


The Lived Experience of Continuous Subcutaneous Insulin Infusion in Adults With Type I Diabetes Mellitus: A Phenomenological Inquiry

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Abstract

Continuous subcutaneous insulin infusion (CSII) is a complex, medical device for the management of Type I Diabetes Mellitus (T1DM). There is limited research exploring the everyday experiences living with this device. The purpose of this study was to understand the lived experience of adults using CSII therapy to manage T1DM. Lived experiences from eight individuals were collected through semi-structured interviews and then analyzed using a hermeneutic approach to phenomenology. Four substantive themes with supporting subthemes were identified and represent the essence of participant experiences; that is, living with CSII eventually took ascendancy over managing T1DM. CSII therapy has gained popularity due to reported improvements in metabolic control and flexibility. However, the burden of the responsibility and psychological implications of CSII took ascendancy over T1DM. Living with CSII impacts the psychological well-being of individuals so psychological complications are as important to assess by healthcare professionals as physical and metabolic complications.

Keywords

Type I Diabetes Mellitus, continuous subcutaneous insulin infusion, diabetes mellitus, quality of life, phenomenology, qualitative research, Canada

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Introduction

Continuous subcutaneous insulin infusion (CSII) is an external, complex medical device for the management of Type I Diabetes Mellitus (T1DM). Although less commonly understood and more recent than multiple daily injections (MDI), CSII is not a new phenomenon. In the last decade CSII has been part of a technological explosion in T1DM management with the goal of improving quality of life (QOL) (Lee et al., 2004). In 2016, more than 350,000 individuals in the United States were using CSII (McAdams & Rizvi, 2016). It is estimated that in the next decade, 40% of individuals with T1DM will be using CSII worldwide (Lee et al., 2004).

CSII devices are insulin pumps in the form of small, computerized devices that deliver insulin. Doses of insulin are delivered through a catheter that is inserted underneath the skin into the fatty tissue with the aid of a small needle. It is secured in place with tape and then changed at minimum every 3 days by the user. This catheter is known as the infusion set (Heinemann et al., 2018). There are two types of

CSII delivery systems that are available known as conventional pump therapy and patch pumps. Conventional pumps have the CSII device connected to the infusion set by a plastic tubing and the CSII device is worn on the body. Patch pumps are insulin delivery systems that are small, lightweight, and free of tubing. The infusion set, or patch, is worn on the body to deliver insulin. However, the CSII device communicates wirelessly to the infusion set and does not have to be worn on the body (Heinemann et al., 2018; Thompson & Cook, 2019).

Current research on CSII therapy for adults with T1DM is limited mainly to studies that focus on clinical data and metabolic outcomes such as blood glucose variability. Beginning

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with the Diabetes Control and Complications Trial Research Group (DCCT) and later followed by the Epidemiology of Diabetes Interventions and Complications study (Nathan, 2014; The DCCT Research Group, 1993), researchers revealed greater glycemic control with CSII as compared to MDI. Other findings included a significant reduction in any type of cardiovascular disease event and non-fatal heart attack, stroke, or death from cardiovascular causes. Since the publication of the DCCT, numerous studies have been conducted to determine which method of intensive insulin therapy (CSII or MDI) is preferred. Studies have focused on hypoglycemia (Bode et al., 2002; Giménez et al., 2007; Pickup & Keen, 2002; Pickup & Sutton, 2008; Pozzilli et al., 2016; Ritholz et al., 2007; Scheidegger et al., 2007), HbA1c levels (Clements et al., 2015; Franklin, 2016; Hammond et al., 2006; Misso et al., 2010; Pickup & Hammond, 2009; Pickup & Sutton, 2008; Pozzilli et al., 2016; Shalitin et al., 2010), and hyperglycemia and ketoacidosis (Bode et al., 2002; Bruttomesso et al., 2009; Joshi & Choudhary, 2015; Rodrigues et al., 2005; Saboo & Talaviya, 2012; Thabit & Hovorka, 2016). A few studies have looked at QOL (Barnard and Skinner, 2007, 2008; Nicolucci et al., 2008; Thabit & Hovorka, 2016; Todres, Keen, & Kerr, 2010; Trief et al., 2013), and the psychosocial impact of CSII versus MDI (Aberle et al., 2009; Balfe et al., 2013; Dahan & McAfee, 2009). Despite some conflicting results, overall, these studies show that CSII offers more glycemic control, a decreased risk of ketoacidosis, and reports of greater QOL than MDI. As well, benefits of CSII over MDI also include increased flexibility, convenience, and independence (Thabit & Hovorka, 2016). Individuals on CSII report worrying less about hypoglycemia, increased satisfaction for both themselves and their family members, and claim that it interferes less with their lives than MDI (Barnard & Skinner, 2008; McAdams & Rizvi, 2016; Reidy et al., 2018). The primary advantage of CSII over MDI is that insulin adjustments can be made immediately based on blood glucose levels (Thabit & Hovorka, 2016).

Despite what is known about CSII for T1DM, research is scarce on how CSII affects day-to-day living for those using the device (Garmo et al., 2013; Hanaire, 2011). The few studies that have been done have been criticized for using measuring tools that lack the sensitivity to understand the lived experience (Barnard & Skinner, 2007; Hanaire, 2011). Several studies (Barnard et al., 2007; Barnard & Skinner, 2007, 2008; Garmo et al., 2013; Nicolucci et al., 2008; Trief et al., 2013) reported a lack of qualitative research on how CSII affects day-to-day life. Although CSII therapy has been found to contribute to increased treatment satisfaction, the burdensome demands of this device cannot be disregarded (Balfe et al., 2013; Barnard & Skinner, 2008; Lilly, 2004; Todres et al., 2010; Trief et al., 2013). The complexity of CSII demands physical and mental endurance to endure the intense education, continuous follow-up, careful glucose monitoring, carbohydrate counting, and engagement with a multidisciplinary

team. It is much more than simply wearing an external device. An individual must be motivated, assume the financial burden, be knowledgeable, and have the physical ability to operate the system such as hand dexterity and visual acuity (Bruttomesso et al., 2009). While preventing complications and achieving near normal glycemic control is often the goal of healthcare professionals, incorporating psychological support for those living with CSII is important. Understanding the challenges of living with CSII will allow healthcare professionals to recognize the unique needs and concerns of each individual and provide the necessary support.

