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“Being in Balance”: Self-Management Experiences Among Young Women with Type 1 Diabetes

Sanja Visekruna

University of Toronto, Toronto, Ontario, Canada, sanja.visekruna@mail.utoronto.ca

Dana S. Edge

Queen’s University, Kingston, Ontario, Canada, dana.edge@queensu.ca

Lisa Keeping-Burke

University of New Brunswick, Saint John, New Brunswick, Canada, lisa.keeping-burke@unb.ca

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Abstract

Women possess characteristics and experiences unique and different from men. Biological processes such as puberty, menstruation, motherhood and menopause may present challenges to self-management for individuals living with type 1 (T1) diabetes mellitus. In this study, descriptive phenomenology was used to uncover the self-management experiences of nine women aged 22- 30 years living with T1 diabetes. Data collection and analysis occurred simultaneously and followed the methodical structure of van Manen (1997). Study findings revealed five themes: 1) elusiveness of control; 2) dualism of technology; 3) forecasting and maintaining routines; 4) dealing with the “ups and downs”; and, 5) interfacing with the health care team. The essence of the experience for participants revolved around trying to achieve a state of “being in balance.” For these young women, self-management encompassed a desire and need to be in balance with their life and blood sugar levels.

Keywords

Diabetes, Descriptive Methods, Illness and Disease, Chronic Illness and Disease, Experiences, Lived Experience, Nursing, Phenomenology, Self-Care, Women’s Health Young Adults.

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Sanja Visekruna

University of Toronto, Toronto, Ontario, Canada

Dana S. Edge

Queen’s University, Kingston, Ontario, Canada

Lisa Keeping-Burke

University of New Brunswick, Saint John, New Brunswick, Canada

Women possess characteristics and experiences unique and different from men. Biological processes such as puberty, menstruation, motherhood and menopause may present challenges to self-management for individuals living with type 1 (T1) diabetes mellitus. In this study, descriptive phenomenology was used to uncover the self-management experiences of nine women aged 22-30 years living with T1 diabetes. Data collection and analysis occurred simultaneously and followed the methodical structure of van Manen (1997). Study findings revealed five themes: 1) elusiveness of control; 2) dualism of technology; 3) forecasting and maintaining routines; 4) dealing with the “ups and downs”; and, 5) interfacing with the health care team. The essence of the experience for participants revolved around trying to achieve a state of “being in balance.” For these young women, self-management encompassed a desire and need to be in balance with their life and blood sugar levels. Keywords: Diabetes, Descriptive Methods, Illness and Disease, Chronic Illness and Disease, Experiences, Lived Experience, Nursing, Phenomenology, Self-Care, Women’s Health, Young Adults.

Worldwide, 382 million individuals are living with diabetes, and this number is projected to increase to 592 million by 2035 [International Diabetes Federation (IDF, 2013)]. Type 1 (T1) diabetes mellitus is an autoimmune, chronic disease caused by no or very limited pancreatic insulin production, thus daily insulin administration either by pen, syringe or insulin pump is required [Canadian Diabetes Association (CDA, 2013)]. The prevalence of T1 diabetes varies widely by country with the highest rates found in Northern Europe and Canada (Frese & Sandholzer, 2013). Commonly diagnosed in childhood or adolescence, approximately five to 10 percent of individuals with diabetes are living with type 1 diabetes (CDA & Diabetes Québec, 2012; Centers for Disease Control and Prevention, 2014). Commitment to self-management health behaviors including routine blood glucose monitoring, insulin delivery and exercise, as well as healthy diet choices, are required to achieve and maintain recommended blood glucose and glycated hemoglobin (HbA1c or A1c) values (CDA, 2013).

Multiple daily injections (MDIs) and continuous subcutaneous insulin infusion (CSII or insulin pump therapy) are two *intensive* insulin regimens used to manage T1 diabetes. MDI therapy involves administration of intermediate- or long-acting insulin by injection once or twice a day, as well as rapid- or short-acting insulin at meal times (CDA, 2013). In contrast, insulin pump therapy is comprised of continuous delivery of small, hourly doses (basal rates¹) of rapid-acting insulin, through a small cannula that lies in the subcutaneous

¹ Basal rate: small dose of rapid-acting insulin that the insulin pump continuously infuses at a pre-set rate (units per hour) “every few minutes” (Chase, 2007a, p. 33). Individuals can have more than one basal rate, to

tissue, typically in the abdomen. For both methods, individuals are required to routinely self-monitor blood glucose levels, and accordingly administer appropriate insulin dosages. Some individuals also manage using an added technology: continuous glucose monitoring (CGM). Users of CGM have a small glucose sensor implanted underneath the skin, which continuously measures glucose levels in the *interstitial fluid* (CDA, 2013). Users of this technology are still *required* to self-monitor blood glucose levels using the finger poke and glucometer method, for calibration and quality assurance purposes (CDA, 2013).

Relevant Review of the Literature

In 2013, the IDF estimated that 184 million women are living with diabetes. Using the previously discussed prevalence rate, this equates to roughly 18.4 million women, worldwide, living with T1 diabetes. Women living with T1 diabetes possess characteristics and experiences that differ from men. For example, puberty, menstruation, pregnancy, motherhood, and menopause can all present challenges for self-management (Homko & Trout, 2006). A1c levels in diabetic women have been reported to be elevated during late adolescence (17-19 years) (Bryden et al., 2001), and during adulthood (late 20's to early 30's) (Lloyd et al., 1999; Pound, Sturrock, & Jeffcoate, 1996). Diabetic women have a potential for poorer pregnancy outcomes, which emphasizes the importance of self-management pre-conception and during pregnancy (IDF, 2009, 2013). Excluding hormonal influences, poor glycemic control in women may reflect behavioral and social factors including demands placed on women, such as family planning, juggling family responsibilities and balancing multiple roles (Pound et al., 1996; Rasmussen, O'Connell, Drummond, & Cox, 2007; Rasmussen, Wellard, & Nankervis, 2001).

From a hormonal standpoint, variability in glycemia and insulin sensitivity during the menstrual cycle has been reported in the literature (Trout & Teff, 2004). In comparison to non-diabetic women, the prevalence of menstrual disorders is also increased in women with T1 diabetes (Auryan & Itamar, 2008). There is limited understanding of *self-management* during this recurring hormonal period, and given the glycemic variability reported in previous literature, it is imperative for health care professionals to understand womens' self-management experiences during this time, from both biomedical (blood glucose monitoring and insulin delivery) and psychosocial (attitudes and behaviors) standpoints, to help inform care plan development.

