Motivations for Insulin Misuse Among Women with Disordered Eating and Type 1 Diabetes

by

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ABSTRACT

MOTIVATIONS FOR INSULIN MISUSE AMONG WOMEN WITH DISORDERED EATING AND TYPE 1 DIABETES

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The present study assessed participants’ motivations for misusing insulin using phenomenological analysis and risk theory. Eleven women with type 1 diabetes were interviewed and asked to discuss body image, their experiences with adjusting to type 1 diabetes, and their particular insulin misuse behaviour. Nine women misused insulin for body image and weight concerns, as a result of diabetes burnout, or a combination of these factors. The majority of participants had poor body image at the time of insulin misuse, and reported feeling more confident following weight loss related to misusing insulin. The opinions of family, friends, and health care providers were, generally, not influential on the women’s self-care behaviour. The perceived benefits of insulin misuse (i.e. weight loss and improved body image) were deemed more important than both short-term and long-term health. Participants in this study did not consider themselves to be at risk of developing diabetes-related complications in the short-term, and this belief appeared to foster their continued insulin misuse. There is a need for health care providers to recognize the signs of insulin misuse behaviour and offer resources where available.
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1.0 Introduction

Insulin misuse has been a topic of interest for decades, and much research dates back to the 1980s. More recently, however, there has been a focus on insulin misuse as a function of disordered eating behaviours and clinical eating disorders. A trend of girls and women with disordered eating behaviours or eating disorders exhibiting higher frequency of insulin misuse for the purpose of weight control has been identified. The short- and long-term risks and consequences of poor metabolic control are abundant, and a better understanding of insulin misuse is required to reduce the prevalence of this behaviour. Notably, though, the majority of the literature is quantitative in nature and assesses the prevalence of insulin misuse among specific populations and frequency of this behaviour. Qualitative studies that seek to identify perceived reasons or motivations for such dangerous weight control strategies are few and far between.

1.1 Type 1 Diabetes

Type 1 diabetes is the autoimmune destruction of insulin-producing beta cells in the pancreas (Canadian Diabetes Association [CDA], 2013). Only a physician is qualified to diagnose an individual with diabetes. Of all patients diagnosed with diabetes, roughly 10% are diagnosed with type 1 diabetes and the remaining 90% are diagnosed with type 2 diabetes (CDA, 2013). Insulin therapy (in the form of a syringe, pen, or pump) is required for all patients with type 1 diabetes, whereas patients with type 2 diabetes can usually manage their disease with diet, exercise, and other lifestyle changes or medications before resorting to insulin therapy (CDA, 2013). While the cause of type 1 diabetes remains unknown and a cure does not
exist, there are ways to manage the disease. Individuals with this disease are required to carefully monitor their food intake and administer medicinal insulin to control their blood glucose levels throughout the day. Failure to control blood glucose negatively affects the function of major organs such as the brain, kidneys, and eyes, as well as neurological and psychological health (CDA, 2013). An indication of long-term blood glucose control is hemoglobin A1c (or HbA1c), and is commonly measured to assess one’s adherence to a diabetes care regimen over the previous 60-90 days (Howe, Jawad, Kelly, & Lipman, 2008). HbA1c is therefore relied on more often than single blood glucose measurements, which are only indicative of the prior several hours of glucose control.

1.2 Diabetes Burnout

Because type 1 diabetes is largely a self-managed disease, the demands of each patient to be aware of their blood glucose and how it is affected by diet, exercise, stress and illness can be overwhelming. The Joslin Diabetes Center (2013) describes diabetes burnout as someone growing tired of managing their disease and choosing to ignore their diabetes. Similarly, Snoek (2002) discusses the burden diabetes can have on a patient, and how cumulative negative experiences with insulin administration, fear of having low blood sugar and the stress of having the “full-time job” of diabetes management can easily lead to diabetes burnout. Burnout can last for any length of time until the patient commits to managing their diet, physical activity and insulin doses to best influence their blood sugar levels (Joslin Diabetes Center, 2013).
1.3 Insulin Misuse

Regular and appropriate administration of insulin is imperative for maintaining optimal blood glucose control and overall health. Daily injections, if not properly calculated, may lead to excess insulin (depending on that day's food intake) and subsequent hypoglycemia; to counter low blood sugar, eating additional calories is recommended (Colton, Olmsted, Daneman, Rydall, & Rodin, 2004). This cycle, however, can lead to weight gain. Misusing insulin is a weight control behaviour uniquely available to those with type 1 diabetes and can vary in terms of frequency and severity of misuse. Insulin omission involves the complete lack of insulin administration for the purpose of weight control and is the most severe type of insulin misuse behaviour (Polonsky et al., 1994). Insulin manipulation and under-dosage, similarly, involves administering less insulin than is required for the amount of food eaten, and this is often done as a means to control weight (Howe et al., 2008). Insulin misuse encompasses all of these characterizations and can range from skipping or lowering an insulin dose to omitting insulin completely.

Girls and women with type 1 diabetes may experience several lifestyle changes as a result of their diagnosis with diabetes, and these changes may be implicated in the development of disordered eating behaviours. Significant weight loss that occurs prior to the diagnosis of diabetes, as a result of insulin deficiency and dehydration, is often followed by a weight gain once insulin treatment begins (Starkey & Wade, 2010). This weight gain may result in increased levels of body dissatisfaction and negatively influence body image (Bryden et al., 1999). Furthermore, paying close attention to dietary intake and an emphasis on physical
activity, both of which are conducive to diabetes management, may foster a drive for thinness (Battaglia, Alemzadeh, Katte, Hall, & Permuter, 2006; Bryden et al., 1999). Unfortunately, with such weight fluctuations and the discovery that insulin misuse may influence glucose, and therefore calorie, uptake, unhealthy weight control strategies may emerge. In fact, one study identified that women with type 1 diabetes were at a 2.4 times higher risk of developing an eating disorder and 1.9 times more likely to develop disordered eating than women without type 1 diabetes (Jones, Lawson, Daneman, Olmsted, & Rodin, 2000).

Insulin misuse is often a result of a fear of weight gain associated with improved metabolic control (Polonsky et al., 1994). Poor metabolic control, however, has far greater consequences than weight gain; women who misuse their insulin are significantly more likely to experience diabetes-related complications, and at a much earlier age, and are estimated to have a threefold risk of dying of diabetes-related complications compared to women who do not misuse insulin (Goebel-Fabbri, 2008; Polonsky et al., 1994).

Decades of quantitative research reveal largely similar findings, yet none of this research uncovers personal accounts of why these women choose to misuse insulin as a weight control tactic. There is a lack of qualitative research that attempts to identify or understand the motivations for insulin misuse and the variables that influence someone with type 1 diabetes to engage in this behaviour. Ultimately, there is a large gap in the literature when considering insulin misuse among women with type 1 diabetes. This study was designed to address these gaps
in the literature and to better understand insulin misuse from the perspective of women who have experienced this phenomenon.
2.0 Literature Review

While insulin misuse has been widely studied, there is poor convergence of results. Inconsistent methodologies and definitions of insulin misuse behaviours, in addition to varying methods of diagnosing disordered eating for the purpose of research, prevent comparing and contrasting results of the research with ease.

Furthermore, researchers may face the challenge of inconsistent results among the same sample of participants. For example, in one study by Herpertz et al. (1998), 26 participants claimed to omit insulin and/or oral antidiabetic agents in a screening questionnaire and 27 participants reported omission during an interview. Interestingly, only 9 of these participants made the same statements in both procedures, indicating that participants may be hesitant to admit to behaviours that are not socially desirable. Another possibility is that participants’ perception of insulin misuse differs from that of the researchers and, as a result, participants may answer a question differently from one survey to another. Whatever the cause of such discrepancies, there remains much confusion in this area of research and, ultimately, this may account for some divergence of the prevalence of insulin misuse in this population.

The existing body of research can largely be divided into three categories of women admitting to insulin misuse behaviour: women with anorexia nervosa, women with bulimia nervosa, and women with disordered eating. Because the prevalence of insulin misuse varies widely among these three categories, they will be reviewed and discussed separately.
2.1 Eating Disorders and Insulin Misuse

Diagnosis of an eating disorder comes from the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) or DSM-III-Revised criteria, wherein a woman answers positively to each of the criteria related to anorexia nervosa or bulimia nervosa behaviour and admits to engaging in all of the behaviours described. If each criterion is not met, patients may be considered to have a subclinical eating disorder (Central Region Eating Disorders Service, 2007).

Women with clinical eating disorders misuse insulin to a greater extent than do women with subclinical eating disorders, or disordered eating, for the purpose of weight control (Affenito, Rodriguez, Backstrand, Welch, & Adams, 1998). Interestingly, these eating disordered women were found to be less educated, hold less professional jobs, and were less likely to be married compared with women with type 1 diabetes who did not have eating disorders (Affenito et al., 1997). Finally, women with eating disorders reported a greater range of insulin doses per day than women without eating disorders, suggesting that eating disordered women were less methodological in administering their insulin; this would contribute to the significantly higher HbA1c values observed in the Affenito et al. (1998) study.

2.2 Anorexia Nervosa and Insulin Misuse

Anorexia nervosa is an eating disorder wherein persons have an intense fear of weight gain and employ strategies such as fasting, purging, laxative use, and excessive exercise to lose weight (PubMed Health, 2012a). Persons with anorexia become obsessed with food intake and achieving a negative energy balance, which ultimately results in weight loss. While the exact cause is not known, this
multifactorial psychiatric condition can result in cognitive decline, muscle and fat wasting, a decline in heart, kidney, and liver function, and ultimately death (PubMed Health, 2012a).

Concurrent anorexia nervosa and insulin misuse in type 1 diabetes is rare but extremely dangerous. There have been conflicting reports suggesting that either anorexia nervosa or a diagnosis with type 1 diabetes and consequent insulin misuse preceded the other, or that anorexia and insulin misuse occurred simultaneously, or that anorexia or insulin misuse caused the other (Herpertz et al., 1998; Ward, Troop, Cachia, Watkins, & Treasure, 1995). Arguments can be made for each of these perspectives; however, there is no conclusive evidence of one perspective or the other.

Whether a diagnosis of diabetes or anorexia preceded the other, the risks for each condition are formidable; some risks exist in both conditions, such as declining kidney function and cognitive decline. Conceivably, the risk of experiencing these complications, and certainly deteriorating metabolic control, is exacerbated when both conditions occur simultaneously (Jones et al., 2000). The reported prevalence of these co-morbid conditions is variable but has been estimated to be between 1% (Rodin & Daneman, 1991) and 4.4% (Affenito et al., 1998). Interestingly, both studies characterized women as having anorexia based on the DSM-III-R or DSM-IV criteria. This methodological consistency is not often seen in this area of research, and should be acknowledged.

Unfortunately, in one of the few studies involving women with anorexia with type 1 diabetes, analysis of the anthropometric measurements and body
composition data excluded these women because their body composition measurements would have been significantly lower than all other groups simply by a diagnosis of anorexia (Affenito et al., 1998). Limitations in the literature such as this restrict our understanding of the severity of physiological damage as a result of concurrent anorexia and insulin misuse in type 1 diabetes.

Rodin and Daneman (1991) identified only one participant, or 1% of their sample, as having anorexia according to the DSM-III criteria; however, when using the DSM-III-R criteria this participant was no longer diagnosable because menses was not absent. Rodin and Daneman continue to alternate between discussing results according to DSM-III and DSM-III-R diagnoses of all participants, furthering the incompatible and confusing results often seen in insulin misuse and eating disorder literature.

Herpertz et al. (1998) reported a 2.4% prevalence of concurrent anorexia nervosa and type 1 diabetes. Unfortunately, this statistic is the only one that isolated anorexia from the other eating disorders in their research, and so other data related to these women, including demographic information and frequency of insulin omission, are not available. For the remainder of the results and discussion, anorexia, bulimia, binge eating disorder, and eating disorder not otherwise specified were discussed as a whole entity, which is another limitation of the literature available in the area of type 1 diabetes and anorexia.

Few, if any, conclusions can be drawn from this information. It is evident that concurrent anorexia and type 1 diabetes is rare, however specific details related to insulin misuse or health complications are not known. Perhaps it is because the
concurrency of these two conditions is so rare that a larger body of literature is not available. Concurrent bulimia nervosa and type 1 diabetes, however, is slightly more common and is more widely studied.

2.3 Bulimia Nervosa and Insulin Misuse

Bulimia nervosa is an eating disorder characterized by overeating or binging on high-calorie foods, feeling a loss of control, and subsequently purging in an effort to prevent weight gain. Purging most often includes vomiting, laxative use, or excessive exercise (PubMed Health, 2012b). Complications can include dehydration, electrolyte imbalances, and pancreatitis, as well as cosmetic disturbances such as scarring on knuckles or damaged enamel on the teeth from forcing oneself to vomit (PubMed Health, 2012b). Individuals with type 1 diabetes, though, may also restrict or omit their insulin dose as a unique method of purging unwanted calories. As was mentioned in relation to women with concurrent anorexia and type 1 diabetes, the risk of experiencing complications associated with bulimia nervosa or type 1 diabetes is exacerbated when both conditions occur simultaneously.

Concurrent bulimia nervosa and type 1 diabetes with insulin misuse is more common than concurrent anorexia nervosa and type 1 diabetes with insulin misuse, however the presence of these comorbidities is still quite rare. The reported prevalence of these concurrent comorbidities ranges from 1% (Jones et al., 2000) to 11.5% (Grylli, Haferl-Gattermayer, Wagner, Schober, & Karwautz, 2005) or 12% (Rodin & Daneman, 1991). Notably, though, while Jones et al. (2000) reported only 1% of their sample as being women with diabetes and bulimia who misused insulin,
this proportion was significantly higher than observed bulimia among matched non-diabetic controls.

Unfortunately, there are some challenges when interpreting some of the literature in this area. Rodin and Daneman’s (1991) estimates of co-existing bulimia nervosa and type 1 diabetes were 12% according to the DSM-III criteria and only 5% according to the DSM-III-R criteria. Powers, Malone, Coover, & Schulman (1990) experienced similar reductions in prevalence when characterizing women as having an eating disorder according to the DSM-III and then, subsequently, the more stringent DSM-III-R criteria. The prevalence of bulimia in their sample dropped from 4.3% to 2.2% upon using the more stringent diagnostic tool, although Powers et al. continue to discuss both prevalence estimates. This mixed characterization of eating disorders according to older and newer tools is a limitation of the small body of research available in this area, and further studies should be conducted using only one diagnostic tool.

