

TYPE I DIABETES AND INSULIN OMISSION: AN IN-DEPTH LOOK

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Abstract

While insulin omission has been found to be a common behavior in those with type I diabetes, it has been primarily studied within the context of disordered eating behavior. Previous research supports medical providers and patients lack of comfort in discussing insulin omission. This study was designed to answer two questions. *Why do young adult college students with type I diabetes omit insulin?* and *what factors facilitate and act as barriers to open communication regarding insulin omission in the patient-provider interaction.* A total 13 (10 females, 3 males) college students completed a qualitative interview focused on insulin omission and communication of this behavior to medical providers, and 11 of the 13 completed a modified EAT-26. Using consensual qualitative research methods CQR (Hill, Thompson, & Williams, 1997), domains that emerged were reasons for insulin, predominant reason for insulin omission, motivators to give insulin as prescribed (i.e., adhere), overall communication of insulin omission to medical providers, and factors facilitating and barriers inhibiting communication regarding insulin omission to medical providers. Typical reasons for insulin omission included forgetting or delaying and forgetting, worrying about hypoglycemia and its social implications, being in situations where limited access to food/medical supplies, planning to be physically active, or being unsure of carbohydrate count in food. Insulin omission as a weight loss behavior was not reported by any of the participants during the interviews and all denied using insulin as a way to control their weight or shape on the EAT-26. Clinical implications and future research directions are discussed.

Keywords: insulin omission, type I diabetes, non-adherence, eating disorder

Type I Diabetes and Insulin Omission: An In-Depth Look

Type I diabetes is one of four types of diabetes caused by an inability of the pancreas to produce and secrete insulin into the individual's body (The Expert Committed on the Diagnosis and Classification of Diabetes Mellitus [ECDCDM], 2003). Type I diabetes makes up 5-10% of those diagnosed with diabetes and is much less prevalent than type 2 diabetes (ECDCDM, 2003), yet one out of every 400 to 600 adolescents and children will be diagnosed with type I diabetes and over 700,000 Americans (or 0.8% of the US population) are currently diagnosed with the chronic disease (American Diabetes Association [ADA], 2007a). The yearly incidences in the past 10 years have ranged from 3.7 to 20 per 100,000 Americans (ADA, 2007a). Once diagnosed, type I diabetics need to take insulin, a hormone essential to regulate glucose and energy in the body, as part of a daily care regimen. Some individuals may choose to take less insulin than prescribed or even skip insulin shots, otherwise referred to as insulin omission (Crow, Keel, & Kendall, 1998). The purpose of the proposed study is to explore *why* young adults with type I diabetes may engage in the behavior of insulin omission.

Insulin Omission

Insulin omission, as defined by Crow et al. (1998), is when:

...inadequate insulin is injected for the calories ingested, blood glucose may increase markedly. As a consequence glycosuria occurs and the volume of urine produced increases. The end result is the excretion of large amounts of glucose (and thus calories) in the urine, resulting in short-term reduction in weight from fluid loss and some caloric restriction. (p. 234)

Within the definition of insulin omission is a lack of specification of potential *reasons why* an individual may choose to engage in this behavior. One current explanation behind insulin omission is weight loss or control (Biggs, Basco, Patterson, & Raskin, 1994; Jones, Lawson, Daneman, Olmsted, & Rodin, 2000; Peveler, Fairburn, Boller, & Dunger, 1992).

Currently, omitting insulin, in order to lose or control weight, could be considered to fit into the second criteria of bulimia nervosa in the *Diagnostic and Statistical Manual of Mental Disorders, fourth edition, text revision* (DSM-IV-TR): “Recurrent inappropriate compensatory behavior in order to prevent weight gain, such as...misuse of medications...” (American Psychiatric Association [ApA], 2000, p. 594). Fairburn, Phil, and Beglin (1990) cautioned against the use of the diagnostic criteria for bulimia that have developed out of observations of individuals in eating disorder clinics, to other very different populations (i.e., those with type I diabetes). Others have also noted concerns about the context, evaluation, and classification of eating disorders in those with type I diabetes (Young-Hyman & Davis, 2010).