Optimal patient outcomes rely on a shared understanding between the patient and the health care team about treatment goals and priorities, hence it is important for health care professionals to understand the distinct experiences, as well as the developmental and biological processes of their patient populations, and the effects on self-management (Hannan, 2009). Within the T1 diabetes literature, only two published qualitative studies were located that focus on women's experiences: 1) an interpretive phenomenological study conducted in the United Kingdom, where researchers explored the experiences of young women aged 18-24 years living with T1 diabetes (Kay, Davies, Gamsu, & Jarman, 2009), and 2) a grounded theory study conducted in Australia, where researchers delineated how women aged 20 to 36 years with T1 diabetes managed transitions (Rasmussen et al., 2007).

It is evident from this qualitative work that diabetes is not the only focal point or priority in women's lives during adulthood. Hormonal influences such as pregnancy, and transitions such as becoming an adult or a mother are additional and significant life events, which women are inevitably required to manage and learn to balance with their diabetes.

characterize different parts of the day, that is, morning, overnight (Chase, 2007a). A temporary basal rate can also be programmed into the pump for a period of time for specific instances such as exercise or illness (Chase, 2007a).

Previous work has uncovered specific strategies to manage life with diabetes, such as denial and “positive reframing” (Kay et al., 2009, p. 247), as well as generating stability in one’s life (Rasmussen et al., 2007). While these qualitative studies provide a broad account of the experiences of women with T1 diabetes, greater understanding is required of what the concept of *self-management*, specifically, means to this population during these new, complex and hormonal experiences.

The primary investigator’s research, clinical and personal interest in the area of T1 diabetes care motivated this qualitative research. The current work is intended to inform health care professionals, in particular diabetes educators and endocrinologists treating young women living with type 1 diabetes, to guide patient care planning and promote the best possible patient care outcomes.

Purpose of the Study

The purpose of the current study was threefold:

- 1) To describe the meaning of self-management for young women living with T1 diabetes mellitus;
- 2) To illuminate the priorities of self-management, and everyday life during young adulthood for this group of individuals; and,
- 3) To describe self-management during the menstrual cycle.

The research question “What are the experiences of self-management among young women living with type 1 diabetes mellitus?” was addressed.

Methodology and Methods

The study was situated in the interpretive paradigm (Schwandt, 2000). Data collection and analysis followed the descriptive phenomenological approach of van Manen (1997), which involves the following activities:

- 1) Researching a phenomenon that interests us and commits us to the world;
- 2) Investigating experiences as they are lived;
- 3) Reflecting on essential themes that describe the phenomenon;
- 4) Portraying the phenomenon through writing and re-writing;
- 5) Sustaining a strong and orientated relation to the phenomenon; and,
- 6) Considering the parts and the whole of the research (p. 30-31).

The aim of phenomenology is to describe the lived experience, or the lifeworld of phenomena, to make explicit what is implicit, and to attain meaning (van Manen, 1997). Reduction is an activity specific to descriptive phenomenology, and is primarily what distinguishes it from interpretive phenomenology (Kleinman, 2004). Reduction aims for discovery of what Husserl termed the “lifeworld” (van Manen, 1997, p. 182). To see a phenomenon for what it truly is, according to van Manen, one must re-evaluate one’s true being, and set aside any personal thoughts, ideas, beliefs or preferences about the phenomena under investigation. He cautions not to forget what is already known, and encourages individuals to make explicit what is implicit. In this study, continuous reflection through journaling assisted in collating thoughts, feelings and inclinations that presented during the research process.

Sampling

The purposive sampling approach was used to recruit participants over six months in 2010-2011. Individuals were selected if they were: female, 22 to 30 years old, had a diagnosis of T1 diabetes for five or more years, not pregnant, and resided in southern Ontario, Canada. Non-pregnant women were selected because self-management is known to be more stringent during pregnancy, as evidenced by the tight glycemic control required to avoid potential complications to the mother and infant (CDA, 2013), and the researcher did not want this to interfere with understanding the day-to-day experiences of young women managing T1 diabetes. To recruit participants, study information was communicated to a southern Ontario diabetes clinic, University health clinic, a not-for-profit diabetes organization, as well as online networks. A total of nine participants who met the inclusion criteria were recruited in the study.

Ethical Considerations

Ethical approval was obtained from one university Human Research Ethics Board and one hospital research board. Participants provided informed written consent prior to the start of the first interview. Confidentiality and anonymity were maintained throughout. Pseudonyms selected by participants were used for tape recordings, data transcripts and all other research documents.

Data Collection and Analysis

Prior to beginning the first interview, participants completed a short information form that captured demographic information including age of diagnosis and current treatment regime. Interviews were digitally recorded and an interview guide (table 1) was used to extract participants' experiences. Each semi-structured interview lasted between forty and ninety minutes. No new themes emerged after the ninth interview, hence data saturation was presumably achieved.

Table 1. Sample Interview Guide Questions

- | |
|---|
| <ul style="list-style-type: none"> • When you hear the word self-management, what does this mean to you? • Describe what kinds of adjustments (if any) you had to make to your diabetic regime <i>before, during, or after</i> your menstrual cycle. • What are your thoughts on pregnancy, and how do they (if so) impact family planning for the future? |
|---|

The lived experience and meaning of phenomena was depicted through thematic analysis. Data analysis was conducted simultaneously with data collection and was an iterative process. To identify themes, the primary investigator read/listened to the transcripts and digital recordings in their entirety several times. The primary investigator manually transcribed the interviews after each interview, upon which the recordings were re-listened to in order to confirm the transcribed data, and any necessary revisions were made at this time.

The primary investigator and co-investigators collaboratively participated in data analysis. A highlighting approach was used to isolate thematic statements that were believed to be meaningful, and which reflected the self-management experiences unique to young women (van Manen, 1997). The task of accurately defining the themes was an iterative process comprised of immersing oneself in the data, and which involved considerable reflection and sustaining a strong and oriented relation to the self-management experience described by each participant, as well as the sample as a whole (van Manen, 1997). Descriptions that were believed to be meaningful were clustered into tables, upon which

“collaborative discussions” (van Manen, 1997, p. 100) with co-investigators took place to identify themes that characterized the data. The task of accurately describing participants’ self-management experiences was a lengthy and iterative process comprised of writing and re-writing, and regular consultations with co-investigators to ensure the descriptions were reflective of the data and one was not extending beyond data description.