Another limitation to research on bulimia nervosa and type 1 diabetes is the pooling of subgroups for ease of discussion. Herpertz et al. (1998) reported 4.4% of their sample of those with type 1 diabetes had bulimia at some point in time; however, this statistic includes both males and females. Pooling subsamples of girls with eating disorders and girls with disordered eating is also common, and this, too, restricts the value of the research because proportions of each subsample remain unknown (Affenito et al., 1998). Jones et al. (2000) pooled results of all participants with any eating disorder for analysis and discussion, preventing readers from understanding unique traits of those with anorexia and bulimia.
2.4 Disordered Eating and Insulin Misuse

Disordered eating may include a wide variety of unhealthful behaviours characteristic of anorexia or bulimia, however they are not present in the same severity as an eating disorder. These unhealthful behaviours often include fasting and purging, as discussed previously. Furthermore, as with patients with anorexia or bulimia who use purging as a weight control tactic, individuals with type 1 diabetes may misuse their insulin as a unique purging tactic to induce glycosuria. Estimates range from 2%-79% of women with type 1 diabetes misuse their insulin for the purpose of weight control (Affenito et al., 1997; Biggs, Basco, Patterson, & Raskin, 1994; Bryden et al., 1999; Colton, Olmsted, Daneman, Rydall, & Rodin, 2004). The prevalence of this behaviour among women with disordered eating is similar to the prevalence observed among women with clinical eating disorders, suggesting that insulin misuse behaviour is common among clinical and subclinical populations alike. For example, while only 1% of Jones et al. (2000) sample had bulimia and there were no women with anorexia, 11% of the women reported misusing insulin for weight loss. Treatment or attention paid to women with clinical eating disorders should not be markedly different from women with disordered eating behaviours, as it is evident that dangerous insulin misuse can affect both populations equally.

It is important to note that the disordered eating behaviour literature discussed below involves women who misuse insulin in the forms of under-dosing (i.e., reducing prescribed amounts of insulin), or omitting insulin doses entirely. These categories are pooled in the interest of organization and conciseness.
Furthermore, several articles have been excluded from this discussion because the authors pooled women with eating disorders and women with disordered eating together during analysis, rendering it impossible to distinguish which characteristics are unique to those women with disordered eating.

Insulin misuse is observed among a greater number of girls and women with type 1 diabetes and disordered eating than is seen among similar populations of women with anorexia or bulimia. Interestingly, there is evidence to suggest that rates of insulin misuse appear to increase as adolescents age, and peaks during late adolescence and early adulthood (i.e. 15-30 years of age) (Polonsky et al., 1994). This is of particular concern because insulin misuse behaviours may continue for many years, increasing the risk of developing diabetes-related complications.

Women with disordered eating have been found to have greater weight preoccupations, neurotic perfectionism (they never feel that they have done their job well enough; they are very intolerant of mistakes and extremely self-critical), and socially prescribed perfectionism (believing that others will value you only if you are perfect) (Pollock-Bar’Ziv & Davis, 2005). Such characteristics likely contribute to a desire for a perfect figure and these women are critical of perceived body flaws. Women who misuse insulin have also been found to have poorer attitudes towards their diabetes (Biggs et al., 1994) and deliberately manipulate their diabetes care regimen (Polonsky et al., 1994). In a study by Polonsky et al. (1994), insulin misusers purposefully reduced their insulin to control their weight and subsequently avoided testing their blood glucose to ignore necessary insulin adjustments. This trend of avoiding blood glucose measurements has also been
observed by Affenito et al. (1997), suggesting that perhaps “ignorance is bliss” for this population. Blood glucose levels quickly become elevated under these conditions, as has been identified consistently by various researchers. Women who misuse insulin have significantly higher HbAlc values compared to women who do not misuse insulin (Affenito et al., 1997; Biggs et al., 1994), pointing to a destructive cycle that can lead to dangerous health outcomes.

There has been a great deal of research in the area of diabetes-related complications among this population of insulin misusers. Complications that ordinarily develop over the long-term have emerged among younger and younger population groups when insulin misuse is present. Neuropathies (nervous system problems), nephropathies (kidney problems), and related hospitalizations are significantly more common among insulin misusers compared to women who do not misuse insulin (Affenito et al., 1997; Polonsky et al., 1994). Further, retinopathies (eye problems) are present significantly more often among this group (Affenito et al., 1997; Polonsky et al., 1994; Rydall & Daneman, 1997). Rydall and Daneman (1997) explored the relationship of disordered eating among women with type 1 diabetes and presence of retinopathies in more depth. They divided their sample into women with highly disordered eating, moderately disordered eating, and non-disordered eating and followed up with participants after 5 years. They discovered that 86% of women with highly disordered eating had developed a retinopathy, compared to 43% of women with moderately disordered eating and 24% of women with non-disordered eating; these results are highly significant (Rydall & Daneman, 1997). The relationship between poor glycemic control and
development of diabetes-related complications is clear, however a high prevalence of girls and women choose to risk their health in spite of this. Insulin misuse has been found to be the first (Rydall & Daneman, 1997) or second (Jones et al., 2000) method employed to induce weight loss among this population.

Fear of weight gain has been identified as a reason for insulin misuse by Biggs et al. (1994) and Polonsky et al. (1994), as has the perception that regular insulin injections would lead to feeling bloated (Polonsky et al., 2004). This preoccupation with body size and weight has also been observed in samples of women with type 1 diabetes studied by Pollock-BarZiv and Davis (2005), suggesting that poor body image contributes to insulin misuse behaviour.

2.5 Body Image and Disordered Eating

Many researchers have examined the impact of poor body image on girls and women, and the potential risks to healthy eating behaviours as a result. Several sources for developing poor body image have been identified, including thin ideals in the media, peer groups, and society as a whole. Objectification from more and more people as a girl or woman ages can lead to the internalization of societal expectations of women’s bodies (or self-objectification) which ultimately can lead to a variety of health risks (Slater & Tiggemann, 2010). Slater and Tiggemann found that body surveillance (or always monitoring one’s appearance), body shame, appearance anxiety, and disordered eating were all significantly related to self-objectification, and furthermore, were more salient in middle adolescence. In a separate study by Tiggemann (2001), adolescents were found to rank physical attractiveness as one of their most important life concerns, preceded only by
academic success and intelligence. An emphasis on slimness was most strongly linked to body dissatisfaction, disordered eating, and self-esteem (Tiggemann, 2001). Popularity with girls was also predictive of body dissatisfaction and disordered eating in this particular sample. It is evident that being slim and attractive is a large concern for young girls, and both peer groups and exposure to thin ideals in the media may foster this concern. Because there is little research in the area, it remains unclear whether girls and women with type 1 diabetes have vastly different body image perceptions and disordered eating behaviours from control populations.

2.6 Insulin Misuse, Body Image, and Disordered Eating

As Slater and Tiggemann (2010) identified, disordered eating, body surveillance, and appearance anxiety become more prominent after age 13. Diagnosis of type 1 diabetes often occurs during childhood and adolescence (CDA, 2013), and as discussed previously, weight gain often occurs upon commencement of insulin therapy. With increasing body surveillance and appearance anxiety, experiencing weight gain at this time in development is understandably viewed as undesirable. Furthermore, following a diagnosis of diabetes, patients are told to meticulously track their food intake so that proper insulin dosage can be administered. Such focus on food intake and insulin administration, alongside weight gain and poor body image, eliminates the luxury of enjoying certain foods and can easily develop into disordered eating.

Meltzer et al. (2001) identified that adolescent girls aged 13 and 14 years with type 1 diabetes were at the greatest risk of developing disordered eating,
which is in line with Slater and Tiggemann’s (2010) findings mentioned above. Colton et al. (2004) also studied girls in this age range and reported a mere 2% of adolescent girls with type 1 diabetes admitted to insulin misuse. However, the researcher believes this number is not representative of the population because many adolescents who refused to participate in the study had elevated HbA1c values, which may have been an indication of insulin misuse. Evidently, this is a time when young girls are susceptible to developing unhealthy eating behaviours.

Higher BMI has been suggested to be significantly associated with the presence of bulimia (Grylli et al., 2005) and increased body dissatisfaction (Meltzer et al., 2001). Meltzer et al. (2001) also suggested that bulimia symptoms were associated with being older, although her sample of adolescents did not exceed 19 years of age. Poor glycemic control, which has consistently been linked to insulin misuse, is also associated with higher scores on bulimia scales and obesity (Meltzer et al., 2001). Similar findings in a study on weight gain among those with type 1 diabetes also discovered significantly higher HbA1c values among overweight 20-year-old women (Holl, Grabert, Sorgo, Heinze, & Debatin 1988), suggesting that overweight and obesity may be related to poor glycemic control and insulin misuse.

It is not apparent whether the participants in these studies experienced weight gain upon diagnosis with type 1 diabetes and thus have a higher BMI, however this information lends credit to the idea that girls and women with type 1 diabetes and troubled body image may be at higher risk of developing disordered eating and, specifically, insulin misuse behaviours.
2.7 Perception of Risk

Risk perception, or intuitive risk judgment, varies between health care professionals and patients (Slovik, 1987). An expert in health care relies on expected mortality rates associated with a particular event or behaviour, whereas a patient’s perception of risk is influenced by a wide range of variables (Kasperson et al., 1988, Slovik, 1987). When a behaviour is voluntary and familiar, such as with insulin misuse, the patient believes he or she has control over the behaviour. This perception of control over the behaviour, and thus the perceived benefit of the risky behaviour, increase risk acceptance a patient may have; ultimately, the level of “dread risk” is low, meaning that a patient does not interpret the risk as being a threat to safety (Slovik, 1987). Additionally, the level of knowledge a patient has regarding a particular risk or behaviour influences that person’s risk perception (Slovik, 1987).

2.8 Limitations

The ages of the girls and women featured in the literature range from 9 to 60 years, which fails to adequately highlight specific challenges unique to women with type 1 diabetes in each life stage group: children, adolescents, young adults, and adults. Furthermore, many studies pooled subsamples of participants (those with disordered eating, those with an eating disorder, and both males and females) in order to effectively analyze their data; however, this limits our understanding of each subsample. This begs the question: are women with eating disorders and women with disordered eating vastly different when it comes to insulin misuse
behaviour? Perhaps there is no significant difference among these groups, and a focus on why insulin misuse appears to be widely used is the important question. To our knowledge, however, this type of research does not exist.

The quantitative research to date focuses largely on the behaviour of insulin misuse and outcomes of long-term insulin misuse. For the purpose of this study, however, the interest lies in the thought process behind insulin misuse rather than the behaviour itself. Studies reporting the triggers for insulin misuse, precipitating factors such as reduced energy levels, and perceived health risks or perceptions of invincibility (not thinking the dangerous health consequences would happen to them) are not available. Such information, however, would be enlightening and provide health care professionals with an idea of how to customize treatment for these women.

Although there are conflicting reports of insulin misuse in the literature, it can be argued that anyone who misuses insulin for the purpose of controlling their weight has some degree of disordered eating. The role of body image is rarely studied in the context of insulin misuse among a population of those with type 1 diabetes, yet it may be a very important angle to consider. Because of the methodological inconsistencies related to operationalizing disordered eating and insulin misuse found in the literature, the behaviour remains largely enigmatic. Using body image as a “leveler” of sorts, rather than focusing on a woman’s diagnosis of an eating disorder or labeling their disordered eating, may enable researchers to learn more about insulin misuse behaviour as it applies to the whole type 1 diabetes population. It is believed that most woman experience weight
anxiety or body anxiety to some degree, which often stems from social norms, and these body image issues need to be explored more deeply in order to understand insulin misuse behaviour.

Finally, as was identified in the literature, insulin misuse is one of the top weight loss techniques used by girls and women with type 1 diabetes. Studies that reported this finding, however, did not discuss why this behaviour is so widely used. When compared to other disordered eating behaviours, such as dieting, purging, or over-exercising, insulin misuse may appear to be the easiest and least visible to others. Administering insulin is largely a private task and skipping or reducing insulin doses would not elicit unwanted attention from friends or family members. Purging, dieting or skipping meals, and over-exercising may all be more noticeable to a woman’s family or social group and could result in these people voicing concerns or monitoring their eating behaviours. So, is insulin misuse widely used because it is the least visible way to control body weight, or is because this behaviour does not require great will power or exertion? These important questions are not yet addressed in the literature.

In light of these limitations, the present exploratory study was proposed. The present study aimed to uncover women’s motivations behind engaging in risky weight control behaviours, specifically insulin misuse in type 1 diabetes. Exploratory, qualitative research can better reveal the thought process, justification for insulin misuse, triggers for misusing insulin, and the risk assessment related to this behaviour. Furthermore, it was hoped that interviews with the participants would allow the researcher to discuss relevant issues in greater detail, probe for
more information, and access information that may not otherwise be observed in quantitative research such as surveys.
3.0 Research Questions

The major research question and related minor research questions guiding this study are:

1. What are the motivations for insulin misuse among women with type 1 diabetes?
   a. Does body image influence the misuse of insulin among women with type 1 diabetes?;
   b. Who influences women to use or misuse insulin?
   c. What analysis of risk, if any, occurs prior to misusing insulin?; and
   d. How do these risks compare to the foreseen benefits of misusing insulin?
4.0 Methods

4.1 Philosophical Underpinnings

For the purpose of exploring the essence and core aspects of the lived experiences of women who misuse their insulin for the purpose of weight control, phenomenological analysis (Starks & Trinidad, 2007) was used. Phenomenological analysis involves thick description of lived experiences and contributes a deeper meaning to the text that is being analyzed (Starks & Trinidad, 2007) than other methodologies provide. For the present study women’s perceptions were examined using an empirical phenomenological approach. Empirical phenomenology emphasizes the essences of the lived experience and relies on the language employed by the participants (Hein & Austin, 2001), thereby maintaining rigor throughout the analysis process. Finally, the researcher remained detached from the participants throughout the analysis process, which was conducive to describing the meaning in the experiences rather than imparting her own interpretation of the meaning (Hein & Austin, 2001).

4.2 Research Methods

Qualitative research methods were used for this study, as the aim was to better understand the lived experience of insulin misuse among women with type 1 diabetes. The questions that were asked of the women during the interviews (see interview guide, Appendix A) were in relation to the experiences of misusing insulin for the purpose of weight control, and how body image might have influenced their decision to use this behaviour. Each interview presented opportunities to expand on particular interview questions or topics of interest, and participants often offered
information that had not been asked of them. At times, this extraneous information was valuable in understanding the participant’s experience during childhood and adolescence, and how their diagnosis with type 1 diabetes influenced their experiences. The interviews were taken in a direction that the participants felt most comfortable with, however the interview guide was followed to ensure that all pertinent questions are asked.