A gap acknowledged in the literature is the lack of qualitative research on what it means to live with CSII. Given the increasing prevalence of CSII, it is paramount that there is an understanding of the impact of CSII on the lives of individuals with T1DM (Barnard & Skinner, 2008; Bruttomesso et al., 2009; Kerr et al., 2008; Lee et al., 2004; Neithercott, 2013; Nicolucci et al., 2008; Scheidegger et al., 2007; Todres et al., 2010; Wood, 2011). With so little known about what it means to live with CSII, the research question for this study is: What is the meaning of the lived experience for adults who are on CSII for the treatment of T1DM?

Method

Heideggerian hermeneutic phenomenology is the philosophical framework for this study. An assumption of Heideggerian hermeneutic phenomenology is that to come to an understanding of human experience in its everydayness, the researcher must consider how an experience relates to the everyday practical world that one is situated (Heidegger, 1927/1962). Hermeneutic phenomenology is the interpretation of the participant's lifeworld, whereby the researcher unveils the subjective world as experienced by participants.

Consistent with Heideggerian hermeneutic phenomenology van Manen's research approach (van Manen, 1997) was chosen for this study, consisting of six research activities: identifying the phenomenon of interest; exploring evidence as it is lived; reflecting on themes; describing the phenomenon through writing; maintaining a connection to the phenomenon; and considering the parts as a whole. Using this methodology, the transcripts and textual data of the participants' stories were examined, and the spoken accounts of the experience were interpreted to discover what was telling, meaningful, and thematic. From the participants' life stories, a rich textual description was produced, and interpreted for meaning. The lived experience was transformed into a written format in a way that challenged normative assumptions whereby the text was made more reflective of what was meaningful.

Participant Recruitment and Selection

Ethical approval was obtained from the Health Research Ethics Authority (HREB) at Memorial University of

Newfoundland. The ethical principles on research with human participants set out by the Tri-Council Policy Statement guided this study (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2014). To achieve a rich and meaningful description of what it is like to live with CSII in its everydayness purposeful sampling was used until data saturation. Inclusion criteria included being able to speak and understand English, aged 19 years or older, currently on CSII therapy to manage T1DM, patients at the diabetes clinic within Eastern Health and willing to participate in the study.

Eight adult participants, four males and four females, who used CSII therapy to manage T1DM participated in the study. No exclusions were made relative to sex, gender identity, socioeconomic status, or marital status. All participants were educated at the university or College level. One female and two male participants were single; one female was in a relationship; and two males and two females were married. Two out of the four that were married had children. None of the other participants had children. Participant duration of living with T1DM ranged from 6 to 34 years with an average of 15 years and the duration of living with CSII ranged from 5 to 14 years with an average of 9 years. All participants were using a conventional tubed CSII device. Recruitment consisted of recruitment posters displayed at two diabetes clinics and by information provided to patients by a certified diabetes nurse educator at a diabetes clinic within the Eastern Health Authority of Newfoundland and Labrador, Canada.

Data Collection

Participants were given the option of picking the time and place of the interview and provided written informed consent before commencement of the interview. Six participants chose to complete the interview in the researcher's office, one participant chose their place of work, and one participant was interviewed in his home. There was little noise or distraction during the interviews and confidentiality, comfort and privacy were maintained. All interviews were carried out exclusively by the primary researcher and lasted from 45 minutes to 1 hour each.

Interview questions were directed at the participants' experiences and feelings of living with CSII. Open-ended questions were used which allowed participants to set the direction of the interview and define important dimensions of the phenomenon. This also allowed them to elaborate on what was relevant to them instead of what was relevant to the researcher. Phenomenologically, an important question was, "Tell me a story that reveals what a typical day is like for you." At times, individuals may not even be aware of the impact until given the opportunity to talk about it. This allowed the participants to discuss what it was like to live with CSII on a day-to-day basis - how it impacted their lives in its everydayness, and to explore the daily challenges of

living with CSII. Other questions asked were, "Tell me how wearing an insulin pump [CSII] has affected your self-image." "Your personal relationships." "Your social interactions." "Your attire." Another question specifically assessed how CSII impacted participants' lives, "Do you feel that your life has changed since starting the insulin pump [CSII]?" Follow-up questions explored salient points of discussion to clarify meaning or to gain a deeper understanding of the context. Throughout the interview, participants were given time to share their stories, thoughts, and feelings about CSII and to talk about anything that would help me understand their experience. Interview times lasted until each participant had exhausted his or her description of the lived experience with CSII and no new information emerged. Non-leading verbal and non-verbal interview techniques were also used to facilitate participants' discussion of their feelings and allowed them to express their experiences in detail. Verbal communication techniques included reflection, probing and clarification. Non-verbal communication techniques included nodding, eye contact, and silence.

Data Analysis

Immediately following each interview audio tape recordings were transcribed verbatim. The primary researcher then reviewed and compared each tape with the typed text to ensure accuracy of data transcription. Using van Manen's (1990) holistic approach of listening, reading, and re-reading the transcripts numerous times, both researchers immersed themselves in each experience to gain greater insight. The next step in thematic analysis was the selective reading and highlighting approach, which contributed to the beginning discovery of significant phrases (van Manen, 1990). Using a line-by-line approach, each researcher independently highlighted the text of each interview to select statements or phrases that revealed aspects of the participant's lived experiences with CSII. Subsequently selected statements or phrases were compiled in a Microsoft Word document for further analysis. During this process, notes and impressions were written down; specifically, ideas and meanings that were expressed by the participants to identify emerging themes. Next, commonalities between lists of selected statements and phrases were noted. Colored highlighters were used to identify similarities and common threads throughout the lists for each interview and these became the basis for themes. Next, lists were re-read to refine the themes that emerged. van Manen (1990) suggests that collaborating with colleagues can strengthen identification of themes by enabling the researcher to see beyond the text and interpret meaning. Both researchers did the analysis independently and then collaborated by discussing the themes. Agreement was reached between the researchers by moving ideas around and re-visiting the original interpretations. Each of the themes was supported by direct quotations from the participants and captured the lived experience of adults living with CSII

Table 1. Themes and Subthemes.

1.	Theme #1: Transitioning: not a quick fix
	Subthemes:
	Disillusioned, overwhelmed, and unsure
	Separation of self before and after life with CSII
	Relinquishing control to CSII: You wear your life
	Owning it
	Taking my life back
	Constantly Vigilant: CSII is a lot of work
2.	Theme #2: CSII: Making an invisible illness visible
	Subthemes:
	Concealing and accommodating CSII
	Being Misunderstood
3.	Theme #3: The internal struggle and impact on mental health
	Subthemes:
	Striving to meet unrealistic expectations: Blaming self
	Inner conflict
4.	Theme #4: The impact on relationships and the meaning of support
	Subthemes:
	Connecting with others who have CSII
	Re-defining relationships: Bringing in a third party
	Negative encounters with healthcare professionals: Antithetical to self care
	The financial burden of CSII

to manage T1DM. Based on the themes the essence of the experience was identified. Although this process of data analysis may appear linear, the researchers often moved back and forth between the “steps” of data analysis.