Qualitative rigor for this study was primarily achieved through credibility and confirmability, as described by Lincoln & Guba (1985). A preliminary draft of the themes was shared with participants to review and determine whether the researcher had accurately described the self-management experiences, and if she did not, what was inaccurately described or interpreted, or what was missed. Four of nine participants provided feedback and indicated that the preliminary themes accurately reflected their experiences.

Findings

Demographics

The average age of the nine female participants was 26 years, with a range of 22 to 30 years-of-age. Two were currently enrolled in university programs, and the remaining participants worked as professionals. On average, type 1 diabetes was diagnosed at the age of 12 years, which coincides with the common childhood or adolescent onset of the disease (CDA, 2015). Participants had been living with the chronic condition for almost 14 years, which for some was nearly half of their lifetime. Two women were managing using MDIs and the remaining seven women managed their diabetes using an insulin pump. Three of the seven women admitted to utilizing CGM intermittently.

Themes

Thematic analysis revealed five themes and one essence of the self-management experiences (figure 1).

THEMES	
1)	Elusiveness of Control
2)	The Dualism of Technology
3)	Forecasting and Maintaining Routines
4)	Dealing with the “Ups and Downs”
5)	Interfacing with the Health Care Team
THE ESSENCE: “BEING IN BALANCE”	

Figure 1. List of Themes. Five themes and an “essence” emerged from thematic analysis.

Elusiveness of Control

Participants spoke about the “numbers” and how the number appearing on the blood glucose meter largely shaped their everyday lives. Self-management for everyone focused on the numerical number, which involved striving for stability in levels and staying within a target glycemic range, which was individualized and at times difficult to achieve. A good self-management day for the participants meant maintaining stable blood glucose levels through diet, exercise and appropriate insulin calculations, avoiding fluctuations and maintaining consistency through routines. Good control was reflected in an overall sense of well-being and feeling good. As Grace described:

I get really excited when my sensor [CGM sensor] has come in and it's sort of flat lined at 5.5 or something because 5.5 to me is the perfect blood sugar...It's a big deal if you can get it and keep it at that level for 24 hours and show that on your graph.

While a good day was described in relation to stable blood glucose levels, the ensuing effects of fluctuating blood glucose levels characterized a bad day.

The importance of maintaining good glycemic control was evident for all of the participants, yet at times was difficult to achieve or maintain. The fear of not achieving good control was reinforced by apprehension of long-term complications such as neuropathy, nephropathy and blindness, and at times influenced making future plans such as family planning. Participants were aware of the consequences of poor management, yet identified circumstances, some controllable and some not, which interfered with their ability to achieve or maintain optimal levels.

Adolescence and experiences in university had been challenging times for many of the participants. Erratic schedules, lack of routine, experimentation, resentment, neglect and new experiences were scenarios that presented obstacles and influenced some participants' willingness and commitment to self-management.

During umm school I would say I had not bad control, but it wasn't the greatest when I was in university and college. Umm cus because being away from home, and the stresses of school and everything, you know kind of put it on the backburner, instead of it being the first priority.... (Sarah)

Managing blood glucose levels during exercise was also a challenge. While the participants understood the importance of incorporating exercise into their lifestyles, scheduling it often proved difficult, as well as frustrating when managing the fluctuations in blood glucose levels at such times. Calculating insulin dosages and carbohydrate intake prior to physical activity was required. Participants described a process of "trial and error" calculations as a common strategy for figuring out appropriate insulin and carbohydrate intake during such times.

Exercise, insulin, eating, trying to figure that out; it's all over the board...I almost accept that my sugar's going to be high at the end of it [exercise] and I'll correct it and that to me is important that I work out for my heart... (Ruth)

At times, the commitment to daily blood glucose monitoring, insulin and carbohydrate calculations, and the interplay of trying to live a day-to-day life presented challenges for the young women to achieve or maintain optimal blood glucose levels. While all participants were well educated, and understood the disease process and regimes needed to achieve "good control," there were circumstances that sometimes got in the way, and prevented them from being able to live "by the book."

Forecasting and Maintaining Routines

Everyone spoke to the importance of routines in everyday self-management. For some, it was especially important that routines were incorporated into their daily lives. For others, lifestyles influenced which routines were established and maintained. Whether

managing by injections or insulin pump therapy, the women in this study established routines to help them stay in control.

Carbohydrate counting was a required, routine self-management activity for everyone. Those who managed using an insulin pump inputted the food's carbohydrate count into the pump and "let the pump do the work" for them, while others mentally calculated the appropriate insulin dosages. Routine blood glucose monitoring, accurate calculations of carbohydrates and insulin dosages, eating consistently and engaging in routine physical activity were activities participants tried to sustain.

I've always been pretty good about recording my sugars and making sure I always check before I work out and before meals...I've always checked my blood sugars four to five times a day, worked out how much insulin I should be taking...It's been a lot easier to manage my diabetes since finishing university, just because I have a consistent, daily routine. (Hayley)

Being able to anticipate, and plan for activities outside of the norm, or increases and decreases in activity level was important because variation affected blood glucose levels, and fluctuations were something participants tried to avoid. Being spontaneous was difficult and impractical. Planning meant negative episodes could possibly be avoided, and participants could have some control over their outcome. "Just in case" situations were always taken into consideration because the severity of potential consequences was too great. Participants knew what they "should" be doing to self-manage, but acknowledged it was not always possible or realistic. Individual goals, lifestyles, and to some extent their phase in adulthood, determined how self-management was approached. The "should" included routine blood glucose testing, accurately calculating carbohydrate and insulin dosages, eating healthy, exercising routinely, paying attention to internal body cues and making necessary adjustments during times of variability. Women strived to keep all of these elements intact, but it was not always easy to consistently follow set routines:

If somebody were to tell me this is exactly what you have to do to keep it [blood sugar] perfect, I almost feel like okay I will do that, unfortunately it's just not that type of disease. What I do today is going to be completely different from what I do tomorrow and the insulin I give myself today will react different than it does tomorrow... like it's so ever changing and volatile, it's what makes me crazy. (Ruth)

Additionally, some women spoke to the demands of their jobs, including shift work, which made it challenging to consistently sustain routine. Adjusting hourly basal rates, scheduling blood glucose testing and mealtimes, as well as the effect of changing sleep patterns on glycemia, were factors that were considered when planning for shift work. Inconsistent schedules did not always warrant desirable control. Planning ahead and maintaining routines were important strategies that the women tried to incorporate into their lives, and which to some extent helped them forecast and/or avoid negative events.