4.3 Sample and Recruitment

Cross-sectional convenience sampling was used to attain the desired sample size, in addition to snowball sampling and word-of-mouth. Snowball sampling, which refers to women who had already been recruited and interviewed extending an invitation to their peers who may also fit the criteria for this study, was relied on for the recruitment of several participants. Using these sampling methods resulted in the recruitment of 11 participants.

4.4 Recruitment

Creswell has suggested that an ideal sample size for a phenomenological study is 10 participants, which is in line with the present goal of a proposed sample size of 10-15 women. Participants were recruited from the University of Guelph campus, the McMaster diabetes clinic, Homewood Health Centre, Women’s College Hospital, Sunnybrook Health Sciences Centre, and through a number of health professionals in the Guelph, Hamilton, and Niagara regions. Each of these hospitals and clinics posted one or both of the recruitment advertisements in an area that was seen by a high volume of persons with type 1 diabetes. Several posters were left with members of the health care team and they shared information with select
patients who fit the inclusion criteria. Additionally, an ad was posted on the Kijiji website seeking volunteers for the present study.

Potential participants contacted the researcher via an email address provided on the recruitment poster. This email account was created for the sole purpose of communicating with potential research participants. Women who responded to the recruitment ads were asked several screening questions:

1. Do you have type 1 diabetes?
2. Do you ever adjust your insulin doses?
   a. For what reasons do you adjust your insulin?
   b. Have you ever adjusted your insulin dose as a result of weight-related or body image concerns?
3. If yes to 2.b., are you comfortable talking openly about this behaviour with a researcher?
4. Are you willing to be interviewed at the University of Guelph (or in Hamilton) in a private conference room?

4.5 Participant Eligibility Criteria

Participant eligibility criteria included the following:

a) Participants had to be female.

b) Participants must have been between the ages of 18-35 years. As Polonsky et al. (1994) suggested, the peak of insulin misuse behaviour occurs between the ages of 15 and 30. The original age range of eligible participants was 18-30 in an attempt to capture the majority of this
critical time period in a women’s life, however this was expanded to include women up to age 35.

c) Participants must have been able to communicate fluently in English.

d) Participants must have admitted to misusing their insulin (ranging from under dosing to complete omission) for the purpose of controlling their weight or addressing body image concerns. It was thought that women who admit to this behaviour via email would be also able to speak about it in person.

e) Participants must have been comfortable sharing details of their insulin misuse behaviour and their experiences with struggling to cope with their type 1 diabetes diagnosis and lifestyle.

The age range of participants, as previously mentioned, was expanded to include women ages 18-35 in December of 2012. After consulting with members of the research committee, it was decided that the age range 18-30 may have been too narrow in order to reach the target sample size.

The recruitment phase for this research lasted from September 1, 2012 until March 31, 2013.

4.6 Study Design – One-on-One Interviews

Prior to scheduling interviews with the participants, the researcher pilot-tested the interview questions with a woman diagnosed with type 1 diabetes but who did not misuse her insulin. It was thought that this woman could relate to the struggles of coping with the disease and managing her weight while maintaining healthy blood sugars. This pilot interview gave the researcher an opportunity to see
how participants may respond to the interview questions, and identify which
questions may be misinterpreted or misunderstood. Potential problems, and
suggestions for potential questions that may yield helpful results, were also
highlighted before conducting the interview with participants. Using this interview
as a guide, the researcher edited the phrasing of several questions and was keen to
pick up on areas of the interview where participants may need additional
explanations to properly answer the question.

Once the interview questions had been finalized, the researcher began
interviewing participants who met the inclusion criteria. She asked the participants
the questions from the interview guide, and each woman was encouraged to only
share information she is comfortable with disclosing. The interviews took place in a
private, quiet room at either the University of Guelph, McMaster University, or a
private room at the Pickering library. One-on-one confidential interviews in private
locations prevented judgment and interjections from bystanders, and because of the
minimal background noise, improved the quality of the audio recording.

Individual interview times were scheduled to best accommodate each of the
women participating to allow for open and honest discussion. Prior to initiating
each interview, the researcher described the proposed study, informed participants
of the potential risks, and asked the women to read the Letter of Information
(Appendix B) and sign the consent form (Appendix D). The participants were given
the Letter of Information for their records, and the researcher kept the signed
consent forms.
The interviews were anticipated to last 45 minutes to one hour, however the actual duration ranged from 35-80 minutes.

4.7 Interviews and Procedure

The researcher met with the participants at the designated interview location. A small, inconspicuous digital voice recorder was placed on the table to record the interviews for use in the subsequent transcription. The finalized interview questions were asked of the women in a conversational fashion. In order to maintain a casual atmosphere, the researcher probed the participants and asked the participants to elaborate on vague answers, and at times shared relevant information that previous participants had reported. When issues or topics arose that had not been previously considered to be significant to the study, the researcher probed further for supporting information. Additionally, these topics were broached with subsequent participants in order to gain a deeper understanding of the issue and the prevalence of particular experiences of behaviours.

Following the interviews, each participant was thanked for her time and contribution to this research, and she was given the Shoppers Drug Mart or President’s Choice gift card worth $35.

4.8 Data Management

For confidentiality purposes, each participant was given an identification number which was recorded on a master list. This list was the only location that matched participant’s names with their identification number. During interview
transcription, the researcher replaced the participant’s names, if necessary, with their identification number.

All electronic files were encrypted using the Win Majic software program to protect participant’s information.

4.9 Data Analysis

The researcher transcribed verbatim the interviews shortly after each interview was conducted, and when scheduling permitted, did so prior to conducting further interviews. The interview transcripts were used in the subsequent analysis. Constant comparative method (reference) was employed throughout the interviewing and analysis processes to continuously consider commonalities and potential themes arising.

MAXQDA11 (VERBI GmbH, 2013), a widely used qualitative analysis program, was used to organize coded meaning units identified in the interview transcripts. Small meaning units, which are words or short phrases, were selected from the interview transcripts and used to form small themes representative of the women's experiences. These small themes ultimately were clustered according to subject matter to construct larger, global themes representative of the lived experiences of women struggling with insulin misuse.

The researcher collaborated with a second coder, who analyzed seven of the nine interview transcripts independently, to ensure that they were analyzed consistently. There was a great deal of overlap between the two coders, and any minor discrepancies were resolved prior to further analysis. Discrepancies occurred in only two areas: the phrasing of a theme title to best represent the data, and
efficiently collapsing subthemes together to form more comprehensive subthemes or contribute to an already existing global theme. There were no discrepancies with interpretation of the data or categorizing participants based on their self-reported motivations for insulin misuse.

Risk theory was the background used to assess information obtained from the participants. As discussed previously, variables such as voluntariness, control, familiarity, and level of knowledge are thought to be influential in risk perception and the decision to engage in risky behaviour (Slovik, 1987; Kasperon et al., 1988). These variables were assessed during the data analysis process.

4.10 Ethics Approval

Approval for this research was obtained from the University of Guelph Research Ethics Board on August 17, 2012. Revisions to the proposed study, however, warranted two revisions to the original ethics submission. Firstly, because Dr. Judy Sheeshka had relocated, her contact information needed to be updated on the recruitment poster. The age of participants had also been expanded from 18-30 to 18-35, and the revised recruitment poster reflected these changes. The second change to the proposed study reflected the need of the researcher to meet participants at various locations. Because some participants lived in Hamilton, Niagara, or Scarborough and could not travel to Guelph, it was necessary to meet them elsewhere and conduct the interview in a quiet, private room in a library closer to their homes. The approval forms from the University of Guelph research ethics boards can be found in Appendix G.
Ethics approval from research boards at various institutions was also obtained. Homewood Health Centre in Guelph, Ontario permitted the recruitment of participants on December 11, 2012. The research ethics boards at Sunnybrook Health Sciences Centre and Women’s College Hospital, both located in Toronto, Ontario, provided their consent for recruitment on December 19, 2012 and December 27, 2012, respectively. These approval forms can be found in Appendices H, I and J, respectively.
5.0 Results

5.1 Participant Information

During the recruitment period, 23 potential participants contacted the researcher. Of these, 12 women did not meet the eligibility criteria and were not invited to an interview. The remaining 11 women were invited to an interview with the researcher in Guelph, Hamilton, or Scarborough, depending on each participant’s location and/or access to transportation. The age range of the participants is 20-34 years. Participants were diagnosed with type 1 diabetes between the ages of 1 and 24 years old. Two of the participants who were interviewed (participants #2 and #11) denied misusing insulin during the interview and their data were not considered for the analysis. The final sample size for this project is nine.

A main objective of this study was to recruit participants who misused insulin as a disordered eating behaviour resulting from poor body image or a desire to control their weight. While some participants did not have disordered eating, three participants self-disclosed a diagnosis with a clinical eating disorder or self-diagnosed eating disorder. Participant #4 disclosed her self-diagnosis with anorexia, participant #6 was clinically diagnosed with bulimia nervosa, and participant #9 was clinically diagnosed with binge eating disorder.
Table 1. Participant Profiles

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Age at Dx</th>
<th>Onset of IM</th>
<th>Evidence of ED?</th>
<th>Sought help**</th>
<th>Still misusing?</th>
<th>Complications?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>22</td>
<td>12</td>
<td>?</td>
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<td>No</td>
</tr>
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<td>No</td>
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<td>No</td>
</tr>
<tr>
<td>4</td>
<td>20</td>
<td>1</td>
<td>Middle school</td>
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<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>5</td>
<td>21</td>
<td>18</td>
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<td>No</td>
</tr>
<tr>
<td>6</td>
<td>23</td>
<td>10</td>
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<td>No</td>
<td>No</td>
</tr>
<tr>
<td>7</td>
<td>34</td>
<td>7</td>
<td>High school</td>
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<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>8</td>
<td>26</td>
<td>6</td>
<td>High school</td>
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<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>9</td>
<td>31</td>
<td>24</td>
<td>Adult life</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>10</td>
<td>28</td>
<td>22</td>
<td>University</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

*dx = diagnosis  
*IM = insulin misuse  
*ED = eating disorder  
**sought help through health care providers to overcome insulin misuse

5.2 Thematic Results

When asked how the women feel about their body image, five reported not being happy with their body or having poor body image. Three women reported having poor body image in the past, but have recently become more satisfied with their bodies. Only one participant reported feeling comfortable and confident with her body.

The extent of the insulin misuse these participants experienced was varied and seemed to fall along a spectrum ranging from mild to extreme insulin misuse.
Some participants minimized their insulin dose by a few units at each meal or delayed taking insulin until hours after eating, meanwhile one participant did not take any insulin for an entire year. Still others experienced both mild and severe insulin misuse at different points in their lives, and reflected on all stages of the insulin misuse behaviour. Each participant had a unique experience with adjusting to her diagnosis with type 1 diabetes and a unique approach to insulin misuse.

Several global themes have emerged from the empirical phenomenological analysis of the interview transcripts, and each of these is supported with subthemes represented in the data. The global themes, shown in Figure 1, are: two pathways to insulin misuse; nothing’s happened yet; poor body image; self is primary influence; and lack of support.
Figure 1: Thematic Results

**Theme #1: Two pathways to insulin misuse**
- Diabetes burnout
  - Hard to be on track
  - Fit in with peers
  - Hate to be low
- Body image and weight concerns
  - “Lucky”
  - Way to control self

**Insulin Misuse**

**Theme #2: Nothing’s happened yet**
- Perceived invincibility
- Keep complications at bay
- Theories about insulin
- Not invincible

**Theme #3: Poor body image**

**Theme #4: Self is primary influence**

**Theme #5: Lack of support**
- Negative relationship with health care team
5.2.1 Theme #1: Two pathways to insulin misuse

The participants reported a multitude of reasons for misusing their insulin and the perceived benefits of doing so. There appears to be two broad categories of women in this sample: the majority of participants (7 out of 9) misused insulin for body image and weight control purposes, and a smaller portion of participants misused insulin as a result of "diabetes burnout" (2 out of 9). These two categories of women do not have mutually exclusive characteristics, though. Many women have experienced diabetes burnout as a predecessor to, or alongside, their insulin misuse; meanwhile, those with primarily body image or weight concerns report misusing insulin first and subsequently felt relief from the constant self-care and diabetes management. Although each category of participants has unique characteristics and motivations for insulin misuse, there are a number of characteristics that are shared between both categories.

5.2.1.1 Insulin misuse as a result of body image and weight concerns

Participants who misused insulin for weight control purposes were, generally, unhappy with their weight or shape. Almost half of the participants had lost weight prior to their diagnosis with type 1 diabetes, and upon starting insulin therapy, gained this weight back. Several participants were very young at the time of their diagnosis and do not remember any negative feelings associated with such weight fluctuations, though. Weight fluctuations, or the risk of gaining weight, influenced their body image and made insulin misuse a more appealing practice. Participant #5 was unhappy with her weight after she experienced weight fluctuations following her diagnosis, and thought her body image would improve if
she could fit into her old clothes. Insulin misuse was part of her explanation of her weight loss efforts:

“I guess I’d feel better if I was back to when I was around 120. I felt a lot better. I’d like to fit in my old jeans again, that’s the goal, so I’m trying not to eat as much obviously, but yeah I probably could give myself more insulin all the time.” (Participant #5)

Women in this category discovered that reducing an insulin dose, or skipping a dose, was an easy way to control their weight. This discovery often happened after experiencing a weight loss before their diagnosis (and subsequent weight gain with insulin therapy) or as a result of unintended improper insulin administration; these women continued to misuse insulin in order to promote further weight loss. Participant #10 shared her experience of intensifying her insulin misuse behaviour after seeing the initial weight loss associated with taking reduced insulin doses.

“I think it started as moderate – maybe like when I started to figure out that I could kind of control my weight with it, and then there was a point where it got severe for a bit.” (Participant #10)

While some women were initially misusing insulin unintentionally, learning about insulin misuse in the media or from trusted sources worsened their behaviour and subsequently made a conscious effort to lose weight using this mechanism. Social influence appeared to be a factor in the cases of several participants, including Participant #4.

“I feel like I was already doing it before I really found out what exactly what it did, because I remember researching and the research was triggering to me because I was like ‘Oh my god, there’s people losing weight by not doing insulin?’ like ‘Oh ok, so I can do this’”. (Participant #4)
Another woman, Participant #6, recalled being fearful of taking insulin because of its role in weight gain.