Findings

From the analysis of participant narratives there were four major themes that captured the meaning of the lived experience of adults who are on CSII for the treatment of T1DM. These themes are presented with subthemes as shown in Table 1. The first theme, *transitioning: not a quick fix* reveals the transitional process of wearing a CSII pump. The second theme, *CSII: making an invisible illness visible* highlights the concealing and accommodating of CSII and the experience of being misunderstood. The theme, *the internal struggle and the impact on mental health*, reveals the unrealistic expectations associated with CSII. The fourth theme, *the impact on relationships and the meaning of support*, highlights the nature of the interpersonal relationships. It is important to differentiate living with CSII and being an individual diagnosed with T1DM. That is, the experiences of CSII and T1DM were not disparate; rather, they were intertwined and together interpreted by the researcher to weave a phenomenological interpretation of what it was like to live with CSII.

Transitioning: Not a Quick Fix

Initiating CSII began a period of transitioning in participants’ lives whereby they often referred to life before CSII and life

after CSII. With time, the initial stress created by dependence on CSII was replaced with trust and a relinquishing of control, whereby participants began to take ownership of the responsibilities and consequences of using CSII and reclaimed their lives. However, CSII was complex and required a lot of work to reap the benefits; there would always be limitations to their lives. The theme of transitioning illustrates the challenges that participants experienced after initiating CSII therapy. It also highlights the emergence of a different sense of self that left participants forever changed.

Disillusioned, overwhelmed, and unsure. Although participants voiced that CSII was marketed as a quick fix tool that would lead to a carefree lifestyle, the reality of living with CSII was much different from initially anticipated. Participants felt that the information presented during education sessions was not realistic. They quickly became disillusioned and overwhelmed. Expectations of what CSII could do was antithetical to participants’ experiences. Online advertising of CSII shows individuals who are smiling, having fun, and living a carefree life. CSII was promoted as a device that would make individuals happy and perhaps take away some of the difficulties, worries, and uncertainty of managing T1DM. However, participants found this to be very misleading and felt betrayed by CSII advertising and by the educators who failed to present CSII in a more realistic way. One woman stated:

I just think that everything needs to be more realistic with respect to pump [CSII] education. Because, again, people say “oh, we’re so glad that you bought our pump” because for the

majority of people, pump education, at the beginning, comes from the reps [CSII industry representatives]. Of course, they want you to buy their product and, of course would have nothing but great testimonials, but in terms of health education and health promotion, we need to be real. I think, at the beginning, before I bought it I would have considered it more. Because I was like, "Oh, give me a quick fix." And then I realized, "Oh no, like, it's going take a year." If it had been more realistic education, I think it would have made my transition better.

Once on CSII, the problems began with participants feeling unsure and that they lacked sufficient knowledge or the readiness to deal with everyday experiences of living with CSII. Participants felt overwhelmed and unable to process information; they felt mentally paralyzed, were unable to ask questions, or anticipate challenges, as one man explained.

There was just so much new information coming at me at once that I didn't have time to ask questions, "Yeah, oh, ok, so, this is this and that's that." It was never, like, "What do I do if this happens or that happens?" because those ideas were so new to me.

Separation of self before and after life with CSII. CSII was a reference point in time that created a duality in participants' lives, whereby, there was a separation of self before CSII and after CSII. "Right away I was able to take advantage of using a pump but at the same time I know what life was like before having it, and the frustration of that, and there's certain times that it hits you." The separation became even greater when T1DM and CSII occurred simultaneously. At 28 years old, she was married, had a successful career, and was living in her own house. Then came the diagnosis of T1DM and the start of CSII. T1DM and CSII forced her to consider and question everything she did, and this constant awareness was overwhelming and consuming. Life had now become complex and full of obligations whereby she grieved her previous self and life. She struggled to make sense of her world, and how T1DM and CSII would fit within it. For her, when she discussed life before and after CSII she was actually discussing CSII and T1DM simultaneously.

The biggest thing for me with being diagnosed with Adult Type I, what I found was you go from not having to worry about anything to having to consider what you eat, take your insulin, your medication, looking at how activity impacts on all of that, counting carbs. I never had to do all that so for me, it was never the insulin, per say, or the medication, or the needles [MDI], or the actual pumping [CSII], when I first started, it was more the regimented, it was more like having to think about these things that I didn't like. If someone could say to me, "Ok, you take five needles [MDI] a day and your sugars will be perfect from now till you die," I'd probably would have stayed on needles [MDI]. . . That's the diabetes pump [CSII], it's, it's just that you're always thinking, it's always there, it's always part of your life. I've lived 28 years of my life that I didn't have to have all these thoughts.

Relinquishing control to CSII: You wear your life. Participants had hoped that CSII would provide immediate control over T1DM and decrease their fears about DM-related complications. As they began to use this tool to manage T1DM there was a sudden awareness and realization that death could occur, and the risk of complications was still present regardless of the management regime. This fear originated from a place of deep uncertainty whereby CSII could not guarantee exemption from DM-related complications and the realization that CSII was their "life support." As stated by one female participant:

It's life sustaining equipment. Right? So, it was very scary for me and, as I say, I was really anxious at the beginning. It's the realization that you wear your life, like this box is keeping you alive. You sit back, and you think about that, you put your life in this box.

The demands of CSII created a sense of imprisonment, making participants feel like a hostage to the responsibilities and obligations of managing T1DM, as one woman explained. "Part of it was, for me, not having control because I said I'd never go on a pump [CSII] in the beginning because I didn't want something else to control. I felt with the needle, I controlled my diabetes." Adjusting to CSII took time where there was a vulnerability created by depending on a machine. Acceptance and relinquishing control meant overcoming fear, uncertainty, and learning to trust the technology. She further stated:

Figure you're going to put it on and everything is going to be great, but personally, it took me, I'd say, a year and a half and that's a long time but to be totally comfortable with my pump and my pump's functions, because it's, it's your life, right? Like this is my life.

Despite participants' fears, they eventually relinquished control. It was as if a relationship developed between the individual and CSII. Giving some of the control to CSII was a process of change, whereby trust was necessary for the relationship to work, as one woman explained. "You develop a relationship with the pump. Well, I mean, it is an inanimate object but you, you have to trust at some point because otherwise you wouldn't be able to wear it."