Dualism of Technology

Participants described the pros and cons of each of the insulin regimes. Insulin pump therapy was key in optimizing self-management for seven of the nine women, and enabled flexibility in daily living, as well as contributed to feelings of normalcy and of being liberated for some. It was important for these young women to be able to go about their daily lives and

to feel in control of diabetes. Participants were not restricted to one standard diet or schedule, and insulin dosages could easily be adjusted. Although routine was essential for most in facilitating self-management, not having to follow a set regime promoted flexibility in decision-making.

I find that with the insulin pump I have more freedom to eat on my own schedule, whereas with MDIs I had to worry about when my long acting insulin would peak and taking the fast acting insulin a half an hour before eating. I even remember planning my wedding dinner around these times.
(Carol)

Utilization of the various features of the insulin pump was individualized. Temporary basal rates were described as valuable for being able to optimize blood glucose levels. Temporary basal rates enabled participants to control for variation in activity levels and periods of instability such as during the menstrual cycle. Basal rates could be increased or decreased depending on need and preference. With guidance from the health care team, one participant implemented a temporary basal rate during the week she was menstruating. She wore a CGM sensor for two menstrual cycles, and was able to control for hyperglycemia in subsequent cycles. Preventing fluctuating blood glucose levels was essential and being able to set a temporary basal rate was one means to attain stability.

Participants managing with an insulin pump had a “bolus wizard” feature incorporated into their pump. This feature enabled the pump to calculate insulin dosages for meals based on individualized settings. Participants had individualized carbohydrate to insulin ratios, and insulin sensitivity factors to correct for hyperglycemia, which were programmed into their pumps. The participants described being able to input blood glucose levels into the pump, and accordingly the pump suggested an insulin dosage. Participants could accept the pump’s suggestion, or input their own desired dosage. Judgment and control were necessary in decision-making when women decided whether or not to override the pump’s suggestion. Older insulin pump models required some women to make mental calculations. Transitioning to a new system meant one needed to trust the pump, which was not always easy.

I’ll input a blood sugar, input any carbs if applicable and it [insulin pump] will give a suggestion. More often than not I’m going off that suggestion. When I first started, it was that trusting thing and I was overriding a lot...(Anna)

Technology also influenced structure and access to the health care team. Participants managing using an insulin pump could download information from the pump. Health care professionals used this information during routine appointments or email communication with the women. The information was evidence of what had transpired over the past few months and which meant there was no hiding from the numbers.

I download my pump data and my sensor data and email it to her [nurse] um as often as I do it. So I’m in contact with her via email at least twice a month, and if I have questions in between then I’m constantly in contact with her.
(Grace)

Participants also identified negative attributes of the pump including the feeling of being attached to a device, as well as not being able to easily conceal and integrate the pump into their wardrobes, which was frustrating for some.

It [pump] does help me to be in better control, but it's also a machine that's attached to you and as a girl actually that's a huge difference because it sucks. Where do you put it? It's in my bra most of the time on the side. It's very superficial, but dresses, where do you put it with dresses? (Ruth)

Insulin pump therapy and continuous glucose monitoring. For the seven participants managing using an insulin pump, three admitted to using CGM sometimes. The ability to continuously track glucose levels, and graphically display results was valuable in helping them to self-manage. A routine blood glucose result provided an instantaneous reflection of glycemia, but did not forecast objectively what would transpire over the next several hours, or during periods of instability.

I think having them [CGM] would improve my ability to self-manage and self-care a whole lot because I would be able to adaptive manage much better because at this point I'm guessing what happens between blood sugar tests. (Jocelyn)

To some extent, individual attitudes, goals and priorities determined the degree to which CGM was used. Some were learning how to balance the demands of work and school with diabetes, which inadvertently influenced the time they could devote to evaluating graphs and trends of their glucose levels. Commitment to self-management evolved over young adulthood and was particularly evident for those hoping to start families, making achieving and maintaining tight control that much more important.

I guess as you get older maybe, I don't know if it comes with age, acceptance, or maybe just in line with the other goals that you have in your life . . . the focus has come down to good management means good things for me in my life as a whole. (Grace)

Some women wanted to use CGM throughout any future pregnancy. Participants anticipated that being pregnant would be a stressful and challenging experience for them because of diabetes. Wearing the CGM sensor would give them confidence, and the reassurance that subtle internal changes were being adequately monitored, and could be detected sooner rather than later.

Having to already wear the standard subcutaneous infusion set, some did not desire to wear an additional apparatus, or to have something else attached to them. Additionally, due to financial cost, accessibility to CGM was a concern for some, and consequently prevented consistent utilization of the device.

Multiple daily injections. Insulin delivery by this mode presented more regimen and structure into participants' lives, which was not desirable for some. The two participants managing with injections, however, did not describe feeling restricted and felt their therapy was "quick and easy."

It's like a little checklist and you key in your management to it. You schedule it in, but it keeps me kind of in a routine, which in turn helps with my diabetes management. (Judy)

The underlying principles of carbohydrate counting and correction dosages for hyperglycemia were the same for both therapies. The substantial expressed difference was that insulin pump therapy offered more flexibility with day-to-day living.

Dealing with the “Ups and Downs”

While dealing with the “ups and downs” of daily living, participants also dealt with the fluctuations of their blood glucose levels. Fluctuations required relentless attention, and affected them physically and psychologically. Participants did not like how fluctuating blood sugar levels affected them, and bad days were typically comprised of fluctuations.

Low and high blood sugar levels. Most participants’ spoke about the negative effect low blood sugars (hypoglycemia) had on their lives. Dealing with hypoglycemic episodes was undesirable and inconvenient. The ensuing effects of hypoglycemia followed one participant into her day:

If I’ve been woken up with a low sugar...you’re just off for the day. You’re groggy. You’re tired. Your sugar is high and then you’re overcorrecting so you’re going low again and it’s really those days...you really feel like you’re diabetic. (Ruth)

Hypoglycemic reactions were something participants were forced to deal with, and anticipating hypoglycemia was a fearful experience. Participants dreaded hypoglycemic reactions; in particular, those who lived alone felt vulnerable, in part because there was no one to rely on at such times.