“I did let my blood sugars run a bit higher because I was just so fearful to give more insulin, thinking that it would lead to weight gain. And that went on for probably 6 or 7 years where I was, I was afraid of insulin.” (Participant #6)

She continued to explain that she attended a diabetes sports conference after her diagnosis with an eating disorder, and felt discouraged by what she heard about intensive insulin therapy.

“So you’re telling me if I want to live a healthy life, blood-sugar-wise, I’m going to be obese? And that set me back, because those were experts telling me.”

(Participant #6)

Whether a woman uses personal experience as a reference, researches the behaviour, or reads reports of it in the media, the relationship between insulin misuse and weight loss is quickly learned and can quickly become part of her daily routine. Participant #8 talks about the relationship between insulin and weight and, in her experience, the positive feedback she felt after losing weight.

“I realized Lantiss was leading to weight gain and I realized if you take less of the Lantiss and the hemolog then I would be losing weight. I mean, it wasn’t significant weight loss, it would be a couple pounds, but to me in my head it was like, ‘Ok well I’m still eating the way I am, I don’t need to change any of that, I just need to adjust something that doesn’t require much effort, so let’s stick with this’. Maybe I lost 5 pounds, 6 at the most, it wasn’t significant, but it was comforting and I was rewarded by it so I continued to do it.” (Participant #8)

This woman was comforted by the ease of weight loss without changing her eating habits, and it reinforced the insulin misuse behaviour. She had been struggling with poor body image and weight control problems previously, so
experiencing this weight loss, while not “significant”, was rewarding and encouraged her to continue misusing insulin.

The trend of noticing a weight loss with reduced insulin doses is common among the participants in this category, however some women took the behaviour to more extreme lengths. Participant #4, for example, talked about intentionally bingeing on energy-dense foods to raise her blood glucose because it would result in weight loss:

“I used to even try to make it high, like, I knew the higher it was the more weight I would lose.” (Participant #4)

She continues to say:

“Like I said, most of the time I did want them [blood sugars] to be high and I would be upset when they weren’t.” (Participant #4)

This woman reported bingeing on bagels, dehydrated fruit bars, pasta, and muffins; any food that was high in carbohydrates became her tool to lose more weight. These are foods that she had previously interpreted as being unwelcome in her diet prior to her insulin misuse, and it excited her to be able to eat these foods again.

This sentiment of being able to eat unhealthy foods is shared among other women who misuse insulin to control their weight. Participant #7 also talks about bingeing on such foods and relying on her kidneys to remove the sugar from her body:

“I wasn’t eating properly at all. I was like, binge-eating on you know, snacks, candy, muffins, whatever, and I would not take any insulin after that and I would drink and pee and drink and pee and drink and pee and get so lethargic and then when I felt like I’d had enough, then I would take some insulin. Thinking ‘Ok, my kidneys have probably gotten rid of most of this sugar by now,
so I’ll just have a little bit of insulin and that’ll kind of you know, keep me somewhat ok’ ” (Participant #7).

As was the case with Participant #4, this woman was aware of the role her kidneys had in filtering waste in the body and used this to her advantage. She intentionally delayed taking insulin in an effort to avoid absorbing the glucose into her body and, ultimately, to prevent weight gain. Waiting several hours for the calories to be expelled was an approach also used by Participant #8:

“I would actually skip insulin all together or I would take it maybe 3 or 4 hours later, after you know, the food’s absorbed” (Participant #8)

During the time that this participant misused insulin, she rarely took her insulin as originally directed by a physician. Additionally, the dose would often be less insulin than was necessary to account for the entire meal because she manipulated a piece of advice from her physician to suit her insulin misuse behaviour.

“She’d explained to me, she’s like ‘Ok, if you do that, you should only take half the dose’ and in my head, I liked that concept better because now I’m taking less insulin! So I would, sometimes I’d deliberately wait...or if I was late in taking it, I’d excuse it by saying ‘Ok good, now I can only take half” (Participant #8)

Ultimately, this category of women who misuse insulin can be summarized with a thought from Participant #5:

“I can just stop taking insulin and lose weight if I wanted to” (Participant #5).

Insulin misuse can be thought of as a unique purging mechanism, similar to vomiting or using laxatives; however, because this purging mechanism isn’t available to everyone, some participants felt that they had an advantage over others trying to lose weight.
5.2.1.1 “Lucky” to have this weight-loss ability

One third (3 out of 9) of the participants saw themselves as lucky because of their unique ability to lose weight quickly and without dieting or exercising. Because of their dependence on insulin for metabolic control, the unique option of purging calories by reducing or eliminating an insulin dose is available only to them.

“I think about the weight loss thing, I’d be like “Yeah!” I was happy about it, and it felt like almost like I was lucky, even though I realize now that I wasn’t. I feel like I can eat these things that other people feel guilty about eating and I normally would, but I don’t have to. And I don’t have to purge it and I can just eat it, and I don’t have to feel guilty.” (Participant #4)

Similarly, Participant #7 enjoyed the ability to indulge on high calorie foods without experiencing weight gain.

“And I actually kind of felt, you know what, I’m luckier than normal people because if I was a normal person, I would eat that cake and I would get fat. But I’m eating my cake, I’m not absorbing it like everybody else and I’ll get thin.” (Participant #7)

This woman enjoyed the weight loss potential associated with misusing insulin. She felt superior to people who were trying to lose weight and restricted their diets to exclude unhealthy foods. For her, excreting the calories of the cake shortly after eating it made her “luckier than normal people” who might have to compensate for those calories by modifying their diet or increasing their physical activity.

Participant #10 also expressed her happiness when learning that misusing insulin could so effectively reduce her weight. Again, a diagnosis with type 1 diabetes became somewhat valuable when the potential for weight control was discovered.
“I had such a difficult time getting down to that [weight] even in high school and staying at that, right, that when I saw ‘Oh my god, I weighed myself and I’m 120, this is amazing’ so now I have this thing in my pocket, I can use it”

(Participant #10)

She refers to her insulin misuse as a tool to lose or maintain her weight, and this was exciting for her because she had struggled with her weight for years.

Insulin misuse, for this category of participants, acted primarily as a weight loss or weight maintenance tool. The improved body image they experienced as a result of misusing insulin was valued, and often perpetuated the behaviour in order to maintain their weight or shape.

5.2.1.2 Way to control self

Some participants misused insulin to feel like they were in control of their diabetes and weight when other areas of their life were out of their control.

Participants who had been diagnosed with eating disorders reported similar experiences as those who had not been diagnosed with an eating disorder.

Participant #6 experienced both insulin misuse and bulimia during her adolescence:

“Anything that affected my self-esteem... anything that would make me feel kind of like I wasn’t in control, I’d think ‘Ok well I can take control of my weight, I’m on insulin’.” (Participant #6)

Just as Participant #6 misused her insulin to gain control of her weight, so did Participant #7 who was not diagnosed with an eating disorder.
“I did it to compensate for something that wasn’t there. Or to feel like I was controlling how my body was or... I was in control of my body. And I guess I liked it and so I just kept going.” (Participant #7)

These women shared similar experiences and reasons for misusing insulin despite the varying degrees of disordered eating that was recognized. Likewise, both women with disordered eating and eating disorders reported some experience with diabetes burnout.

5.2.1.2 Insulin misuse as a result of diabetes burnout

The second category of women in this sample misused insulin as a result of diabetes burnout; they felt exhausted because of the extensive planning and commitment that are required to maintain optimal blood glucose levels. While only two participants exclusively misused insulin as a result of diabetes burnout (despite experiencing improved body image as a result of subsequent weight loss), several other participants experienced diabetes burnout alongside their weight-related insulin misuse.

Participant #9 misused insulin primarily as a result of diabetes burnout, however she developed a desire to control her weight as the insulin misuse continued and she experienced weight loss:

“I wasn’t hoping to lose a lot of weight but I didn’t want to gain the weight back. I knew if I went back on the insulin I was going to start gaining weight again.” (Participant #9)

Because diabetes is largely a self-managed disease, the participants grew tired of the responsibility associated with scheduling and attending appointments
with health care providers, ensuring they had enough supplies (i.e. insulin, needles, testing strips, etc.), and planning their extracurricular activities around their diabetes management.

Participant #3, who exclusively misused insulin as a result of diabetes burnout, described her desire to fit in with her peers, and the responsibility of carrying around her diabetes supplies became burdensome:

“I had had [diabetes] a while then, and kind of, I wanted to be like all the other kids, you know? And not have to deal with it and not have to bring my insulin around and not have to do any of that” (Participant #3)

This woman’s response to diabetes burnout was to take her insulin pump off when she felt it would get in the way of her activities, and often forget to put it back on:

“So you know, if I had gym class or something I would take it off, but then would go to my next class and forget to put it on, and I remember one time I left it in my locker over the whole weekend so I had to go back to injections for the weekend.” (Participant #3)

For this participant, neglecting her insulin pump was not a result of body image or weight loss concerns, however the rejection of diabetes self-care continued for approximately 6 months. The constant pressure to manage blood sugar with diet, physical activity and insulin, and be able to respond to changes in blood sugar, can become overwhelming for those with type 1 diabetes.

“This is too hard, I can’t deal with this. If I’m going to die young, so be it, but I can’t deal with this” (Participant #6)

Participant #6 misused insulin in conjunction with her eating disorder, but felt that the responsibility of diabetes self-management was too much to bear. This participant is not the only woman to experience diabetes burnout alongside
disordered eating.Participant #7 also rebelled against her diabetes care as an adolescent:

“I think high school was definitely, that’s when it started, the anger towards it and the resentment for having it” (Participant #7)

As mentioned previously, there is an overlap of characteristics among participants in these two insulin misuse categories. Participant #7 rebelled against her diabetes and family members who tried to ensure she was taking care of herself, and also valued the weight loss that accompanied her insulin misuse.

“I think I was probably rebelling against the control that was normal diabetes care and my mom and my dad... And also, be thin at the same time because well, pressure was to be good looking and thin so I think it was probably a couple of factors.” (Participant #7)

Participant #4 is another excellent example of concurrent insulin misuse for weight loss and resulting from diabetes burnout. Having been diagnosed at age 1, her whole life had been centered around maintaining healthy blood glucose levels. The micromanaging of food and insulin, though, eventually became burdensome for her and she too, credits her insulin misuse to both diabetes burnout as well as self-diagnosed anorexia. She stopped taking insulin in order to lose weight and be less restrictive with her diet:

“I think part of the reason I stopped, too, is I wanted to be able to eat whatever and not care, I was so sick of caring so much...I knew that without giving my insulin I could eat whatever I wanted and I didn’t have to care and I didn’t have to, like, throw it up either” (Participant #4)

While a smaller proportion of participants in this study misused insulin as a result of diabetes burnout, many of these women can relate to feeling overwhelmed with the responsibility of managing their diabetes.
5.2.1.2.1 Hard to be on track all the time

The demands of being aware of and controlling so many aspects of daily life caused some participants to be less diligent with testing their blood sugar and maintaining metabolic control. The level of commitment involved proved to be overwhelming for some women.

“I think it’s just easier. I think that’s what it is. It’s really hard to be on track all the time” (Participant #4)

Another woman has attention deficit hyperactivity disorder (ADHD) and found the work to be too much, and it contributed to her insulin misuse as well.

“But with diabetes you have to keep track of everything, like, that you eat and how much insulin you take and they’re constantly asking you, keep food journals and like, my meter readings and it’s just, it feels like a lot of work for someone who doesn’t like doing that sort of stuff. So I still struggle with it.” (Participant #9)

Experiencing an overwhelming sense of responsibility associated with having well-managed diabetes is another reason some women choose to misuse insulin. In addition to the demands of maintaining control of their diabetes, some participants found it difficult to maintain a sense of normalcy when spending time with friends or family.

5.2.1.3 Fit in with peers

A number of participants avoided taking insulin in social situations and let their blood sugars go high because of a desire to fit in with peers and avoid attracting attention.

“I might take less because, if I was in a social situation with my friends or something, or with new people that I didn’t know, I would be worried about my sugar going low... so I might kind of shy on the less insulin, like not give as much.” (Participant #3)
The burden of taking insulin when out with family and friends was something that was discussed with several participants, and it was the reason for some insulin misuse events.

“It was so inconvenient: you’re out with friends, you’re out with family, and you know, I wasn’t one to always pull out my syringe and just do it at the table, I’d always have to go to the bathroom and do it, and I hated doing that, so I wouldn’t take that” (Participant #8)

Feeling like they could not, or did not want to, leave a social situation was described as being a reason for skipping insulin doses in this sample. Meanwhile, the fear of experiencing low blood sugar also influences the decision to use insulin or not.

5.2.1.4 Hate to be low

All participants talked about their symptoms of high and low blood sugars, and several women discussed their preference of maintaining higher blood sugars than risking experiencing a low blood sugar.

Low blood sugar, that’s probably the worse one. (Participant #5)

These women prefer to have a higher blood sugar than risk the dangers of having lower blood sugar; there is a fear associated with feeling helpless and the possibility of more immediate health risks.

I’m a bit afraid of how it feels to be low and I’d rather keep it a little higher.  

(Participant #10)

This preference to maintain elevated blood sugars is another reason some participants were less likely to tightly control their blood sugar. Interestingly, though, the vast majority of the sample, when misusing insulin, did not consider
themselves to be at risk of developing diabetes-related complications in the near future.

5.2.2 Theme #2: Nothing’s happened yet

Although the complications of poor compliance to diabetes self-care are well known, the majority of participants did not consider themselves to be at risk of developing any of them. All participants reported being aware of the dangers of insulin misuse. Whether their health care team or family members had explained these to them, or they sought the information themselves, these women were educated in the area of diabetes-related complications. Many were aware of complications such as neuropathy, nephropathy, retinopathy, and ketoacidosis, however they chose to either ignore the risk or they felt invincible to the dangers of these complications.

“You know, you read stuff on the Internet, you’re like ‘Yeah this could happen to me, there’s a chance I could get this, a chance’... you still you feel invincible to it.” (Participant #4)

At times, the participants revealed that their youth helped them feel less worried about the potential risk of developing complications. Because this sample was quite young, and some women had only had type 1 diabetes for a few years, there was a sense of protection from those complications that might be common in an older population of people with diabetes.

