacy issues, is also important. Likewise, asking emerging adults about their support networks can help HCPs identify ways to connect them with others through university groups such as Students with Diabetes or College Diabetes Network, blogs, or groups within the community or their own practice.

Services with such social components can encourage increased responsibility, provide support, and promote acceptance. The Maestro Project (28) is an intervention built on this need for connection with peers and with HCPs and has been used in Canada to decrease the number of emerging adults lost to follow-up care. This model is designed to facilitate relationships at a time when they are crucially needed by a vulnerable population.

Collaborative goal-setting with their HCP is a way to provide emerging adults with a sense of control

and to promote their growing sense of responsibility for diabetes self-management (21,31). If emerging adults perceive that their adult HCPs lack understanding of what is going on in their lives and make arbitrary changes that often involve only increasing their insulin dosage, this sense of disconnect may have a negative impact on their clinic visits at a time when they are most vulnerable.

Conclusions

The convergence of meaning from the participants in this study provides a greater understanding for diabetes health care teams. Understanding the unique challenges and strategies of emerging adults will assist HCPs as they design and implement evidence-based, patient-centered care practices. Although this age-group may seek control, accepting responsibility when abruptly facing the realization that “I am on my own” is a process that takes time. The emerging adult years can be considered a period of gradual acceptance of the ongoing responsibilities and consequences associated with the everyday demands of diabetes management with an insulin pump. Recognizing the need for members of this age-group to connect with others at similar points in the diabetes journey, HCPs should consider strategies that link younger adult patients through creative scheduling, as well as communication strategies that consider the needs and preferences of this age-group. Through a plan of care designed for these patients who are no longer adolescents but not yet adults, HCPs can assist emerging adults in mastering the tools and gaining the confidence necessary to successfully continue their journey.

Duality of Interest

No potential conflicts of interest relevant to this article were reported.

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