Similar to the work required to deal with hypoglycemic reactions, high blood sugar levels (hyperglycemia) entailed a process of needing to “figure it out.” Fear of complications resulting from hyperglycemia was expressed. The psychological effect of hyperglycemia was something participants had to deal with.

What I wouldn’t want from it [diabetes], well obviously the complications in the long-term the just not having to worry about that would be nice. (Hayley)

Concurrently, while committing to a daily diabetic regimen, individual mind-sets helped participants get through difficult times, including hyperglycemic episodes.

I do my best to control it so you just have to realize that it’s not going to be perfect. (Hayley)

Being proactive, and following individualized regimes did not always secure desirable blood sugar levels. Frustration dominated when they could not “crack the code.” Participants were realistic and accepted that perfection was not always attainable, and dealt with elements that were within their control.

Menstrual cycle. The effects of the menstrual cycle on glycemia, and the resultant self-management attitudes and health behaviors were explored among participants. Most participants admitted that their menstrual cycles affected them, both physiologically (fluctuations in blood sugar levels and insulin resistance) and psychologically (emotional effects commonly reported with menstruation). Fluctuations in blood glucose levels were the norm during specific times of the menstrual cycle. Most women experienced periods of hyperglycemia a few days before and during menstruation. Some also experienced insulin

resistance, whereby hyperglycemia was unchanged despite delivery of uncharacteristically large amounts of insulin.

I want to say it tracks to ovulation kind of early, mid cycle where my blood sugar's just high and it won't come down no matter what I do and I'm just like okay it will be 20...or if it comes down it's because I've pumped so much [insulin] into my body it just crashes. (Jocelyn)

Some women also experienced hypoglycemia.

I have gone low during that time too and it's a pretty weird extreme like I've been low to almost to the stage of passing out...that actually happened during my last cycle; I dropped down to like 2.9 and almost didn't have time to treat it. It was pretty intense. (Judy)

On any given day, a combination of factors could contribute to a flux in blood glucose levels. The connection to menstruation and its affect on blood glucose levels was not always made. When their bodies were “wreaking havoc,” elevated blood sugar levels were treated similar to other imbalances such as illness, stress or periods of physical activity. Strategies participants used during this time included adjusting hourly insulin pump basal rates, programming temporary insulin pump basal rates, treating hyperglycemia with correction doses of insulin, and/or testing blood glucose levels more frequently. The ensuing feelings from hyperglycemia were undesirable, but were accepted as short-term, and dealt with as they occurred. Hormones evidently caused “ups and downs” in blood sugar levels during the menstrual cycle, however, participants did not dwell on the outcomes, but rather made adjustments to their diabetic regimes to deal with this period of hormonal imbalance as best that they could.

Fluctuating weight. Some women shared their frustration and challenge of maintaining a healthy body weight. One participant admitted that both exercise and insulin pump therapy caused her weight to fluctuate. As an alternate strategy to accommodate for hypoglycemia, instead of consuming additional carbohydrates, she decreased her hourly basal rate prior to exercising.

It does kind of frustrate me just in terms of weight loss. It makes it a lot harder to lose weight and my weight does fluctuate a lot especially since switching to the pump on Humalog® [rapid-acting insulin], it's really sensitive. I do try and be conscious of how many grams of carbs [*sic*] I'm having in a day. (Hayley)

Similarly, another participant shared this frustration with weight fluctuation, and additionally, endured a significant period of rebellion in adolescence, intentionally withholding insulin to lose weight, which had negative repercussions to her diabetes management and overall wellbeing.

I went from three injections a day down to one injection a day and that one injection was probably about half of what it should have been; just enough to stop you from feeling like you wanted to throw up every two seconds but enough that the weight was coming off and then I did that for about six months and I got quite sick. (Grace)

A combination of insulin, exercise, self-image and attitudes influenced the “ups and downs” that some women faced with managing their weight.

Feelings and attitudes. Feelings and attitudes towards diabetes evolved over time as participants accepted and learned to live with their disease.

I think that it's [diabetes] changed my personality...and I've noticed it around me as well...it carries over, and again trying not to...um take on... poor feelings about yourself but at the same time taking on all the good feelings that come along...the independence...(Anna)

Participants worried about the future and sometimes attributed negative feelings towards the diabetes, including frustration, annoyance, stress, and the notion that diabetes was an added, constant burden.

Individual differences existed between participants, including age, relationship status, desire, and diabetic readiness in terms of achieving the recommended A1c. Only a few participants were ready and had the desire to start families, and they were working hard to achieve the target A1c level recommended prior to pregnancy. It was evident that the pressure of trying to achieve tight glycemic control affected them psychologically as they prepared for this new phase in their lives.

I think the stress just from fine-tuning your management and trying to really zone in to get your A1c down is stressful...I feel like I'm really making an effort and I'm working towards the 6's, but the harder I work the further it kind of gets away from me. (Grace)

The “ups and downs” of blood sugar numbers, hormones, weight, and emotions endured by participants were elements of their daily lives, which they were learning to deal with in order to live their lives. Individual mind-sets and strategies helped them get through difficult times, which were sometimes as a result of blood sugar levels.

Interfacing with the Health Care Team

Living with diabetes meant demonstrating a commitment to attending routine endocrinology appointments with a diabetes health care team was important. The extent of commitment, and attitudes toward the team varied and was influenced greatly by the nature of the patient/provider relationship.

Participants distinguished between their experiences in the pediatric and adult health care systems. Particularly, some participants spoke highly of their pediatric experiences, and appreciated the team approach that predominated during this phase of their development.

I really struggled with the difference [in adult care] because I had gone to the clinic [pediatric clinic] and with that sort of approach you spend a whole half-day there and you see everybody in one shot. You see your dietician; you see your endo [*sic*]; you see your nurse. Sometimes they would suggest you see a social worker as well to sort of hash out any problems you may or may not be having. (Abby)

These participants voiced experiencing a greater degree of attentiveness and monitoring from practitioners in various pediatric settings in comparison to adult healthcare practices.