“Like I said, you think old people get that and it’s only been a couple years since I’ve had this, I don’t think anything’s going to happen now.” (Participant #10)
Feeling that her youth was a shield to the dangers of insulin misuse was not a characteristic unique to Participant #10. Participant #8 shared this thought because of the phrasing members of her health care team used when describing the potential complications, and used it as reassurance that she was protected as a young person.

“I think because they also said, ‘When you’re older’ and this is when I was, you know, younger, I was like “Ok, well I still have time, it won’t happen to me yet”, so I continued.” (Participant #8)

This woman has also highlighted a trend in thinking with this sample; the use of the word “yet” appeared frequently in conversation with the participants. There was an acute awareness of the potential dangers of prolonged insulin misuse, however each woman who misused insulin once believed that she had not yet reached a dangerously low level of self-care.

5.2.2.1 Perceived invincibility, at least for now

Several other participants also discussed their perceived temporary immunity to complications using the word “yet”. The use of “yet” so commonly heard in this study suggests that the perceived invincibility may be temporary, though. Feeling a sense of protection because of their youth, or that their insulin misuse was not severe enough, may have been understood as a short-lived feeling and that correcting elevated blood sugars did not need to be acted on until their condition worsened.

Participant #6 shared an experience she had with an endocrinologist who used a scare tactic intended to correct her behaviours leading to elevated blood
sugars. The appointment and the endocrinologist’s approach, however, did not influence her behaviour as the perceived invincibility she had was more powerful.

“I’ll never forget when my endocrinologist took one of these devices and touched it to my toe to check the nerve sensation in my feet... I knew he was doing that as a scare tactic because I don’t have nerve damage yet.” (Participant #6)

Participant #7 had misused her insulin for approximately 7 years, to varying degrees of severity, and she too was aware of the risks. She felt invincible, at least temporarily, to the complications her mother had warned her about.

“But I guess I just thought ‘Whatever, it’s not going to happen to me. Sure, that’s what they say but you know, nothing’s happened yet.” (Participant #7)

Other participants have shared similar feelings about their perceived invincibility, also using the word “yet” when considering their short-term and long-term health.

Participant #5 revealed that there is little consideration for long-term health or diabetes-related complications because of her good health at the present time.

“Well we never think about it until it happens to us in a sense. Since I don’t have any problems yet I don’t think about it. I try not to think about it.” (Participant #5)

Both Participants #5 and #4 said they tried not to think about the danger their insulin misuse has put their health in. These participants’ preference is to live their lives without the worry of developing complications, and instead dealing with the reality of them when they happen.

“I really try not to think about it because it hasn’t happened yet, so why worry about it?...I still feel a little bit invincible, like I’m really hoping that I don’t end up with any...serious complications. Like, I don’t want to say that I’m expecting
complications but at the same time I am aware that they are likely going to happen to me because of this. But I try not to think of that.” (Participant #4)

This passive approach to expecting complications is one that was discussed by a number of participants and seemed to be more prevalent. Remarkably, though, several participants adopted a proactive approach when they believed they were at risk of experiencing diabetes-related complications. These women believed they could temporarily intervene on the development of these complications by using insulin when they absolutely needed to.

5.2.2.2 Keep complications at bay

Because these participants were aware of the complications associated with insulin misuse, they were keen to watch for the symptoms of, for example, ketoacidosis, neuropathy, or retinopathy. If their fingertips felt numb or their vision became blurry, they would take some insulin to curb this side effect of prolonged elevated blood sugars. There was an expectation that taking insulin when these symptoms appeared would reverse the looming damage. Once they felt that the small doses of insulin had reversed the damage, the participants were able to continue misusing insulin.

“I was like ‘Oh it won’t happen to me, I’m watching.’ Like, I felt like if I knew the risks I could watch for the symptoms, and then just kind of start taking insulin if I felt any of the symptoms.” (Participant #9)

This participant did not take insulin for over a year following her diagnosis with type 1 diabetes because she was not willing to change her lifestyle to accommodate the demands of controlling her disease. However, in an effort to continue avoiding the hospital and her health care team, she administered insulin when she felt it was
necessary to preserve her health. By the same token, Participant #10 wanted to avoid having members of her health care team step in and interfere with her insulin misuse.

“I did know the ketoacidosis... I knew that, but I guess I was like ‘Ok, maybe if I back off a bit when that starts, when I really start to feel bad, then it’ll kick me back to being fine and I can stop myself from going into ketoacidosis’.” (Participant #10)

While these women were convinced that short-term insulin use would preserve their health, some other participants were also under a false impression about the etiology of diabetes and insulin.

5.2.2.3 Theories about how insulin works

When participants were asked to explain their daily routine while misusing insulin, or asked to discuss their expectations of this behaviour, it became clear that there are several misconceptions of how insulin works in the body. Insulin misuse was, at times, a product of women being confused about how their bodies react to food in the absence of insulin or how the body absorbs glucose with a given insulin dose. Participants #8 articulated her thought process as follows:

“So my blood sugars would be high, I’d be forced to drink water because I need to bring myself back to normal, I in my head, thinking ‘That flushes out all my food, I didn’t eat anything’. And I’d keep doing that.” (Participant #8)

Although she too was confused about the insulin mechanism and had a different interpretation of how insulin worked, Participant #4 also articulated her intentions well:

“It feels like extra...so if my level was 19 and I have 30 carbs or whatever, normally I would just give 3 units for those 30 carbs. But if I’m having to give 6 units it feels like I’m eating double that way, for some reason. I know that’s not
really how it is but in my mind it’s like ‘Well that’s practically 60 carbs then’. It’s like, ‘But I don’t want to have eaten 60 carbs, I didn’t even eat that much’.” (Participant #4)

This woman believed that giving herself a correction dose of insulin to manage the initial blood glucose level of 19 mmol/L and bring it to a normal level (~7 mmol/L), in addition to giving herself insulin for the food she was consuming, meant that her body would process that meal as containing twice the amount of carbohydrates actually found in the food. Given that she self-diagnosed herself with anorexia, it is understandable that she would avoid meals with excess energy and carbohydrates and therefore restrict her insulin dose.

Despite the widespread feeling of temporary invincibility or believing they are in control of how insulin is used in the body, two participants have in fact experienced negative health repercussions as a result of their insulin misuse behaviour.

5.2.2.4 Not invincible to complications

Participants #4 and #7 have experienced some complications from prolonged elevated blood glucose levels. Participant #7, who, as mentioned above, ignored her mother’s warnings about nephropathy, amputations, and retinopathy, experienced the reality of one of these complications following 7 years of insulin misuse.

“In December of last year, I had retinopathy – enough so that my right eye needed to be laserered, like, heavily.” (Participant #7)

Only after this health scare did she internalize the severity of her behaviour and the impact her uncontrolled blood glucose could have on her health. This woman has
since stopped misusing insulin, however not all participants who experienced complications have done the same. Although she has not received treatment for her side effects of insulin misuse, Participant #4 lives with symptoms of neuropathy, a byproduct of her insulin misuse:

“I do expect there to be damage and even my fingers, they’re already going numb.” (Participant #4)

This young woman, who is only 20 years old, anticipates kidney damage to surface in the coming years and is aware that she will have induced these health problems by her own hand. Interestingly, she continues to misuse insulin in order to maintain her weight. The invincibility to complications she once felt is no longer present, however the assurance of weight control associated with insulin misuse is sufficient motivation for this participant to continue with her disordered eating behaviour.

It is clear that several participants have struggled with moderate to severe insulin misuse, both in the past and presently, and the most consistent factor associated with this behaviour is a self-reported poor body image.

5.2.3 Theme #3: Poor body image

When asked how the participants felt about their weight and shape, an overwhelming majority (8 out of 9) of participants were not happy with their body. Several of these women stopped misusing their insulin and learned to accept their bodies, however, the most participants still report having poor body image.

“I’m critical of myself, but I know that I’m lucky that I’m the size I am, but…I’m always criticizing myself and trying to change things.” (Participant #1)
Some women have been struggling with poor body image or weight control for many years:

“I’ve always had a poor body image, like since I was young. Like, I don’t think I’ve ever been able to look at my body accurately.” (Participant #4)

Weight fluctuations had a lasting impact on Participant #5, who has been struggling with controlling her weight since she entered high school:

“I’ve been struggling since a long time. It started back in high school when I was 13, so I started putting on weight because of the way I was eating and stuff...so I started putting on weight and stuff and obviously I was self-conscious, hated it.” (Participant #5)

Another participant remembers her body image as being negative since she was a child. Comments from family members and other children at school contributed to her poor body image:

“I always kind of had not the best body image because I was a little bit of an overweight child and I had kids making fun of me and... my grandma and my aunt, they always were talking about weight.” (Participant #6)

Participant #7 expressed that her body image influenced her on a daily basis:

“I had huge struggles with body image and trying to be thin and as thin as possible, and look as good as possible, and it was a, like a constant thing for me, daily. Like, every hour of every day, that’s you know, kind of what I was thinking about.” (Participant #7)

As with Participant #7, this woman’s weight was the biggest influence on her body image:

“I wasn’t happy with the way I used to look. Mostly because of weight. I’ve lost quite a bit of weight in the past year so I’m a lot more satisfied with the way I look.” (Participant #8)
Participant #9 has also struggled with her body image for many years and remembers feeling negatively about herself regardless of her size:

“I’m not happy with my shape and size. I’ve never really been. I’ve always thought of myself as bigger than I actually am, because I remember at some points I was maybe like size 8 or 10, and...I thought I was huge.” (Participant #9)

Finally, Participant #10 expressed similar sentiments as other participants who have struggled with body image for years. This woman, though, has experienced a decline in her body image since her diagnosis with type 1 diabetes:

“I’ve always like, kind of not been happy with my weight and stuff like that, but it’s gotten worse as I’ve like, as I said with the insulin and I saw how quickly I put on weight” (Participant #10)

The participants in this sample have reported a wide variety of reasons for their poor body image. Several women began their struggle with body image as young girls and the weight and shape concerns perpetuated into adolescence and young adulthood. Other participants reported their body image declining in high school as a result of natural changes their body underwent during puberty and the desire to be thin and attractive became a higher priority. Regardless of the age poor body image began influencing the participants, most participants credit some of their insulin misuse to struggling with their body image. The only exception in this sample is Participant #3, who says:

“I’m satisfied with the way that I look, I’m comfortable, I’m confident with my body image” (Participant #3)

Interestingly, this woman is one of only two participants (the other is Participant #9) who temporarily misused insulin as a result of diabetes burnout. Her confidence
and satisfaction with her body may be one of the reasons she had a different, and much less severe, experience with insulin misuse.

As mentioned previously, diabetes is largely a self-managed disease. However, people close to the patients often support them throughout their journey of coping with, and managing, diabetes.

5.2.4 Theme #4: Self is primary influence

Participants were asked to explain how their family, friends, and health care team each influence their insulin use behaviour. Overall, the participants themselves were the primary influence of their diabetes care and insulin use or misuse behaviour. Parents, friends, and health care teams often had an input into how the women should be taking care of themselves, however the desires and goals of the participants were the dominant influences.

Friends rarely had an influence on how the women cared for their diabetes. Several women mentioned that their friends’ primary concern was if alcohol was being consumed and they wanted to ensure it was safe.

“*My friends, they’re not very involved. The way that they are involved, though, is if I go out to a party and I’m drinking. They’re always at my back, being like ‘What’s your blood sugar, check your blood sugar, check your blood sugar’.**”  
*(Participant #6)*

Aside from safe alcohol consumption, though, friends of the participants did not insert themselves into the women’s management of diabetes. Generally, of the three sources of input, friends had the smallest influence on the participants’ self-care behaviour.

Depending on the age of diagnosis, parents were more or less involved with the diabetes care regimen. For participants diagnosed at a young age, parents were
originally responsible for administering insulin and preparing balanced meals. However, when participants were at an age where they sought more independence, parents became less of an influence on their insulin use and self-care. The opinions and satisfaction of their parents still remained more important to these women than did their friends’, though. When discussing people who influence her health, Participant #1 ranked herself as most important, followed by her parents and her doctor.

“My parents worry about me, so I want to be able to tell them, like, ‘Hey I’ve had perfect blood sugars for 2 weeks’ or something, and I want my A1c to be better, that’s with the doctor related… And primarily for myself, I’d say” (Participant #1)

This sample of women often felt some kind of pressure from their health care team to control their diabetes. More often than not, this influence was not well received and the participants did not consider the advice or recommendations of their health care team to be more important than their own goals with self-care. For this reason, among others, it was not uncommon for participants to avoid seeing their physicians:

“I try to avoid my endocrinologist as much as possible because I don’t know, it stresses me out.” (Participant #7)

For women who do see their physicians and hear their advice, many times the feedback or advice does not make a lasting impact on their behaviour:
“I did make changes but it was still hard and I did kind of slip back because you know the longer it goes from something you just forget about it.” (Participant #4).

Participant #5 had a difficult time coping with her diabetes because she did not receive a lot of support or guidance from her health care providers, and because she was diagnosed at age 18, her parents were not involved in her diabetes management; she is the primary influence over her self-care. In this case, it was not an avoidance of health care teams or a choice to ignore the advice given to her. Instead, she felt that her health care team was ineffectual and too busy to teach her about diabetes management, so she took the initiative to learn on her own.

“I started doing my research and whatever and that’s how I kind of helped myself, in a sense, not really the health care system.” (Participant #5)

Many participants shared negative experiences they had with members of their health care teams during their insulin misuse, and they continue to struggle with these relationships.

5.2.5 Theme #5: Lack of support for insulin misusers

Almost half of the participants who recognized that they needed help to overcome their insulin misuse behaviour sought advice or treatment. Unfortunately, these women found little relief and assistance from the medical community and felt that their issue was not recognized or there was no appropriate treatment process.

“I started going to Trellis and they wanted to send me to inpatient actually, but there’s none in Canada that will actually take a diabetic. They have like centers for diabetes, they have centers for eating disorders, they don’t have any that actually combine because while they’re very, very interconnected, they’re also separate things to treat, right?” (Participant #4)
Like Participant #4, Participant #6 felt that her insulin misuse was not acknowledged by her health care team:

“No one ever took me to the side and said ‘#6, why are you doing this?’. It was always from the medical angle, you know, ‘You gotta give more insulin, you gotta get your blood sugars down’. Help me! You know? Don’t just tell me, help me.” (Participant #6)

Some of these women did receive some kind of therapy, but they found it was not helpful for their particular disordered eating issue.