Owning it. To live with CSII meant accepting that staying alive depended on self-care and this came with a deep sense of ownership. Because CSII therapy was ultimately the participants' responsibility, they experienced highs and lows of success and failure and saw their own actions as reasons for success and failure. One woman stated:

There's such a sense of ownership and control where you feel really good about yourself when you do really well and really bad when you do really poorly. If you think about it, sometimes the stress response just elevates your blood sugar. When you go

through menopause you don't feel like that but with the pump you definitely take ownership. I know I do, I feel really, really good when things go great.

CSII technology was complex, adding to the pressure of T1DM self-management. Owning the responsibility of CSII therapy contributed largely to perpetual self-blame and to some extent, almost all participants internalized the guilt. Living with CSII was described as a feeling of aloneness. Aloneness was the weight of carrying this burden not alleviated even with the presence of family or friends. Feelings of aloneness created a disconnect between themselves and others, whereby others could not understand the burden of being responsible for making life and death decisions.

As participants accepted responsibility for CSII therapy, eventually, it became more of a daily routine. For one participant, CSII ownership became a source of motivation for T1DM self-management. CSII was more work than MDI but he could foresee the benefit of having increased freedom and flexibility not attainable with MDI. CSII required a commitment to lifelong learning, which he perceived as an investment in health and QOL. His acceptance of CSII came with much reflection about the changes and advancement that he experienced with T1DM management for over 30 years.

You've got to be willing to learn and then you've got to use the information that you learn, to make it work for you right. You're not just going hook it up and suddenly, you're like someone without diabetes anymore right, it doesn't work that way. You got to work at it. It's not just plug in and go on, and do whatever you want to do, eat whatever you want to eat, and you're going to be fine.

Taking my life back. Although they would never be their pre-undiagnosed self, CSII helped participants to reclaim freedom, flexibility, and blood glucose control. CSII eventually gave them back some decision-making and control over their lives and made them feel closer to normal, or more like everyone else as one man stated. *"You kind of feel a little bit normal. What people have on the inside [pancreas], you have on your outside [CSII] so it's closer to normal."*

CSII increased sensitivity to symptoms of hypoglycemia and allowed for earlier intervention. It allowed participants to make frequent changes to insulin delivery during activities, such as exercise, resulting in fewer of the hypoglycemic events. This allowed them more freedom and flexibility to participate in activities that were restricted with MDI. It provided immediate access to medication and supplies compared to MDI. This resulted in more flexibility, by reducing the need to carry as many supplies; and reassurance during social outings, knowing that insulin was always with them. CSII included all the supplies needed to maintain survival and this was reassuring to participants.

Participants were able to do or achieve anything, but at the same time, they recognized that there would always be

limitations when managing T1DM. Living with CSII would never match the expectation of leading a normal life because participants still had T1DM. One male participant stated:

I think there's always a little bit of a limit, like, being on a pump, even with all these things, there are some things you can't do. You can't just because you're on a pump, just pretend you're 100% healthy.

Constantly vigilant: CSII is a lot of work. T1DM in and of itself requires a great deal of vigilance. However, the paradoxical nature of CSII was that it offered freedom and flexibility with management of T1DM, but it was a manually operated device with infinite obligations and never-ending responsibilities and requiring constant vigilance. Participants believed that the public often mistakenly believed CSII was automatic and self-regulating, even though it actually required more care and vigilance than MDI. CSII required constant attention in every aspect of participants' lives. It was a harsh realization of the amount of vigilance required to reap the benefits, yet these benefits were not instantaneous.

Constant vigilance also meant always having to think about CSII. The necessary level of thought and care required for every action, every activity, and every decision was consuming at times, as one woman stated. *"It's always there but you always have to be conscious that it's there—every little alarm or every little beep."* One participant described her experience as a "catch 22" where the freedom she acquired with CSII came at the price of having to be constantly vigilant. For some it was a point of contention, as CSII was supposed to take away some of the onerous work of managing T1DM, not increasing it and thus some participants thought about reverting to MDI. *"Having to always think about it is so frustrating. . . I just, I don't know anything about life without it and sometimes I think I'd like to go back on needles [MDI] because it [CSII] requires so much work."*

CSII: Making an Invisible Illness Visible

Wearing an external device brought visibility to an otherwise invisible illness; CSII was symbolic that something was wrong. This had a significant impact on how participants believed others viewed them and how they viewed themselves. Participants wanted to hide CSII; hide the illness; and hide the scarring, fearing they would be misunderstood and stigmatized by the public. They also did not want to be reminded that they had an incurable disease.

Concealing and accommodating CSII. CSII was a physical reminder to participants that they had T1DM, and for many this was the most unappealing aspect of the device. It revealed that something was broken in their body and that something was wrong with them. One woman stated: *"So, when you put a pump on you, you have an external reminder*

that your pancreas sucks.” Although auditory reminders on CSII were meant to improve the management of T1DM, they also externalized the illness to the participant and the public, as this female participant explained. *“I have alarms that go off a lot of times. . . it’s [CSII] not only a visual reminder, it’s also an auditory reminder, too, that you have this disease.”*

The visibility of CSII changed individuals’ sense of being in the world and the relationships they had with themselves and others leading to the desire for concealment and/or accommodation. The effort put into concealing CSII reflected participants’ self-awareness of how they presented themselves to the world and how others perceived them. CSII brought criticism and judgement and created an opportunity to use T1DM as a punchline for jokes. This made social situations difficult and further amplifying participants’ feelings that they were different from others. Concealment of scars caused from infusion sets was important because they felt self-conscious, ashamed, or embarrassed about their body image. The desire to conceal CSII was also to eliminate the constant physical reminder that they had an incurable chronic illness and to avoid talking about CSII or T1DM with strangers or acquaintances; thus, they took active measures to conceal the device to render it “invisible” to themselves and to others, as one man stated:

I cover it up, just because I don’t care for the extra questions, “What is that? What does that do?” I’m not bothered by them, I just can do without everyone asking, everyone looking. So, I just cover it up.

Accommodation of CSII for some participants was for practicality and comfort, to prevent it from falling off their bodies. For others accommodation was about finding a place to store it on their bodies. Accommodation of CSII was a daily challenge for participants, especially choosing the right attire. Increased body awareness and re-inventing ways to accommodate CSII was challenging at times.