It was difficult for some to adjust to the transition into adult care, a system characterized by new expectations, structures and processes. Moreover, finding a suitable endocrinologist in adult care often proved challenging. Routine adult care appointments were structured similarly for all, and the participants described similar distinctions between members of the health care team. Time spent with endocrinologists primarily focused on blood glucose and A1c values. In contrast, diabetes educators spent time communicating and personalizing appointments to meet individual needs and goals.

Varying experiences with health care teams existed. Not only did the roles of team members differ, participants generally perceived more positive experiences with diabetes educators in comparison to endocrinologists. Participants expected support and resourceful information from their health care team. Negative experiences ensued for some, as they often did not feel adequate support, in particular from endocrinologists.

You go and see an endocrinologist every six months. They know nothing about you. All they look at is your A1c. In their minds, why can't you get it to six? Why can't you get it to seven? Why are you always hovering at the eight mark? So you feel like, you feel like crap...They barely know your last name yet they're telling you to change everything you do. (Ruth)

Women had individual expectations and preferences, which were evidently not always acknowledged by the team. Diabetes was something that the participants were living with and learning to manage. They developed individual regimes that were working for them, and it was important for providers to acknowledge, and not dismiss elements of individuality, which they possessed and applied to their daily lives. A disconnect between patient/provider expectations was sometimes evident and influenced attitudes towards selected members of the health care team, and approach to self-management. Additionally, one participant pointed out the prevalence of T2 diabetes in adult care.

Unfortunately they're [health care team] really in tune with T2 diabetes and seem to have this disconnect when it comes to their T1 adult patients. They don't seem to understand why someone who's managing diabetes for the past [number] years would have any questions, and it's frustrating to say the least. (Grace)

Although the services of the health care team were routinely sought, managing diabetes was something the participants tried to do themselves. There was an agreement that individual responsibility and accountability were required for successful self-management, and there was also a shared feeling of not wanting to do it alone. A combination of individualized regimes, and support from loved ones and the health care team was essential for enabling optimal self-management health behaviors. Relationships with health care teams evolved over time, and as phases in adulthood and priorities changed, some participants relied more heavily than others on the health care team. A shared feeling of making diabetes a priority existed, and was reinforced by the long-term goals that the participants envisioned. Sometimes they had to "tighten the strings" on their management, including taking the responsibility to seek out and utilize the health care team more efficiently. For some, teams were more active in self-management, while other participants relied very much on themselves. Participants needed to trust the health care team and to be in balance with the domains of their lives; women needed to interface with the health care team.

The Essence: “Being in Balance”

“Being in balance” was the essence, of what was believed to embody the self-management experiences of the nine women living with T1 diabetes who participated in this study. The concept of self-management very much involved an interplay of multiple factors including commitment to the diabetes regime, individual strategies such as the maintenance of routines, attitudes and goals, involvement of the health care team and dealing with the “ups and downs.” Participants characterized the concept from similar standpoints. In particular, the concept of self-management centered on achieving and maintaining stability in blood sugar levels. Women were asked what self-management meant to them:

Self-management means keeping myself out of the hospital. It means just being healthy so I am able to live, to work, to do what I need to do to finish going to school...Keeping my blood sugars at a very stable range; keeping them hopefully lower...And just being able to control everything so I can live.
(Judy)

The goal of “being in balance” was not easily, or always attainable. Several factors influenced or hindered their ability to achieve balance. They did not have control over inevitable biological processes, the external environment or unexpected situations that confronted them. Individualized adaptations were adopted, which enabled them to live to the fullest in hope of diabetes not dominating their lives. Maintaining routines was important for achieving and sustaining “good control.” Some depended greatly on routine in their daily days, and others had difficulty establishing routines due to the demands of their lifestyles. It was difficult to be spontaneous, hence forecasting and planning were dominant self-management strategies.

Learning to deal with the consequences of the “ups and downs” of blood sugar levels, and the consequential influence on daily lives was part of the overall self-management experience. Individual glycemic goals existed, and women strived to stay in balance with their personal goals, as well as those set out by the health care team. Sometimes there was a disconnect between the patient/provider expectations, which the participants found frustrating. Overall, the onus of self-management lay with participants, and commitment to self-management determined the outcome of blood sugar levels. Women expected guidance and support from the health care team, yet understood that individual action and commitment to self-management dictated a future, where outcomes could not always be predicted.

Technology played a significant role in promoting and optimizing self-management. Insulin pump therapy offered flexibility, and helped some women to stay in balance. Seeing the numbers and trends from the insulin pump’s output also helped some participants optimize and evaluate success in self-management, and this required immense commitment.

Women knew what the “should” of their diabetes regimes entailed, but admitted it was not always feasible, or realistic to live strictly by the cards that they were dealt. Being a “good diabetic” meant abiding to individual regimes as best that they could, and sustaining positive mind-sets when goals were not reached.

...I’m not always the greatest diabetic and that’s fine, and kind of coming to terms with that and trying not to feel guilty all the time cus you can get trapped in those cycles... (Jocelyn)

Coming to terms with living with diabetes took time, and with maturity, the young women grew to accept the disease as a part of their lives. Self-management was something that

evolved over time, and something with which they were all still trying to grasp. To be in balance, women had to consider all realms of their everyday lives while concurrently managing the “ups and downs” of their blood sugar levels and associated symptoms. Perfecting self-management was not the ultimate goal, but rather, the goal was being able to live their lives in balance with diabetes. Ultimately, being in balance with oneself was equated to being in balance with the numbers.

Discussion

The experiences of living with type 1 diabetes have been extensively described in the qualitative literature, yet the meaning of self-management has not been previously explored from the perspective of the young adult female. Having a chronic disease requires commitment to self-management over time and the young women in this study expressed that this is not a linear process, but an iterative experience of highs and lows. The descriptions of self-management expressed by participants resulted in the emergence of five consistent and coherent themes. The theme, *elusiveness of control*, captures how participants tried to achieve and sustain stable blood sugar levels, but that often control was something that was hard to grasp and hold on to. A focus on the “numbers” was evident, and influenced daily outcomes and attitudes towards diabetes and self-management. Likewise, Rasmussen and colleagues (2007) identified the “basic social problem” (p. 301) in a grounded theory study for women living with T1 diabetes as “being in the grip of blood glucose levels” (p. 301). By explicitly exploring the meaning of self-management in the current study, participants very much defined self-management, not only in relation to their blood sugar levels, but how they needed to attain stability in the numbers so there was a translation into positive outcomes for daily living.