“I told my doctor that I was doing that, the endocrinologist, she sent me to an eating disorder clinic. Of course they didn’t do anything for me because I wasn’t really skipping food and the programs that they had were so intensive that it really didn’t fit what I needed.” (Participant #10)

While some therapy provided participants with clarity of their disordered eating behaviour, it did not treat the insulin misuse.

“I went to every appointment and I was you know, diligent about it, and we did cognitive behavioral therapy, and it kind of, it helped. It made me get a picture of what I was doing but it wasn’t, that wasn’t the end of my issue. It certainly gave me more of a perspective on things, but things still kind of tapered on for a couple years after that.” (Participant #7)

After struggling with insulin misuse, some women tried to recover with the help of health care professionals, but did not find this route to be appropriate. It is understandable to think some women would seek help at an eating disorder clinic, though, as there are similarities in behaviour among those with eating disorders and those who misuse insulin.

5.2.5.1 Negative relationship with health care team

The participants often had negative relationships with members of their health care teams. There were several reports that physicians were not able to build rapport with these women because they did not listen to their problems, did not
offer helpful advice, or approached the women and the topic of insulin misuse with a lack of understanding and compassion.

“I find they’re not helpful at all, at least that’s how I feel” (Participant #5)

This participant often felt that her doctors, nurses, endocrinologists, dietitians, and diabetes educators passed the responsibility of teaching her about diabetes and using insulin off to one another, ultimately leaving this woman feeling confused and angry. As a result of this kind of negative experience, as discussed previously with Participant #7 as an example, several participants avoided seeing their physicians or were dishonest with them during their appointments. Another woman switched doctors because felt that she couldn’t be honest about her high blood sugars:

“I felt like I could have told my doctor that but also I feel like he intimidated me into not to. I’ve changed doctors” (Participant #1)

Some participants also felt that their struggles with controlling their blood sugars were not understood by their health care team.

“There’s always kind of been, with me and the healthcare team, a little bit of a negative relationship simply because I’ve always felt like they don’t... listen to what their patients are saying” (Participant #6)

This participant also said that she did not share details of her insulin misuse because her physicians did not ask. The negative relationship she had with members of her health care team prevented her from receiving support from them, and her insulin misuse continued for several years. Participant #8 also felt that the approach taken by members of her health care team was important in how she reacted to their questions during appointments.
“It was her approach. She was like ‘This is what it is’, like, whereas the nurses would be like ‘Why aren’t you doing this?’ Like, don’t ask me why, because I can give you a million reasons. I liked how [the endocrinologist] approached me.”

(Participant #8)

The participants did not respond to physicians who were judgmental or those who appeared not to listen to their unique situations.

“They go by textbook and it really makes me frustrated just to not have what I’m saying acknowledged” (Participant #6)

Not all participants had this negative perception of their health care team, though. Some contradictory results came from Participant #10, who was very open and honest about her insulin misuse when meeting with her health care team.

“I figured ‘Ok, I’m going to have to tell them’ and... they were pretty good about it. Like, and they were happy that I was telling them, too. ‘At least you’re admitting it, and we can go from there. But if you hide it, we can’t help you’.”

(Participant #10)

While the majority of women in this sample did not have positive experiences with members of their health care team, the same cannot be said for every participant.
6.0 Discussion

The results of the present study have identified numerous core elements of the lived experiences of women with type 1 diabetes who misuse insulin. It is important to note, however, that with a sample size of nine women and a wide variation of reported experiences with insulin misuse, theoretical saturation was not attained.

6.1 Perception of Risk and Risk Theory

Risk theory and perception of risk were used throughout analysis to assess how these women approach the issue of insulin misuse. The goal was to determine whether these participants weighed the risks and perceived benefits of insulin misuse prior to making the decision to the misuse, or if any thought of “pros” and “cons” influenced this decision. We hoped to determine how these participants perceived the risk of insulin misuse and the threat of developing diabetes-related complications. Furthermore, we hoped to understand the variables of risk perception (i.e. control, familiarity, level of knowledge) that influenced the participants to accept the risk associated with insulin misuse.

Using risk theory to frame this study enabled us to assess whether participants were aware of the risks associated with insulin misuse, how they felt they could manage these risks, and gave us insight into the thought process behind a decision to misuse insulin. We learned that these women were acutely aware of the risks associated with poor metabolic control and prolonged elevated blood glucose and that these women did not necessarily think they were at immediate risk of developing diabetes-related complications. While we were able to learn about the
risk analysis behind these participants’ insulin misuse, not all women were able to articulate their thought process behind this behaviour.

Parents, friends, and health care professionals offered advice or concern periodically throughout the participants’ insulin misuse behaviour, however the insulin misuse was not a product of interplay between these groups. Rather, participants considered the risks of insulin misuse, considered how the risks did or did not apply to them, and then persisted with their desired behaviour until they chose to better their health. As discussed above, a precipitating event or a decision to seek professional help to overcome insulin misuse was arrived at independently. This supports the suggestion that women who misuse insulin are the only people associated with her actions.

As Slovik (1987) discussed, the perception of risk among health care professionals and among patients are vastly different. Health care professionals are primarily interested in assessing the statistics of morbidity and mortality associated with an event or a behaviour and determine the level of risk using this information. Patients, however, are influenced by a number of variables when determining the riskiness of an event or behaviour. The perceived benefit of a risk and acceptance of risk increase when a person perceives a favourable level of control of, and familiarity with, a particular behaviour. The level of knowledge associated with a behaviour also influences perception of risk. Because these participants were educated on diabetes and insulin administration, familiar with insulin administration, and they controlled the amounts of insulin they gave or withheld, the perceived level of risk was low. Additionally, as insulin misuse resulted in
weight loss, weight maintenance, or relief from diabetes burnout, the perceived benefits of insulin misuse were high. Ultimately, because of the perceived low level of risk and the perceived benefits were highly desired, the risk acceptance of insulin misuse was common among this population. Despite being well-educated about the dangerous complications associated with insulin misuse, these participants ultimately perceived the dread risk to be low and thus insulin misuse was perceived as being an attainable weight-control strategy with manageable risk. The voluntary nature of insulin misuse, and the ability to control the severity of insulin misuse, further increased risk acceptance and perpetuated the risky insulin misuse behaviour.

6.2 Areas of Interest

While the original objective of this research was to interview women who misused insulin as part of an eating disorder, which was subsequently adjusted to interview women with disordered eating, only three women self-disclosed their history of having an eating disorder. The researcher unexpectedly learned that a number of factors unrelated to eating disorders and disordered eating influenced these participants to misuse insulin. Because much of this research is unique and the issue has not been studied with a qualitative approach, there is limited literature with which to compare the present results. The following discussion refers to the insulin misuse literature when appropriate, however some results do not share commonalities with any literature known to the researcher and therefore is not compared and contrasted with previous work.
With a narrow age range and a very specific population to sample from, the researcher distributed posters using general, socially acceptable terms. This resulted in more than half of the respondents not qualifying for the one-on-one interview; however, the researcher maintains that this approach to recruiting was the most ideal way to reach young women with type 1 diabetes. Because of the sensitive nature of this research, the screening questions did not use the phrase “insulin misuse”, or suggest that the intent of this research was to criticize or pass judgment on women who misuse insulin. As a result, despite meeting requirements of the screening questionnaire, two participants (#2 and #11) did not misuse insulin for weight control, because of body image issues, or even as a result of diabetes burnout. The miscommunication that occurred via email, unfortunately, could only have been resolved after meeting with these women and discussing the issue in further detail.

An unexpected motivation for insulin misuse is exhaustion and frustration with constantly worrying about diabetes management; this is commonly referred to as diabetes burnout. While the researcher was aware that this exhaustion and frustration was prevalent among those with diabetes, it was not believed to be a associated with insulin misuse behaviour. Many of the participants reported experiencing these frustrations and the relief they experienced when they discontinued using insulin as directed by their doctors. The freedom to eat and drink what they wanted, when they wanted, and forget worrying about insulin doses proved to be a luxury for these women. In some cases, though, the resulting weight loss lead participants to continue misusing insulin in order to continue losing
weight or to maintain their weight. Likewise, participants who misused insulin as a result of weight or body image concerns found relief from the constant worry that comes with maintaining blood glucose control, and reported that this relief perpetuated their misuse as well. Two thirds of the sample reported experiencing diabetes burnout and said their insulin misuse was related to this burnout. While this finding was unexpected for this particular study, the concept of diabetes burnout has been presented in the diabetes literature. Snoek (2002) reported that numerous negative experiences contribute to a patient’s eventual diabetes burnout, and that this is not uncommon. The sample in the present study is consistent with this idea.

Another surprising result was the idea that having type 1 diabetes, and the ability to misuse insulin to lose weight, made these women “luckier than normal people” (Participant #7). It was thought that insulin misuse is a hidden, private disordered behaviour and this would be attractive to women with type 1 diabetes struggling to control their weight. It emerged during interviews, however, that the secrecy associated with misusing insulin was not a forefront thought. The “luck”, they explained, comes from being able to binge on energy-dense foods that women without diabetes would typically avoid if they were trying to lose weight. This perception of feeling lucky was unexpected, which is not surprising as to our knowledge, there is no existing literature reporting this phenomenon.

While perceived invincibility to a major health crisis or disease is somewhat common and well-researched, this sample was remarkably different in their expression of current health and future health status. The majority of participants
used the word “yet” when describing their motivations for misusing insulin and their long-term expectations. Like many patients, these participants felt somewhat invincible to the complications associated with insulin misuse – at least for now. The tendency for these participants to check the sensitivity in their fingers and toes suggests that they do feel at risk of developing diabetes-related complications, but not to a degree that would motivate them to use their insulin as directed.

Contradicting, yet concurrent, feelings of vulnerability and invincibility to complications make this sample unique. There is no known literature that discusses similar findings, though, so this sample cannot be compared to a broad spectrum of women with type 1 diabetes.

The confusion among several participants surrounding the way insulin works in the body was an unexpected and interesting result, as well. Participants #4 and #8 appeared to have distorted ideas of how insulin works to absorb glucose into the body, and this confusion played an important role in their insulin misuse. The “theories” described by these women are incorrect and fuel disordered eating behaviours because of their perceived ability to control how much glucose, or calories, they were actually taking in compared to how much glucose they were excreting. In thinking that they could manipulate glucose uptake, their desire to continue misusing insulin to lose or maintain weight was reinforced. Further, advice given to participants from health care professionals may be selectively understood to best serve their insulin misuse habits. For example, after her doctor told her that waiting several hours after a meal to take insulin meant she should only take half a dose, Participant #8 said “sometimes I’d deliberately wait” in an effort to reduce her
daily amount of insulin. It is important for patients to have a strong understanding of diabetes in order to maintain metabolic control; it appears that without this understanding, dangerous misinterpretations such as this can result.

As shown in Table 1, four of the participants sought help for their insulin misuse behaviour. Participants #4, #7, #9, and #10 opened up about their insulin misuse with a health care professional in hopes of overcoming this behaviour. Psychiatrists, therapists, eating disorder clinics and outpatient programs were all resources used by the participants to improve their metabolic control by addressing their disordered eating. Interestingly, a precipitating event shocked Participant #6 and encouraged her to end her insulin misuse without the help of a health care professional. Also interestingly, not all attempts to overcome insulin misuse were successful because some participants continued to misuse insulin despite the efforts of these health care specialists. It is clear that varying degrees of insulin misuse warrant various approaches to treatment and recovery. For some patients, an eating disorder program designed for those with anorexia and bulimia is too extreme for their mild or moderate insulin misuse, and some patients seeking help through a therapist require more intensive treatment for their severe insulin misuse.

Most participants had misused insulin in the past and corrected their behaviour prior to meeting with the researcher. These women were able to reflect on their experience with insulin misuse and discuss their feelings and motivations during the insulin misuse as well as offer their opinion in hindsight. Two participants, though, were still misusing insulin at the time of the interview. Participants #4 and #5, who were the two youngest participants, reported that they
still restrict their insulin in an attempt to maintain and lose weight, respectively. These women were well educated and were aware of the complications, however the promise of weight control remained more important to these women than preventing further damage to their bodies.

One of the above mentioned participants, Participant #4, is one of two participants who have experienced complications as a result of their insulin misuse and poor metabolic control. Participant #4 has symptoms of neuropathy and Participant #7 received laser treatment to correct her severe retinopathy. These women misused insulin for roughly the same amount of time (~6-7 years) when their complications arose, and both women rated their insulin misuse as severe. As Rydall & Daneman (1997) discussed, those with more severe disordered eating were at a much higher risk of developing complications, particularly retinopathy. The present sample is consistent with this, and supports research that suggests those who misuse insulin are at risk of developing complications at a much younger age (Polonsky et al., 1994).

Lastly, the researchers had assumed that insulin misuse was so prevalent among those with type 1 diabetes because it is largely a private practice and no one would notice if a woman did or did not administer insulin at any given time. It was believed that, compared to other purging techniques like vomiting, over-exercising, or laxative use, which may be more apparent to friends or family members, insulin misuse would be a very hidden behaviour. Although none of the research or interview questions directly assessed this, it was discovered during the interviews that the participant’s believed the opposite to be true. They believed that family
members and friends may not notice if she vomited or used laxatives after eating and that over-exercising would be interpreted as a healthy behaviour to control blood sugar levels. With these purging mechanisms, there are no lasting effects on energy levels or mood. Insulin misuse and the associated elevated blood sugars, however, resulted in fatigue, irritability, and excessive thirst and bathroom breaks. According to some participants, the change in energy levels and mood were quick identifiers to parents and friends that their blood sugar levels were too high and that insulin was not being used properly. So, the previous assumption that insulin misuse is a hidden behaviour (which was thought to add to it’s desirability and may have accounted for it’s high prevalence) appears to be incorrect.

6.3 Strengths, Limitations and Implications for Future Practice

6.3.1 Strengths

This study used qualitative research methods to build rapport with participants and uncover the motivations for misusing insulin. One-on-one interviews allowed the researcher the opportunity to share with participants her personal reasons for studying insulin misuse, and allowed the participants to share details about their life and health that would remain confidential. The interview was semi-structured and flexible to allow the participants to share information that was not asked of them, but that was important to support their explanations and stories. The researcher also had the freedom to share anecdotal stories that previous participants had shared in an effort to assure to women that they could be honest about their insulin misuse without being judged or reprimanded. Many times, the extraneous information discussed in between prepared interview questions became
a topic of conversation that proved to be invaluable to answering the research questions at hand.

Another strength is that a second coder was used during data analysis. The researcher and second coder met several times to discuss coding the transcripts and, ultimately, the emerging global themes and subthemes. There was minimal variance between the researcher and the second coder, and any discrepancies were discussed in detail and revised to best reflect the data.