Being misunderstood. There was a perceived lack of knowledge and understanding from the public about CSII and T1DM. For example, as a visible device CSII was often confused with electronic devices, such as a MP3 player, leaving participants resentful that they had to explain it to the public. One man shared his experience:

I was never ashamed to be diabetic, but I didn’t announce it to the world either. . . I don’t think there’s a disadvantage to wearing the pump, but I think there’s a general lack of understanding from the population as to what a pump is, what diabetes is. A bunch of my teachers in junior high thought it was an MP3 player. So, it happened a bunch of times where I was using it in class and they were, like, “Pay attention.” It’s a negative. It’s a lot of questions that you don’t want to have to answer, that you don’t want to be bothered with.

Participants were embarrassed and fearful that others would misinterpret CSII as something used by an illicit drug user. Others frequently offered their opinion to participants on how to manage T1DM based on assumptions and their interpretation of CSII and T1DM. Participants resented these encounters and felt stigmatized.

Encounters with the public often led to warnings and advice about T1DM. Participants disliked the constant, not so subtle, cautionary messages about what they should be eating or how “bad” their T1DM was because they had CSII. Seemingly harmless advice from the public undermined participant knowledge of T1DM and the work they put into living with CSII and further reflected the lack of public knowledge, leaving participants having to defend their choices. For some participants, the public would never truly comprehend their experience of living with CSII because they could not put themselves in the situation, therefore, public perception was irrelevant to them.

The Internal Struggle and Impact on Mental Health

CSII therapy was a constant and often overwhelming responsibility, permeating every part of participants’ lives. Endless responsibilities and demands were often met with unrealistic expectations from healthcare professionals that left participants experiencing guilt and self-blame. There was a punishing reality of losing oneself—losing time with children, losing energy to socialize or care for oneself, and losing opportunities to do everyday tasks. Inner conflict was often present from the opposing demands and responsibilities of CSII.

Striving to meet unrealistic expectations: Blaming self. There was an expectation from healthcare professionals that participants would adhere to a prescribed treatment. The perceived cookie-cutter set of expectations provided by healthcare professionals was unrealistic to apply to all individuals with CSII. Healthcare professionals failed to take into consideration variables in participants’ busy, non-routine lives; what may have been achievable for one individual was not necessarily achievable for another. Although participants strived to meet these expectations they often struggled to do so and felt frustrated, as one man expressed. *“I’ve never had an A1C of six. I don’t know how I would get there, I mean, they don’t want you to have lows but I really don’t know how I would get to that point.”*

The terms “good” and “bad” were often used interchangeably by healthcare professionals during interactions with participants and typically referred to controlled and uncontrolled blood glucose levels, respectively. Participants described the use of such terms as a consistent reminder of the inherent goal of keeping blood glucose levels within “normal” limits. It also perpetuated the idea that maintaining target blood glucose levels was behaving well and having

blood glucose levels outside the target was behaving badly. They felt judged for not meeting expectations that were sometimes out of their control due to the unpredictability of T1DM causing them to feel frustrated and discouraged.

The challenge of infertility was difficult for one participant as she struggled to reach glycemic targets. Healthcare professionals treated her as if she was non-compliant, however, achieving the necessary blood glucose targets seemed like an unreachable task. She was left with feelings of personal blame for not being able to get approval for in-vitro fertilization or to conceive and she felt unfairly judged by healthcare professionals.

Dr. X wouldn't sign off on me going away [for in-vitro fertilization]. There's lots of people that get pregnant if they're Type 1; they make that choice, but I didn't have a choice. It was between Dr. X and Dr. Y. They would have a conversation whether or not I could go and try to get pregnant. It was a really bizarre experience and people almost making a judgement on me that, "Why do you have that high sugar?" "What are you going to do to correct that?" We had waited so long to get accepted to Calgary, to be able to go through in-vitro fertilization, there could have been somebody wherever that had a totally crappy A1C, and got pregnant on twins, you know that's it.

The lack of approval for in-vitro fertilization was like punishment for doing something wrong, where her efforts were just not good enough, and she was not good enough. Not only did she feel that healthcare professionals let her down, but she shared feelings of self-betrayal due to the fact that she could not meet the targets and she believed her body was defective. Ultimately, the reality of having another child was out of reach.

Inner conflict. It was a struggle to live a balanced life with CSII. Participants were often torn between making decisions, such as spending time with family or attending to CSII. Participants faced inner conflict on a daily basis when making choices that were potentially life-altering. This back and forth inner dialogue of discussion, negotiation, and arguments eventually became an automatic, natural part of thinking. Constantly having these thoughts left participants feeling submersed in a life dominated by CSII.

Self-blame and guilt riddled the participants' narratives and further emphasized their inner conflict. Guilt manifested itself in many ways—guilt for not being there for their children, guilt for not taking care of themselves, and guilt for how well they were managing T1DM; thus, guilt played a large part in the participants' experience with CSII. Balancing guilt and satisfaction revealed the incessant tide of emotions that compounded their exhaustion, as explained by this woman.

When you end up getting that excellent A1C, or like yesterday, I went for a run, and my sugars were beautiful the entire day and then you feel so good about yourself. At the same time, you

know you shouldn't judge yourself based on what that number is, but you can't help but it's kind of like school, like, "Ok, today, I passed today" because I got this excellent blood sugar and I managed my diabetes really well and then other days, well, "I suck because I did this." There's so much emotion and self-worth and self-esteem just attached to these numbers that it's hard.

For one participant, a mother trying to take time for herself and manage T1DM with CSII, it was a heartbreak like no other because as a parent she wanted to seem invincible and never show weakness to her children. T1DM and CSII, however, took this away and she often experienced a heavy sense of failure—failure to her family for taking time for her health and failure to herself for not taking the time to manage T1DM with CSII. Taking the necessary self-care moments to use CSII caused significant inner conflict. Choosing her own health over spending time with her family left her feeling selfish and guilty, as she felt she was putting herself ahead of her children.

You should take that time, right at that moment to go change your reservoir, change your site, do this, do that. You know, it is only three to five minutes, max but, you're so caught up with playing street hockey with the boys and enjoying that time, I put it off because I am choosing my children over my own health, if it comes down to it. Those are the real life experiences and that's probably one of the most difficult, and most challenging, taking the time for yourself. I know you need to take that time for yourself and for your health, but it's just an ongoing battle.

Persisting inner conflict often led to feelings of depression. On some days, managing T1DM with CSII overwhelmed their coping strategies, and participants felt utterly defeated. Although an individual may not have a clinical diagnosis of depression, the effects on mental health can be debilitating. The inability to break away mentally was a struggle described by one male participant.