Successful self-management relies heavily on commitment to *forecasting and maintaining routines* such as daily blood glucose testing, A1c testing (every 3-6 months), routine meals, physical activity, appointments with the health care team and screening for potential complications (CDA, 2013). Although the participants in this study acknowledged the importance of sustaining these health behaviors and activities, the demands of everyday life, including school and work, sometimes interfered with their commitment. Rasmussen and colleagues (2007) corroborate this finding as they found transitions into the workplace characterized by fluctuating blood sugar levels for women with T1 diabetes. In the current study, the introduction of new and complex responsibilities in the workplace posed self-management challenges for some. In particular, ensuring routine blood sugar monitoring and consuming regular meals influenced whether one could achieve and sustain target blood sugar levels. Individuals living with chronic disease(s) must learn to deal with the social, emotional and economic consequences that they face (Holman & Lorig, 2004), which strengthens the notion that managing blood sugar levels is an elusive process, where multiple factors can enable and hinder individuals’ ability to stay in balance with the domains of their lives, including blood sugar levels.

Insulin pump therapy has evolved to become an essential self-management strategy for individuals living with T1 diabetes. Several advantages of this insulin delivery system exist and can include an increased sense of freedom, flexibility, convenience in day-to-day living, decreased hypoglycemic episodes, ease of dose adjustments and improved glycemic control (Chase, 2007b). There are also disadvantages to this therapy mode including financial cost, weight gain, risk of ketonuria or ketoacidosis (complications that can result from hyperglycemia), and the feeling of being attached to the pump (Chase, 2007b). Some women in this study confirmed that they experienced a feeling of attachment, as well as the challenge of integrating the pump into their wardrobe.

Participants who utilized CGM voiced advantages including the value and desire to wear the device during pregnancy. Undoubtedly, some believed that CGM could optimize their overall self-management during such a time when commitment to self-management is precedent, and disease process consequences, such as hypoglycemia may be more prevalent (de Valk & Visser, 2011). An A1c value of $\leq 7.0\%$ pre-conception and the following blood glucose values during pregnancy have been recommended: 5.3 mmol/L fasting plasma glucose; < 7.8 mmol/L one-hour postprandial; and, < 6.7 mmol/L two-hour postprandial (CDA, 2013). It is evident that tight glycemic control is important pre-conception and during pregnancy to avoid potential complications to the mother and infant (CDA, 2013). Participants' descriptions in the current study reinforced that the complexity and commitment to engage in self-management would be heightened during this time, and support from loved ones and the health care team would be critical.

While the participants' recollections of their self-management experiences included both the advantages and disadvantages of select disease management technologies in their everyday T1 diabetes self-management, it was also evident that not everyone was in a position to fully utilize all of the available features of the technology. In this regard, the qualitative reports in the current study are consistent with patient perceived ratings identified in previous quantitative work. In Rubin and Peyrot's (2009) study, merely 67% of individuals with T1 diabetes in the Real-Time CGM/CSII treatment group indicated utilizing the data management software, a similar finding to the current study where some participants reported not taking full advantage of an insulin pump self-management computer software. Moreover, identified as a valuable and essential self-management strategy, some participants expressed that the CGM sensors were not covered by their health insurance plans, which in turn creates a barrier for consistently utilizing the device.

Self-management descriptions among participants coalesced into the theme of *dealing with the "ups and downs"* of everyday life and blood sugar levels. The strain of managing hypo- and hyperglycemic reactions greatly affected participants, both physically and psychologically. In particular, the fear of developing complications as a result of diabetes was evident among all participants, and this finding is supported by previous research (Ingadottir & Halldorsdottir, 2008; Kay et al., 2009; Rasmussen et al., 2007). Participants acknowledged that the need to take responsibility for their health came at different points in time. For some, this recognition resulted from negative experiences, including purposefully withholding routine insulin dosages to maintain a desired body weight and image. This finding is confirmed in previous qualitative work exploring weight loss concerns/behaviors, and disordered eating among a group of young women and men with T1 diabetes (Balfe, 2013).

One aspect of forecasting in this study included assessing the effects of the menstrual cycle on glycemia. Participants shared how the menstrual cycle influenced their blood sugar levels and ensuing self-management regimes. Similar to this study, fluctuating blood sugar levels prior to (luteal phase) (Babata, Adan, Netto, & Ramalho, 2013), as well as during menstruation (Cawood, Bancroft, & Steel, 1993) have been previously reported in the literature. In the current study, specific self-management *strategies* participants applied when having to deal with the "ups and downs" of blood sugar levels during the menstrual cycle were described. In particular, the ability to program individualized temporary basal rates and utilizing CGM were described as valuable during such a time.

For most participants, the health care team played an important role in their overall self-management. Some participants during their adult care experiences, however, reported a paternalistic inclination, whereby their knowledge and expertise was not always recognized. The traditional compliance model approach to self-management where practitioners direct and inform the outcomes of patient care, disenfranchises individuals and does not promote feelings of self-efficacy in daily self-management (Thorne & Paterson, 2001), and such was

the case in some of the experiences of the participants in this study. The importance and need for collaborative relationships between patient and provider are reflected in national standards (CDA, 2013; Funnell et al., 2009). Such collaboration was not always reflected in the stories told by participants in this study as some expressed frustrating experiences with practitioners. Conflicting perspectives on educational needs and treatment goals characterized these relationships. A “*bad girl or good girl dichotomy*” (p. 304) was coined by Rasmussen et al. (2007) to describe feelings women possessed toward health care professionals. This dichotomy was visible in some of the stories of the current participants who felt that for the medical professionals, it seemed to be all about the numbers, which became reflective in the women’s overall sense of being.

As participants reflected upon their pediatric and adult health care experiences, clear differences, including introduction of challenges upon entry into the adult care system were obvious. Consistency in care, specifically finding a suitable endocrinologist in adult care was something several participants struggled with. Evidently this is not just a Canadian dilemma, as participants in another study were affected by the structure of Australia’s health care system, and described the system to be “. . . non-logical and resource consuming” (Rasmussen et al., 2001, p. 630). The process for accessing specialty services, including obtaining a referral to an endocrinologist, was complex (Rasmussen et al., 2001).