Although insulin misuse has been studied extensively, this is the first known study to adopt a qualitative approach to better understand insulin misuse behaviour. Using the themes discussed in this research, the quantitative health studies may be interpreted with an added degree with empathy and understanding for the women who have misused insulin. This research helps to fill several gaps in the literature regarding motivations for insulin misuse and the influence body image has on this behaviour. The degree to which the research questions have been discussed in the present study offers a more comprehensive view of reasons women misuse insulin, the role of body image in this behaviour, and the influence health care professionals have on such patients.

6.3.2 Limitations

Although this research was exploratory in nature and the researcher was unsure of what she would learn about insulin misuse among this population, there are several limitations that should be addressed.

Firstly, the final sample size of nine women is smaller than was anticipated and hoped. Although the recruitment phase continued for seven months, some
health care facilities’ research ethics boards did not approve the study until months after the initial contact with a staff member. Additionally, after ethics approval was granted, some health care providers hesitated to advertise the recruitment posters because they were unsure of where to place them. Had this confusion been avoided, it may have resulted in a greater interest from potential participants and, perhaps, a greater number of eligible participants. A second limitation contributing to the small sample size is that the target population age range is quite narrow. Despite widening the age range mid-way through recruiting, it is thought that opening the study to all women who have misused insulin, regardless of age, would have resulted in a greater sample size. Due to time constraints associated with a Masters thesis, however, it was not possible to extend the recruitment phase and open the interviews up to a wider population.

A limitation related to the small sample size and the diverse sample of participants, theoretical saturation was not attained. It was expected that, if enough participants were interviewed, common ideas and explanations would arise. Unfortunately, because each woman had a different experience with insulin misuse, there was little overlap between experiences. While the data were rich and the participants were open with the researcher, there are still uncertainties that cannot be resolved without conducting future research.

Another limitation of the present study is that the self-reported information and experiences shared by the participants cannot be verified. So, the truthfulness of the women’s reported experiences is questionable; however, this cannot be avoided in qualitative research.
Lastly, some women had trouble articulating their thoughts and rationalizing their behaviours and decisions. Because they had never talked about insulin misuse with anyone prior to the interview, and upon hearing themselves attempt to explain the behaviour, several women found themselves confused and at a loss for words. As Participant #8 explained, 

"Like I said, you were the first person to ask and you’ve probably asked other people the same questions, and it’s really hard to get out. Because it’s just such a deep thought that you have, but you never think about it in your day-to-day life, so if whatever I said just doesn’t make sense, it’s because it never made sense to me in the first place, but it just felt ok to do."

6.3.3 Contribution to Existing Research

Previous research has identified that insulin misuse increases the risk of developing diabetes-related complications (Affenito et al., 1997; Polonsky et al., 1994; Rydall & Daneman, 1997). The present sample was women between the ages of 18 and 35 years, and two of these participants had experienced complications typically labeled as “long-term” consequences of poor metabolic control. One woman experienced retinopathy requiring laser treatment and another woman, the youngest participant at 20 years old, experienced symptoms of neuropathy and anticipated nephropathy to develop in the coming years. Therefore, in a young sample of nine women with type 1 diabetes who misuse insulin, two had already experienced some diabetes-related complication, supporting the existing literature that suggests these complications are more prevalent among those with prolonged elevated blood sugars.

Self-reported poor body image was prevalent among the majority of participants in the present study, which supports existing research suggesting that women with disordered eating have greater weight preoccupations (Pollock-BarZiv
& Davis, 2005). Eight of the nine participants in the present sample reported feeling negatively about their bodies or wished they could change parts of their bodies. Furthermore, some participants indicated that while their body image was poor as children or adolescents, it worsened with their diagnosis of type 1 diabetes and subsequent insulin therapy resulted in weight gain.

This study suggests that women with disordered eating behaviours may struggle with insulin misuse as much (or worse) as women with clinical eating disorders. These results support including insulin misuse in the DSM-V as a disordered eating behaviour contributing to both anorexia nervosa and bulimia nervosa. Further, perhaps including diabulimia as a diagnosable eating disorder would be a step to improving the treatment options available to those who misuse insulin. All patients with diabetes who misuse insulin should treated similarly, though, and a diagnosis with a clinical eating disorder should not be necessary in order to access treatment for overcoming insulin misuse.

6.3.4 Implications for Future Research

As noted previously, there are several topics that the participants discussed that were unexpected to the researcher and further study is warranted. Firstly, additional research should be done to better understand how and why women develop unique “theories” to understand their diabetes and justify their insulin misuse. Perhaps if these “theories” could be prevented, and those with diabetes had a comprehensive understanding of how insulin works and how their body’s function in the presence and absence of insulin there would be fewer women misusing insulin.
Another surprising result was that some women feel lucky to have diabetes because of their unique weight loss potential through insulin misuse. This attitude towards diabetes is incomprehensible to the researcher at this time, and it would be beneficial for researchers and health care professionals alike to understand this perspective in order to correct it.

Future studies should continue to use a qualitative approach to study insulin misuse in order to establish a comfortable relationship with those who are sharing personal, and at times distressing, details of their diabetes management. Using this approach to learn about how these women would like to be treated by health care professionals could be a great resource.

6.3.5 Implications for Practice

The global themes that have emerged may be useful to health care professionals who work closely with this population in order to better understand how to approach the women and offer support. Health care professionals who work closely with women who have type 1 diabetes may use this research to approach the topic of insulin misuse with a greater degree of sensitivity and understanding. The participants in this study often felt that members of their health care team were judgmental and unapproachable, which limits the patients’ desire to be honest about their insulin misuse behaviour.

Being aware of specialized programs for patients with concurrent type 1 diabetes and eating disorders or disordered eating is essential when dealing with this population. Offering resources to patients who exhibit warning signs of insulin
misuse, or who have admitted to misusing insulin, is a practice that some participants wished their practitioners used.
7.0 Conclusions

The present study aimed to better understand women's motivations behind engaging in risky weight control behaviours, specifically insulin misuse in type 1 diabetes. The researcher used a qualitative approach to these objectives, and the results were drawn from interviews with 9 participants.

Overall, the participants had poor body image or had poor body image during the height of their insulin misuse behaviour. This poor body image and weight control concerns was one major route to insulin misuse. Another major route to insulin misuse was diabetes burnout, wherein a participant felt overwhelmed and exhausted with the responsibilities and burden associated with maintaining proper metabolic control. Each participant had a unique approach to misusing insulin, at times negotiating with themselves what the appropriate insulin dose should be for a given meal or snack. Some participants theorized how to best manipulate their insulin doses to minimize glucose uptake, which indicated a poor understanding of type 1 diabetes and/or disordered eating tendencies.

Remarkably, many participants felt a temporary invincibility to developing diabetes-related complications as a result of insulin misuse despite an acute awareness of the risks associated with prolonged high blood glucose. Because each participant was the primary influence over her health behaviours, the family, friends and health care practitioners involved were unable to enforce change in the insulin misuse behaviour. A large part of this is that the participants felt there was a lack of support or resources to overcome insulin misuse, and many of these women had negative relationships with members of their health care teams.
While this study fills a small gap in the literature, several unexpected reports from participants pointed out additional areas of insulin misuse that are misunderstood and will require future attention and research.
8.0 References


9.0 Appendices

Appendix A: Sample Interview Questions

Does body image influence insulin misuse among women with type 1 diabetes?

1. What does body image mean to you?

2. How would you describe your thoughts and feelings about your body shape and size?

3. Does your body image have an influence on your day-to-day behaviours?

4. When were you diagnosed with type 1 diabetes?
   a. Describe your experience of learning to cope with your disease.
   b. Did you experience weight fluctuations when you started your insulin therapy?
   c. Has the length of time you’ve spent using insulin affected anything in your day-to-day life? For example, have you developed new eating habits, exercise habits, social circles, etc.? Do you have periods of high or low glucose levels that impact your mood or physical health?

5. Has your diagnosis with type 1 diabetes changed your thoughts and feelings about your body?
   a. Do you think about your body shape and size differently now?

6. Do you think that your prescribed insulin dose has an effect on your body shape and size?
   a. Does your prescribed insulin dose create any anxiety or worry for you?
7. Do you feel pressure from your parents to adhere to your diabetes care regimen?
   a. From your friends?
   b. From your health care team?
   c. Does this influence how you use your insulin?

8. Would you say that you take less insulin than you should?
   a. How often would you say this happens per week? Per month?
   b. Do you think this amount is mild, moderate, severe? Any other comments?

9. When did you start adjusting your insulin?
   a. What do you call this behaviour (ex: insulin restriction, omission, under dosing, misuse, etc.) [to remain consistent and reflective of their language]

10. How did you learn about using your insulin to control your weight?
    a. Was it something that you discovered on your own or did you hear about it through friends?

11. Are there certain things that trigger you to adjust your insulin doses?

12. Are you aware of any health risks associated with restricting your insulin doses?
    a. If yes, walk me through your decision to restrict your insulin or not.
    Do you weigh the pros and cons of skipping insulin doses?

13. What happens when you adjust your insulin doses?
    a. How do you feel when you’re reducing or skipping doses?
b. What are the benefits you see from doing this?

14. Do you experience any repercussions from your insulin adjustments?
   a. How are your energy levels after adjusting your insulin?
   b. What is your expectation for the short-term? Long-term?

15. Do you use any other methods to control your weight? [Purge, over-exercise, diet?]

16. What would your doctor say if you told him/her about your insulin adjustments?

17. Is there anything I haven’t asked about that you would like to share?
LETTER OF INFORMATION ABOUT THE RESEARCH STUDY:

Does body image influence insulin misuse among women with disordered eating and type 1 diabetes?

You are asked to participate in a research study conducted by Drs. Judy Sheeshka, Michèle Preyde, and Janet Madill, and graduate student Robyn Tyo of the Department of Family Relations and Applied Nutrition at the University of Guelph.

If you have any questions or concerns about the research, or would like a copy of the results of the research, please feel free to contact Dr. Judy Sheeshka at judy.sheeshka@vu.edu.au, or Robyn Tyo at rguvrem@uoguelph.ca.

PURPOSE OF THE STUDY

The goal of this study is to explore how women with type 1 diabetes feel about their body, and whether this affects how they use prescribed insulin.

PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:
- sign and date a consent form
- participate in a one-on-one, digitally-recorded interview with the researcher Robyn Tyo (approx. 45-60 min.)

You may contact the researchers listed above to obtain a copy of the study results.

POTENTIAL RISKS AND DISCOMFORTS

If you feel uncomfortable you may withdraw at any time and for any reason without penalty. You do not have to answer any question that makes you feel uncomfortable, and all information is kept completely confidential. If you choose to withdraw from this study, it will have no affect on your ability to receive counselling or treatment for your diabetes or other health services.
POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

The purpose of this study is to explore how women with type 1 diabetes feel about their bodies and adjust their insulin dose. Further, the researchers aim to understand the evaluation of risk women use when deciding to adjust insulin. Participants may be directed to health care facilities as needed to access services that may improve overall health or provide treatment for insulin adjustment behaviour.

PAYMENT FOR PARTICIPATION

You will not receive payment for participating in this study. However, you will be given a $25 gift certificate to Shopper’s Drug Mart or President’s Choice after completion, as a thank-you for your time and effort in participating in the study. Additionally, a $10 gift certificate will be given as a compensation for travel and/or parking expenses.

CONFIDENTIALITY

Every effort will be made to ensure the confidentiality of any information that is obtained in this study. Your name will not appear anywhere, and a pseudonym will be used during transcription and analysis of the interview. The digital recorders will be kept in a secure place until the student researcher can download the recordings onto an encrypted password-protected laptop that belongs to the researcher. The recordings will then be transcribed using a word processing program and the files stored on a password-protected computer in encrypted files. The digital recordings will be permanently erased from the recorders and computer; when the analysis has been completed, the transcriptions will be shredded.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. Should you volunteer to take part, you are free to withdraw at any time without penalty. You may refuse to answer any questions and still complete the study. During the interview or after the interview is completed, you may still withdraw from the study by contacting one of the researchers.

RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. This study has been reviewed and received ethics clearance through the University of Guelph Research Ethics Board. If you have questions regarding your rights as a research participant, contact:
Research Ethics Coordinator
University of Guelph
437 University Centre
Guelph, ON  N1G 2W1

Telephone: (519) 824-4120, ext. 56606
E-mail: sauld@uoguelph.ca
Fax: (519) 821-5236
LETTER OF INFORMATION ABOUT THE RESEARCH STUDY:

Does body image influence insulin misuse among women with disordered eating and type 1 diabetes?

You are asked to participate in a research study conducted by Drs. Judy Sheeshka, Michèle Preyde, and Janet Madill, and graduate student Robyn Tyo of the Department of Family Relations and Applied Nutrition at the University of Guelph.

If you have any questions or concerns about the research, or would like a copy of the results of the research, please feel free to contact Dr. Judy Sheeshka at judy.sheeshka@vu.edu.au, or Robyn Tyo at rguevrem@uoguelph.ca.

PURPOSE OF THE STUDY

The goal of this study is to explore how women with type 1 diabetes feel about their body, and whether this affects how they use prescribed insulin.

PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:
- sign and date a consent form
- participate in a one-on-one, digitally-recorded interview with the student researcher Robyn Tyo (approx. 45-60 min.) at the University of Guelph in a private conference room.

You may contact the researchers listed above to obtain a copy of the study results.

POTENTIAL RISKS AND DISCOMFORTS

If you feel uncomfortable you may withdraw at any time and for any reason without penalty. You do not have to answer any question that makes you feel uncomfortable, and all information is kept completely confidential. If you choose to withdraw from this study, it will have no affect on your ability to receive counselling or treatment for your diabetes or other health services.
POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

The purpose of this study is to explore how women with type 1 diabetes feel about their bodies and adjust their insulin dose. Further, the researchers aim to understand how women think about risk when deciding to adjust insulin. Participants may be directed to health care facilities as needed to access services that may improve overall health or provide treatment for insulin adjustment behaviour.

PAYMENT FOR PARTICIPATION

You will not receive payment for participating in this study. However, you will be given a $25 gift certificate to Shopper's Drug Mart or President's Choice after completion, as a thank-you for your time and effort in participating in the study. Additionally, a $10 gift certificate will be given as a compensation for travel and/or parking expenses.