I can see how the strict schedule and just not being able to kind of do what you want more or less can definitely lead to a lot of depression. You always have good days and bad days when you're a diabetic and some days you feel like you can't get it right, you got a bunch of low blood sugars and you have a situation with your pump and you just feel like I just can't do this today and sometimes that can build up.

The Impact on Relationships and the Meaning of Support

The importance of support in helping participants manage and cope with CSII was prevalent within each of the participant's interviews. Support was sought from a variety of sources including informal support, such as other individuals with CSII, family members and significant others. Formal support included healthcare professionals such as physicians, registered nurses, certified diabetes educators and

registered dietitians. Financial support was also identified as important. Participants acknowledged that informal support networks enhanced their coping skills. Formal support networks, such as certified diabetes nurse educators, were praised by participants for their availability, knowledge, and helpfulness. However, formal support from physicians and certified diabetes educators from disciplines other than nursing often left them disappointed and frustrated, limiting the resourcefulness of such support networks.

Connecting with others who have CSII. Living with CSII often came with a sense of aloneness until participants connected with individuals who were also living with CSII. This connection with others who were experiencing something similar helped ease the burden of managing the disease and living with CSII. There was a uniqueness to the relationship, a comradery, where there was an automatic sense of understanding, a sense of knowing and acceptance, not found with individuals who were not using CSII. One woman described this connection as a break from having to explain what it is you are experiencing, a break from judgement and not having to worry that the other individual would not understand. This connection provided a comfort and support even for those who had strong support from family and friends.

The majority of people that I have met with an insulin pump it's like this connection or something or this comradery. It doesn't matter who you are or if you've ever seen them before in your life, it's, like, when you pull out that pump you're automatically in that club and that person actually knows what you're talking about.

Participants expressed that other individuals with CSII “got it,” referring to shared feelings of acceptance and a feeling of something that could not be described. It was being able to relate to each other’s experiences. One participant shared his experience of resisting CSII until he connected with an individual who was living with the device. Though he appreciated advice from healthcare professionals, those living with CSII provided an insider’s point of view.

Connections with other individuals on CSII through an online network of support groups also helped dissipate feelings of isolation and aloneness. Belonging to a community where other individuals were experiencing similar challenges and struggles, participants felt understood, knowing they could put themselves in her situation. Face-to-face connections with friends or family on CSII were undeniably a source of support for participants as well.

Re-defining relationships: Bringing in a third party. Participants, family members and significant others all felt that having CSII was like bringing another person into their relationships. Interactions within relationships were altered and would never be the same as they were before CSII. One female participant’s husband perceived CSII as a more

intensive therapy than her previous regime of MDI, whereby her starting on CSII was indicative of the decline and progression of T1DM. CSII was a tangible object in their relationship. It was always with them, creating fear and concern for her husband; fear that CSII would cause more harm than T1DM alone; or fear that he would break the device, injuring or causing death to his wife. Before CSII, T1DM was vague; however, CSII was reflective of the disease. *“I think he was afraid of it at first. He was afraid he was going to break it and I was going to die in the bed.”*

For some, CSII presented an awkwardness in relationships due to having to explain the device or adapting to its presence, while for others it simply got in the way during intimate moments. This was particularly challenging for one female participant and her husband. *“My husband said to me, when I was thinking about getting the pump, it's like, ‘Sure, do you have to wear that on you all the time, hanging off of you’ He was appalled.”* There was a need for maintaining togetherness with her husband, yet the ways of relating to each other had changed and become complex as CSII was now the third party. Intimacy was challenging and difficult for both partners as they moved forward in their relationship with each other and CSII. Humor became a positive strategy they used that helped lighten the burden that CSII had on intimacy.

I think it does impact, not so much sex, but just cuddling in at night when you're going to sleep. . . we've had to learn, we've had to learn together about what we can do with it and how it impacts us.

Considering when and how to reveal CSII to significant others was an individualized experience. CSII brought the opportunity to alter relationships in the way they related to each other and during intimacy. While some participants expressed that they were open to others about T1DM and the CSII device early in the relationship, others preferred not to expose their diagnosis or the device, initially. The physical presence of CSII and visibility of the tubing would often raise questions and facilitate the conversation. Participants stated that the discreetness of MDI gave more control over disclosure, allowing them to withhold that information until they were ready to talk about it.

Negative encounters with healthcare professionals: Antithetical to self-care. Participants hoped to have a relationship with healthcare professionals that offered support, guidance, knowledge, consistency, and the ability to work together as a team. However, encounters with healthcare professionals were often a negative experience that were antithetical to the capacity to achieve successful CSII self-care. Multiple factors contributed to this negativity, such as healthcare professionals’ lack of knowledge, lack of insight and lack of consistency. Participants often left encounters feeling frustrated and disappointed rather than feeling supported. Participants were

encouraged to pursue CSII self-care; however, at times they were given very few resources. They felt lost and frustrated within a system that failed at providing care and support. One male participant stated:

I went to see, I believe it was an endocrinologist. He specializes in Type II. . . and he called me to his office and he just kind of said, like, "I don't know anything about this and I don't even know where to start with Type I" and, so, it was basically a, "I'm sorry, that you were referred to me but I can't help you type of thing."

Participant decisions based on financial constraints were often misinterpreted and judged as being non-compliant. Feelings of guilt and shame progressed to frustration and resentment at not being understood by those meant to provide support. They felt that healthcare providers often failed to recognize that CSII was a complicated piece of equipment that was operated by the participant and not be suitable for everyone.

Encounters with different healthcare professionals often resulted in a disconnect in their care. The need to connect with a healthcare professional was important in providing a sense of comfort, encouragement, and up-to-date information on CSII management while a lack of continuity resulted in participants receiving mixed messages about CSII management. This did not facilitate a trusting rapport or provide the holistic care participants were hoping, as one woman explained.

For the longest time I actually saw a dietician, a dietician that was a certified diabetic educator, and I got to tell you, I think we need nurse educators because, and nothing against dieticians. I do know is that the nurses that I've had are far more holistic. But, what I found when I started was I was kind a bounced around in the beginning from one nurse to another nurse to whatever. So I found I was getting all this mixed information.

Interactions with physicians were often one-sided, where participants did not feel like an active partner in their own care, leaving them feeling disrespected and insignificant. The limited availability and lack of accessibility of a physician was a deterrent to starting CSII whereby it contributed to feelings of aloneness in T1DM management with CSII. Appointments with physicians left participants feeling rushed with little time to ask questions, or few opportunities for them to get to know each other. In contrast, all participants noted that certified diabetes nurse educators made themselves available and took the time to discuss patient care. One participant stated that having a consistent team of certified diabetes nurse educators that knew his history alleviated the need for him to explain himself at each appointment.