In contrast to pediatric care, where the patient population traditionally has been exclusively comprised of individuals with T1 diabetes, entry into adult care means a clinic setting that oversees care for a combination of individuals living with T1 and T2 diabetes. As voiced by participants in the current study, there are apparent differences between the two types of diabetes, yet at times misconceptions materialize, which consequently causes frustration among individuals (Rasmussen et al., 2007).

The desire individuals living with chronic disease have for “*being in balance*” is not an uncharacteristic expectation, and others have described the importance of attaining and sustaining this milestone (Ingadottir & Halldorsdottir, 2008; Paterson & Thorne, 2000; Paterson, Thorne, Crawford, & Tarko, 1999; Rosenbek Minet, Lønvgig, Henriksen, & Wagner, 2011). Paterson and colleagues (1999) described individuals’ experiences of living with T1 diabetes as “*transformational*,” whereby individuals constantly discovered and learned new capabilities about themselves, which inevitably influenced their outlook on the diabetes and self. Moreover, integration, whereby individuals are both physically and psychologically healthy, requires a combination of the diabetic and personal self, and is a process characterized by the need for acceptance, realization and ownership (Hernandez, 1996). Participants’ experiences in the current study were “*transformational*,” and their level of integration distinguished this. Being in balance required the ability to take ownership of the diabetes and self-management, and to maintain cohesion with other aspects of daily living. Self-management evolved and changed over time; comparable to Hernandez’ conceptualization of “*lifeways*” (p. 47), participants in this study relied on the interplay of multiple self-management health behaviors to help them achieve balance.

Although previous qualitative literature has conceptualized the importance and value of sustaining balance during the course of living with a chronic disease, it is important to recognize the significance of the current study’s findings, meaning and relation explicitly to the concept of *self-management*. Participants defined self-management in relation to their desire to achieve favourable blood glucose and A1c values. Participants’ aspirations, experiences and relationships with the health care team further contributed to the essence of self-management and its meaning. To be in balance with oneself meant one would concurrently be in balance with the blood sugar levels. Participants’ narratives confirmed the notion that individuals living with T1 diabetes are “*in the grip of blood sugar levels*” (Rasmussen et al., 2007, p. 303). The blood sugar levels resemble the building blocks of self-

management is equally notable, as the output on the glucometer may very well predict the cascade of activities that follow throughout the course of a day.

Study Limitations

The age range of the sample is fairly narrow; hence increasing the range to 35 years may have facilitated richer self-management descriptions, particularly from the perspective of more women in the family planning and/or motherhood phase of their lives. Moreover, the sample in this study is fairly homogeneous. For example, from a socioeconomic standpoint, women in the study were well educated, Caucasian, predominantly employed, and most were self-managing using an insulin pump. Management using an insulin pump requires access to a health care team and a financial commitment, which is not characteristic of all women living with T1 diabetes. Moreover, although it is not the intent of qualitative research to generalize findings, it should be noted that findings of this study may not be generalizable to women within the lower socioeconomic class, as their experiences may differ as a result of economic and social circumstances. A study of greater heterogeneity would be valuable to determine whether experiences of women across socioeconomic classes are comparable, or how they differ.

Nursing Research, Policy and Practice Implications

Findings from the current study reflect that technology has a substantial role to play in everyday T1 diabetes self-management. Additional quantitative research investigating the effectiveness of CGM for self-management, achieving and maintaining optimal blood sugar and A1c levels, and the quality of life of individuals with T1 diabetes would contribute to the diabetes literature.

In 2013, 548 billion in U.S. dollars was spent globally on diabetes expenses for individuals between 20 and 79 years (IDF, 2013). As technology continues to advance, the need for financial resources to sustain optimal T1 diabetes management health behaviors is likely to increase. The Ontario Ministry of Health and Long-Term Care (2012) Assistive Devices Program (ADP) is an example of one financial assistance program available in Canada to support children and adults with T1 diabetes managing with an insulin pump, and places a strong emphasis on self-management, a requirement to receive funding.

The long-term disposition of T1 diabetes reinforces the need for self-management programs and practitioners to focus care around the individual. While clinical parameters, including daily blood glucose and A1c values may be vital in identifying and assessing for potential complications, in the midst of everyday living and routine health care appointments, the elements of individuality affecting treatment preferences, goals, challenges, attitudes and lifestyles cannot be negated. In the context of the patient-provider relationship, individuals expect support beyond the numbers. Practitioners need to acknowledge diabetes self-management to be more than a prescriptive regimen and support the stance whereby the individual living with diabetes "...is indeed the most reliable and accurate source of information about his or her physiological function" (Thorne & Paterson, 2001, p. 87).

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Author Note

Sanja Visekruna, RN, MSc, is a doctoral student at the Lawrence S. Bloomberg Faculty of Nursing at the University of Toronto. She received Bachelor of Nursing Science and Master of Science (Nursing) degrees from Queen's University, Kingston, Ontario. Her nursing career has encompassed direct care roles in critical care, and pediatrics (type 1 diabetes self-management focus), as well as an indirect care role in nursing education policy. Sanja's research interests fall under the nursing health services research field, with a particular interest in the area of type 1 diabetes care. Correspondence regarding this article can be addressed directly to: Sanja Visekruna at, sanja.visekruna@mail.utoronto.ca.

Dana S. Edge, RN, PhD, is currently an Associate Professor in the Queen's University School of Nursing in Kingston, Ontario. Dr. Edge received her BSN from the University of Iowa, her MSN from the University of North Carolina at Chapel Hill, and her doctorate in epidemiology from the University of Toronto. Her research interests focus on the health of rural and remote populations, primary care, rural nursing and community resiliency. Correspondence regarding this article can also be addressed directly to: Dana S. Edge at, dana.edge@queensu.ca.

Lisa Keeping-Burke, RN, PhD, is an Associate Professor in the Department of Nursing & Health Sciences at the University of New Brunswick and an Adjunct Assistant Professor with Queen's University. She has Bachelor and Master of Nursing degrees from Memorial University of Newfoundland and a Doctorate of Philosophy in Nursing from McGill University. Her program of research includes the management of adult chronic diseases across institutional and community settings. Correspondence regarding this article can also be addressed directly to: Lisa Keeping-Burke at, lisa.keeping-burke@unb.ca.

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