CONFIDENTIALITY

Every effort will be made to ensure the confidentiality of any information that is obtained in this study. Your name will not appear anywhere, and a pseudonym will be used during transcription and analysis of the interview. The digital recorders will be kept in a secure place until the student researcher can download the recordings onto an encrypted password-protected laptop that belongs to the researcher. The recordings will then be transcribed using a word processing program and the files stored on a password-protected computer in encrypted files. The digital recordings will be permanently erased from the recorders and computer; when the analysis has been completed, the transcriptions will be shredded.

Confidentiality may be broken if you disclose information that suggests you may be a harm to yourself or to others (e.g., that you have fallen asleep while driving after altering your insulin dose, and similar behaviours). Under this circumstance, the researchers may consider an obligation to report the harmful behaviour to your medical practitioner. If the behaviour is reported, only the information regarding insulin adjustments and the harmful behaviour will be disclosed. Other personal information you have discussed during the interview will remain confidential.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. Should you volunteer to take part, you are free to withdraw at any time without penalty. You may refuse to answer any questions and still complete the study. During the interview or after the interview is completed, you may still withdraw from the study by contacting one of the researchers.
RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. This study has been reviewed and received ethics clearance through the University of Guelph Research Ethics Board. If you have questions regarding your rights as a research participant, contact:

Research Ethics Coordinator
University of Guelph
437 University Centre
Guelph, ON N1G 2W1

Telephone: (519) 824-4120, ext. 56606
E-mail: sauld@uoguelph.ca
Fax: (519) 821-5236
Appendix D – Consent form

SIGNATURE OF RESEARCH PARTICIPANT

I have read the information provided for the study “Does Body Image Influence Insulin Misuse Among Women with Disordered Eating and Type 1 Diabetes?” as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

________________________
Name of Participant (please print)

________________________  ______________
Signature of Participant Date

SIGNATURE OF WITNESS

________________________
Name of Witness (please print)

________________________  ______________
Signature of Witness Date
Appendix E – Budget

Each of the participants will be remunerated with a gift card redeemable at Shoppers Drug Mart or grocery stores using President’s Choice cards. The cards will each be loaded with $25, and additional costs for transportation and parking (estimated to average $10 per participant) will be compensated. For each of the 15-20 participants, an additional gift card in the amount of $10 dollars will be provided for transportation and parking costs. A total of $700 in gift cards is needed for this study.

Transportation costs for the researcher will total about $300. Round trip GO Bus fares from Hamilton to Toronto are roughly $25, and the researcher anticipates conducting 10 interviews in Toronto. Additionally, the researcher may drive from Hamilton to several Guelph locations to conduct interviews, totaling roughly $50 for gas.

Making long-distance phone calls on a cell phone are anticipated for screening participants, scheduling interviews, and contacting hospitals or clinics where interviews may take place. For this cost, an estimated $50 will be reimbursed to the researcher.

Finally, a cost of $25 is anticipated for printing posters that will be placed around the University of Guelph campus to recruit participants.

A total budget of $1075 is required for this proposed research.
Appendix F: Recruitment Posters
Researchers at the University of Guelph are looking for females with type 1 diabetes to complete an interview about body image, weight and using insulin.

You must:

1. be 18-35 years of age
2. have type 1 diabetes and use insulin

A $35 gift certificate will be provided to all participants.

Judy Sheeshka, PhD, RD  
Family Relations and Applied Nutrition  
University of Guelph  
judy.sheeshka@vu.edu.au

Robyn Tyo, MSc Student  
Family Relations and Applied Nutrition  
University of Guelph  
diabetesresearchstudy@gmail.com

This project has received approval from the University of Guelph Research Ethics Board # 12JL013
You must:

1. be 18-35 years of age
2. have type 1 diabetes and use insulin

We will require approx. 60 minutes of your time. If you are interested, please e-mail diabetesresearchstudy@gmail.com for more information.

A $35 gift certificate will be provided to all participants.

Contact Information:

Judy Sheeshka, PhD, RD
Family Relations and Applied Nutrition
University of Guelph
Gudiabetesresearchstudy@gmail.com

Robyn Tyo, MSc Student
Family Relations and Applied Nutrition
University of
Appendix G: University of Guelph Research Ethics Board Certificate
RESEARCH ETHICS BOARD – General

REB-G
Certification of Ethical Acceptability of Research
Involving Human Participants

APPROVAL PERIOD: August 17, 2012 to August 17, 2013
REB NUMBER: 12JL013
TYPE OF REVIEW: Delegated Type 1
RESPONSIBLE FACULTY: JUDY SHEESHKA
DEPARTMENT: Family Relations and Applied Nutrition
SPONSOR: N/A
TITLE OF PROJECT: Does body image influence insulin misuse among women with disordered eating and type 1 diabetes?

CHANGES:
3 Dec 12: B.13 Recruitment
21 Dec 12: D.17 Consent
21 Jan 13: B.10 Methodology

The members of the University of Guelph Research Ethics Board have examined the protocol which describes the participation of the human subjects in the above-named research project and considers the procedures, as described by the applicant, to conform to the University’s ethical standards and the Tri-Council Policy Statement, 2nd Edition.

The REB requires that you adhere to the protocol as last reviewed and approved by the REB. The REB must approve any modifications before they can be implemented. If you wish to modify your research project, please complete the Change Request Form. If there is a change in your source of funding, or a previously unfunded project receives funding, you must report this as a change to the protocol.

Unexpected events and incidental findings must be reported to the REB as soon as possible with an indication of how these events affect, in the view of the Responsible Faculty, the safety of the participants, and the continuation of the protocol.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and approvals of those facilities or institutions are obtained and filed with the REB prior to the initiation of any research protocols.

The Tri-council Policy Statement, 2nd Edition, requires that ongoing research be monitored by, at a minimum, a final report and, if the approval period is longer than one year, annual reports. Continued approval is contingent on timely submission of reports.

Membership of the Research Ethics Board - General: S. Banerjee, Community Member; J. Carson, Community Member; C. Carstairs, COA; S. Chuang, FRAN (alt); K. Chuong, Graduate Student; J. Clark, PoliSci (alt); J. Devlin, OAC; J. Dwyer, FRAN; M. Dwyer, Legal; B. Ferguson, CME (alt); H. Gilmour, Community Member (alt); J. Goertz, CME; B. Gottlieb, Psychology; B. Giguere, Psychology (alt); S. Henson, OAC (alt); L. Kuczynski, Chair; R. Ragan, Legal (alt); V. Shalla, SOAN (alt); R. Stansfield, SOAN.

Approved:
per
Chair, Research Ethics Board- General                       Date: ______________________

100
Appendix H: Homewood Health Centre Ethics Certificate

December 11, 2012

Ms. Robyn Tyo,
Graduate Student,
Department of Family Relations & Applied Nutrition,
University of Guelph.

Email: Robyn Tyo: rguevrem@uoguelph.ca

Re: Does body image influence insulin misuse among women with type 1 diabetes?

This is to confirm that annual approval has been granted for the above study. This approval expires on December 10, 2013.

Please know that further approval is required from Homewood Research Ethics Board (REB) prior to making any significant changes to the protocol, consent process or advertisement of the study.

Homewood REB needs to be promptly informed of adverse events and/or reactions that may arise from this study as per standard practice.

All researchers are required to enter into a Privacy Agreement with the appropriate custodian of clients’ personal health information prior to the commencement of the study. All researchers and their staff are responsible for possessing knowledge of, and ensuring compliance with, privacy legislation requirements, e.g. Personal Health Information Protection Act, 2004.

Upon completion of the study, Homewood REB would appreciate confirmation of the completion of the study and a brief summary of the results.

Homewood REB is constituted and functions in accordance with the ICH GCP and the Tri-Council Policy Statement (Ethical Conduct for Research Involving Humans) guidelines.

With kind regards,

Steve Abdool
Bioethicist & Chair, Homewood Health Centre Research Ethics Board
Appendix I: Sunnybrook Health Sciences Centre Ethics Certificate

Sunnybrook
HEALTH SCIENCES CENTRE

To: Dr. Julia Lowe
Endocrinology and Metabolism
Room H1 45

From: Dr. Philip Hébert

Date: December 27, 2012

Subject: Does Body Image Influence Insulin Misuse among Women with Disordered Eating and Type 1 Diabetes?

Project Identification Number: 410-2012
Approval Date: December 27, 2012
Expiry Date: December 27, 2013

The Research Ethics Board of Sunnybrook Health Sciences Centre has conducted a Delegated Board review of the research protocol referenced above and approved the involvement of human subjects on the above captioned date. The quorum for approval did not involve any member associated with this project.

Sunnybrook REB approval has been granted for the recruitment phase of this study only. Patients who agree to take part in this study will sign a University of Guelph Informed Consent Form and be University of Guelph research participants. The approval of this study at Sunnybrook includes the following documents:

- Protocol (received December 17, 2012)
- Screening Questions (received December 17, 2012)
- Poster (received December 17, 2012) (Submit to Sunnybrook Communications & Stakeholder Relations for approval prior to posting.)

☐ A formal Informed Consent Form (ICF) is not included in the approved documentation for this study as it is considered not required by the Sunnybrook REB; consent requirements, if applicable, have been otherwise dealt with.

All correspondence with the REB must include the assigned Project Identification Number. The REB requires immediate notification of all internal serious adverse events and significant deviations. Study continuation beyond one year requires submission of a renewal form prior to the expiry date or a study completion report must be received to close the file with the REB.

All REB approved studies may be subject to review by the Sunnybrook Quality Assurance and Education Program and, as Principal Investigator, you are responsible for the ethical conduct of this study. Approval by the Sunnybrook REB entails compliance with current legislation outlined

The Research Ethics Board of Sunnybrook Health Sciences Centre operates in accordance with the Tri-Council Policy Statement 2nd Edition, ICH-GCP Guidelines, Part C Division 5 of the Food and Drug Regulations, Part 4 of the Natural Health Products Regulations, and Part 3 of the Medical Devices Regulations. All Health Canada regulated trials at Sunnybrook are conducted by a Qualified Investigator.

Fully affiliated with the University of Toronto
in the Ontario Personal Health Information Protection Act (PHIPA) and all policies and
guidelines established by Sunnybrook. All applicable contracts and agreements must be
submitted to Sunnybrook Legal Services before this research may be initiated.

Philip C. Hébert, MD PhD FCFPC
Chair, Research Ethics Board

OR

Brian Murray, MD FRCP(C) D.ABSM
Vice-Chair, Research Ethics Board
Appendix J: Women’s College Hospital Ethics Certificate

Request for Administrative Review and/or REB Exemption Application Form

SECTION 1 Project Information

Project Title: Does body image influence insulin misuse among women with disordered eating?

Sponsor/Funder: Dr. Judy Sheehka

Is funding held at Women’s College Hospital?

Yes ☐ No ☐

If no, where will funding be held? University of Guelph

SECTION 2 Contact Information

Name of Principal Investigator/Grantee: Robyn Tyo

Department/Division/Program: University of Guelph, Master of Science, Applied Human Nutrition

Telephone: 519-820-1666

e-mail address: guevrnem@uoguelph.ca

SECTION 3 Request for REB Exemption - Please check off which category this project falls under:

☐ ICES Project (If yes, please provide proof of Privacy Impact Assessment)

☐ Research that relies exclusively on publicly available information (TCP52 Article 2.2)

☐ Research involving the observation of people in public places (TCP52 Article 2.3)

☐ Research that relies exclusively on secondary use of anonymous information or biological materials so long as the process of data linkage or recording or dissemination of results does not generate identifiable information (TCP52 Article 2.4)

☐ QA/QI Projects (e.g., program evaluation activities, performance reviews, testing within normal educational requirements when used exclusively for assessment, management, or improvement purposes) (TCP52 Article 2.5)

☐ Creative practice through which an artist makes or interprets a work or works of art (TCP52 Article 2.6)

☐ Requesting to post a flyer/poster at Women’s College Hospital for an external study. There is no active recruitment and no other study activities occurring at WCH (please provide proof of REB approval from home institution, a letter of support from department where you would like to post the flyer, and copy of advertisement [e.g., UHN, Sick kids, UOIT, etc...])
SECTION 3 PROJECT SUMMARY - In the space below please provide a lay summary of the project/study. Please include a brief description of the purpose, the objectives, the methods, and involvement of any human subjects or data. Please also describe any data linkage that will occur.:

A trend of girls and women with disordered eating behaviours or eating disorders exhibiting higher frequency of insulin misuse for the purpose of weight control has been identified. Insulin misuse, though, results in higher blood glucose levels and increases the risk of developing diabetes related complications. It is important to identify the motivations behind these dangerous insulin misuse behaviours in an attempt to prevent or minimize these risks in the future. The vast majority of this research is quantitative in nature, and so there is little understanding of the reasoning behind such risky behaviour. For this reason, I will be doing qualitative research for the duration of my studies.

I will conduct one-on-one interviews with women aged 18-35 who have type 1 diabetes and who misuse their insulin as a weight control strategy. My goal is to understand the experience of restricting insulin for weight control purposes and the risk analysis behind this behaviour. Further, I would like to understand how body image influences a woman’s decision to jeopardize her health in this way. Interviews will last about 1 hour, and participants will be given a $35 gift card to either President’s Choice or Shoppers Drug Mart as a thank you for their time.
SECTION 5 Documents Attached for Review

- Proposal/Project Summary
- Proof of Funding Document
- Privacy Impact Assessment Forms (for ICES studies)
- Study Budget
- Poster/Advertisement
- REB Approval from external institution(s)
- DEPARTMENTAL LETTER OF SUPPORT FOR POSTING FLYERS IN CLINICS
- OTHER (SPECIFY)

SECTION 7 Principal Investigator Attestation

This signature attests that the PI or Grantee (henceforth referred to as ‘the applicant’) has reviewed this application of REB exemption and believes that the aforementioned project does not require REB review/approval. The applicant also attests to have read articles 2.2-2.6 of the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans. Further, if at any point, the nature of this project changes such that REB review/approval may be required, the applicant will not implement any changes to, or deviations from the protocol without prior Research Ethics Board consultation to ensure that REB approval is not required.

Robyn Tyo
Print Name

Robyn Tyo
Signature

12/05/2013
Date (dd/mm/yyyy)

SECTION 8 RESEARCH ETHICS OFFICE USE ONLY

ADMINISTRATIVE REVIEW COMPLETED BY:

ALEXANDRA CHAPPELL
REB COORDINATOR
Signature
13/MAY/2013
Date (dd/mm/yyyy)

MANAGER, Research Operations
Signature
Date (dd/mm/yyyy)