It's nice because I've had the same two people [diabetes educators] now, for seven or eight years. So, we've built, like, a good rapport or they know my lifestyle. They probably know

more about my lifestyle than my parents do. I can't imagine seeing new people every three months, having to explain my situation, to re-explain my lifestyle because our meetings still go an hour, an hour and a half. They know that already so we don't have to waste time, each time, doing that, but I find with my doctors I almost have to re-explain my situation because they are constantly switching or moving to different clinics or gone away for six months so, it's really nice having that, like, consistent team.

Participants found comfort and reassurance in connecting with a certified diabetes nurse educator who was understanding, knowledgeable and available at a moments notice, outside regular working hours. Support from the industry supplying CSII devices was also important for troubleshooting and device replacement.

The financial burden of CSII. The financial burden of CSII was as a major stressor, as participants struggled to cover the costs of using the device. The financial burden was substantial even with insurance, and out-of-pocket costs for CSII were significant. Without insurance, many participants stated that CSII would not be a feasible option for diabetes management. Participants feared having to return to MDI, due to financial concerns, to manage their T1DM, as this was seen as a step backwards, as stated by a female participant.

Moving home, I'm quitting my job, I didn't know if I was on my boyfriend's insurance or not and I know that there's a provincial drug coverage but it won't cover pump supplies. "That's \$150.00 out of my own pocket that I have to pay a month" and I was really worried about that and financial worries would be my main issue with the pump. I've just come so far now that going back to syringes is like a dozen steps backwards.

For others, CSII was viewed as a treatment for a serious disease, much like an individual would view treatment for cancer. CSII was necessary to stay alive; therefore, financing for CSII was incorporated and accepted as part of treatment costs.

Discussion

This study explored the phenomena of living with CSII in its everydayness within the lifeworld of existentials as presented before thought or reflection. The way the participants ascribed meaning to events in their lives, throughout their journey with CSII, influenced, and was influenced, by almost every aspect of their everyday lives. Transitioning with CSII was more than just learning to cope and adapt. Lived time was not measured in seconds, minutes, or days, but rather a collection of moments dominated by CSII. Lived time was experienced by participants as a state of perpetual readiness where days seemed to be a continuous loop of assessing, making decisions, and having to be constantly engaged with CSII.

Participants' stories were of how they separated their lives into before CSII and after CSII. They were the same people before CSII, yet they were transformed after initiating CSII whereby they separated their lives into pre- and post-CSII identities. Temporally, there was a duality of participants' lives, whereby they had a past without CSII and a present with CSII. Reidy et al. (2018) found that adjusting to insulin pump therapy took time as fears that the device would malfunction and the thought of giving up control required psychological and practical adjustments. Similar to Reidy et al. (2018), study participants learned to master the technology, the initial feelings of stress and vulnerability created by depending on CSII were replaced with feeling autonomous, whereby eventually they described CSII as "an extension of myself."

Rasmussen et al. (2011) and Ritholz et al. (2007) found that CSII compounded the stress of managing diabetes due to visibility of the device and having something constantly attached to their body, the cost of the device, and worries about glycemic control. Congruent with Rasmussen et al. (2011) and Ritholz et al. (2007), participants described transitioning to CSII as a life-altering event that was more significant than being diagnosed with T1DM. Initially, participants felt "imprisoned" by CSII—the "walls were closing in." Eventually, they reached a point of acceptance given there was no cure and no freedom from T1DM and so the only course of action would be to learn to live with CSII. As integration and normalization of CSII occurred, participants had to find a new sense of purpose and meaning. Corporally, participants viewed themselves differently in the world. They had to go beyond being someone with T1DM to an individual living with CSII. Eventually living with CSII took ascendancy over living with T1DM. Temporally, the idea of time was immeasurable.

Although CSII made them feel closer to normal it was still a reminder that they had a chronic illness. Participants recognized that death could occur if hypoglycemia was not urgently treated and then they spent hours thereafter trying to bring blood glucose levels back within normal range. A salient finding from this study was that participants continued to look into the future and fear the long-term effects hypoglycemia and hyperglycemia would have on the development of complications and possibly death, even with CSII.

For the participants, CSII made an invisible illness visible to themselves and to others. CSII was an appendage with bells and whistles and required attention to operate. CSII required accommodation within the lives of the bearer. To the public it symbolized that something was different or maybe not normal. Public misconceptions about CSII led to participants frequently having to explain the device or the decisions they made about their management. It was evident that this experience became frustrating and tiring. To avoid these negative interactions participants sought to conceal CSII from others. It has been well documented in the literature that CSII heightened body awareness and

self-consciousness (Barnard & Skinner, 2007; Garmo et al., 2013; Hayes et al., 2011; Heinemann & Krinelke, 2012; Kay et al., 2009; Ritholz et al., 2007; Saarinen et al., 2014). The internal disease was now externalized, causing participants to question what they looked like to the world; CSII drew attention to themselves and their body. Sartre (1956) describes consciousness as the relation of the body to the world where both consciousness and body are both the person as a presence to the world. In health, we do not take notice of our corporeal being, thus the body is often neglected or "passed over in silence." When an individual's well-being is disturbed one can no longer live in a self-forgetful, passed over relation to the body and sense of self and body is changed. The body is the consciousness that becomes the self-consciousness. The self-conscious body knows itself as being looked at with curiosity or aversion and this can be confirming or criticizing. According to the literature CSII heightens body awareness and self-consciousness (Barnard & Skinner, 2007; Garmo et al., 2013; Hayes et al., 2011; Heinemann & Krinelke, 2012; Kay et al., 2009; Ritholz et al., 2007; Saarinen et al., 2014). With T1DM came a disruption of the smooth non-reflective functioning of the taken-for-granted; the body had broken down. One does not normally have to attend to the pancreas. Now, however, participants had to pay attention. Maintaining the lived body now had to be a consideration. CSII imposed upon this smooth non-reflective way of previously being-in-the-world.

Living with CSII brought expectations to meet stringent guidelines, devote time to self-management, and attend to everyday aspects of life, such as work and family. Participants struggled with balancing these obligations and sacrificed time for self-care and time with family. Failing to succeed in meeting these expectations came with a sense of guilt and blame. Thus, inner conflict was experienced on a daily basis by participants as they tried to devote time to aspects of their home life and with CSII self-management.

Previous studies by Balfe et al. (2013), Bruttomesso et al. (2009), and Trief et al. (2013) identified the presence of DM distress with CSII and other negative emotions but did not identify the underlying factors. In this study, participants spoke about several stressors; in particular, taking ownership for CSII therapy. They were uncertain asking themselves, "Am I doing it right or not doing it right?" Also, they asked, "Am I doing everything that I can be doing?" They blamed themselves when they did not meet metabolic targets. In addition, while participants recognized and accepted that self-management of T1DM with CSII was their responsibility and they had to deal with it themselves. It was not uncommon for study participants to experience the burden of dealing with the device, alone. As days marched on into weeks and months, participants realized there would never be a definite end to these feelings of loneliness.

Self-management of T1DM with CSII often meant choosing between self-care with CSII and daily activities of their

normal lives. Inner conflict was the dilemma about daily decisions that was happening inside participants' minds to self-manage with CSII and a daily process of accepting and forgiving themselves for what could and could not be achieved. Everyone experiences inner conflict; however, it was revealed that for participants with CSII it was much more than just fighting an urge because the results and consequences would have long-term effects on their lives. Hood and Duke (2015) discovered that individuals often forgot CSII self-care at times because their busy lives became a distraction. Balfe et al. (2013) found that management of T1DM with CSII therapy often resulted in other areas of participants' lives being overlooked, whereby feelings of guilt became part of the daily routine. More recently, Robinson et al. (2018), described the emotional turmoil of T1DM self-management with CSII leading to a higher incidence of mental illness. The realization that lack of self-care could have serious consequences left one participant feeling "horrible." Time was measured in accordance with the missed moments with children or family and considerations, whereby other aspects of their lives were often neglected resulting in inner conflict and guilt. Occasionally, participants intentionally made life choices knowing it would result in unfavorable consequences, such as increased blood glucose. These decisions were made to promote their mental health by living even for a short period of time, without adherence to a strict set of rules.

Relationally, participants needed to feel connected and supported by others to self-manage with CSII. Participants sought support from other individuals living with CSII. Having CSII meant relationships had to be re-defined at home with family and significant others. Support from healthcare providers was also significant, as well the financial implications of living with CSII. Support enabled participants to face the daily demands of self-managing a chronic illness with a complex device. Without these connections and support participants felt disconnected from others.

The introduction of CSII was stressful, altering participant relationships with family members and significant others. Golics et al. (2013) reported that chronic illness negatively affects 69% of relationships by increasing stress, tension, and arguments. Congruent with Rintala et al. (2013), increased fear with CSII for family members and significant others stemmed from uncertainty; lack of knowledge about the device; and, uncertainty how to respond to an emergency, such as hypoglycemia. Reidy et al. (2018) identified that it was awkward explaining CSII to a partner, but beyond that there is little exploration of the challenges of CSII during intimacy in the extant literature. It was made explicit in this study that CSII had a significant impact on intimacy that went beyond awkwardness; it was as if a third party had been brought into the relationship. Intimacy with CSII became

stressful for both partners due to uncertainty of what to do with CSII during intimate moments.

The desire to build a positive relationship with healthcare professionals was evident in participants' stories and not new to the literature. However, in this study, support from healthcare professionals was lacking; lack of emotional support in providing a non-judgmental environment; lack of physical support in terms of availability; and, knowledgeable support about CSII was inadequate, resulting in unmet healthcare needs. Participants wanted healthcare professionals to recognize the individuality of living with CSII, whereby CSII was experienced in different ways. Participants revealed that healthcare professionals often failed to consider the consequences of CSII, such as the financial implications, or would recommend the device to patients with low literacy levels and who were computer illiterate. Self-management within a system that was lacking in support made it difficult to achieve recommended targets and achieve optimal outcomes.

Implications

Findings from our study have important implications for healthcare professionals in clinical practice, with an emphasis on registered nurses and certified diabetes educators, as participants identified these health care professionals as having the most impact on their experience. Implications for practice included developing partnerships, reducing stigma, and considering the psychological implications of using CSII. Psychological implications of living with CSII are not screened on a routine basis and are often overlooked by healthcare professionals in favor of achieving metabolic targets. However, our research showed that living with CSII impacts the psychological well-being. This study highlights that psychological complications attributed to living with CSII are as important to assess as physical and metabolic complications. Through regular assessment these complications can be prevented or at least treated at an earlier stage and allow healthcare professionals to provide a more comprehensive plan of care for patients improving their overall QOL. Additionally, patient, and public education and peer mentoring should also be important considerations in clinical practice. The lack of knowledge by healthcare professionals identified by participants also highlights the significance of healthcare professional education in the education system and in clinical areas. Findings from this study also serve as a foundation for further qualitative research to advance understanding of the immense psychological effects of CSII. Lastly, this research study highlights the critical role of the certified diabetes nurse educator in the care of patients living with CSII, thus, highlighting the need to change existing policies to increase the number of certified diabetes nurse educators.

Limitations of the Study

There are several study limitations that must be acknowledged. First, is that the study consists of a homogenous population of only eight participants. Although no participants were excluded relative to sex, gender identity, socioeconomic status, or marital status all participants were Caucasian, educated at the college or university level, and resided in an urban location. This is in part due to the homogeneity of the population of the province of Newfoundland, in which the study was conducted. Thus, a similar study that included participants that were non-Caucasian, had less education, and living in a rural location may have revealed different experiences with CSII. Given emerging evidence of the influence of gender-related factors on health seeking and management of health-related conditions, this should be considered in future research. Secondly, participants in the study were using CSII for at least five years. Hence, CSII experiences before the one-year period may have been different than those who participated in this study. Thirdly, all participants were using a tubed CSII device. Participants using a tubeless CSII device may have reported different experiences.

Conclusion

The benefits of life with CSII has mainly focused on meeting glycemic targets. The findings from this study shed some light on the meaning of CSII for T1DM management. CSII was experienced through the body and mind. One's primary relation to the world is a matter not of reflective thought, but rather practical involvement (Merleau-Ponty, 1945/1962). "The body is the vehicle of being in the world, and having a body is, for a living creature, to be involved in a definite environment (Merleau-Ponty, 1945/1962, p. 82). Time is more than a discrete past, present, and future. The events in our lives are meaningful because time is connected. Participants experienced a duality in their lives; before CSII and after CSII. For individuals with CSII missed time was not clock time, but rather time lost with family and friends. Lived space was perceived as a threatening environment full of anxiety, fear, and distress. In relation to lived body participants spoke to the visibility of the device and stigma perceived from the public. Lived relation referred to the support and challenges with family, significant others, healthcare providers and peers.

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