Meta-analyses have attempted to summarize the empirical studies to date that have investigated the prevalence rate of “eating disorders” and disordered eating in females with type I diabetes (Crow et al., 1998; Daneman, 2002; Nielsen, 2002; Nielsen & Molback, 1998, Rodin & Daneman, 1992). Many studies investigating insulin omission (as a purge behavior for weight loss/control) report it as a very common behavior among those with type I diabetes (Crow et al., 1998; Daneman, 2002; Rodin & Daneman, 1992). The prevalence rates of insulin omission in females found in the context of disordered eating ranged from 5.9%-39% (Herpertz et al., 1998; Stancin, Link,

& Reuter, 1989) and the prevalence rate of insulin omission in males found in the context of disordered eating ranged from 0% – 0.006% (Bryden et al., 1999; Fairburn, Peveler, Davies, Mann, & Mayou, 1991.; Herpertz et al., 1998; Peveler et al., 1992). In the four identified studies that examined the prevalence rates of insulin omission outside of disordered eating, the reported prevalence rates of insulin omission had a much narrower range for females, 25%-31% (Goebel-Fabbri et al., 2008; Morris et al., 1997; Polonsky et al., 1994; Weissberg-Benchell et al., 1995). Morris et al. (1997) and Weissberg-Benchell et al. (1995) separately examined insulin omission outside of disordered eating in males and both found a prevalence rate of zero. Results of the cross-national diabetes attitudes, wishes, and needs (DAWN) study investigated insulin compliance (defined as *complete success*) in those with type I diabetes and found a self-reported non-compliance rate to insulin of 17% and a providers' reported non-compliance rate to insulin of 27% (Peyrot et al., 2005).

The methodology used to measure insulin omission has varied across studies and several studies have used a single item measure of insulin omission (i.e., “I take less insulin than I should,” Polonsky et al., 1994, p. 1180) with no clarification about the reason or purpose of the behavior. Possible reasons for omitting insulin in these measures were either unclear (Goebel-Fabbri et al., 2008; Morris et al., 1997; Weissberg-Benchell et al., 1995) or assumed that the behavior was a way to lose and control weight and manipulate body shape (Jones et al., 2000; Peveler et al., 2005). Thus, an accurate understanding of why individuals may choose to engage in this behavior remains unclear. Overall, what *can* be concluded from the studies on prevalence rates is that insulin omission (as it has been measured) in those diagnosed with type I diabetes is not

uncommon, especially in young adult and adult females.

Appropriate use of insulin is one essential component for glucose control and intense glucose control has been seen to delay and even prevent complications that are associated with diabetes (Lachin, Genuth, Nathan, Zinman, & Rutledge, 2008). Rubin and Peyrot (1999) found that the more complications an individual with diabetes has developed, the lower quality of life and more depressive symptoms they are likely to report. It has been estimated that over 15% of individuals with type I diabetes diagnosed in childhood will be dead by the age of 40 due to diabetic complications (Marrero & Guare, 2005). Given that Type I diabetics who report omitting insulin have been found to have even higher rates of morbidity (diabetic complications) and mortality (Goebel-Fabbri et al., 2008) than those not reporting insulin omission, a more complete understanding of why type I diabetics engage in insulin omission is essential. Along with investigating reasons why individuals with type I diabetes engage in insulin omission, a better understanding of what would help open communication between patient and physician regarding this behavior also needs to be obtained.

Patient-Provider Communication about Insulin Omission

Cameron, Northam, Ambler, and Daneman (2007) advocated that mental health screenings be considered as important as or even more important than complication screenings in youth with type I diabetes. Considering that clinical depression and generalized anxiety have been found to be at least twice as prevalent in individuals with diabetes than those in the general population, (Anderson, Freedland, Clouse, & Lustman, 2001; Grigsby, Anderson, Freedland, Clouse, & Lustman, 2002), the suggestion by Cameron et al. (2007) appears supported. Yet, no recommendations have been made of

past, current, or future screenings for adherence to insulin regimen even though non-adherence rates as high as 31% have been found in those with type I diabetes and as high as 39% when studied in the context of disordered eating/eating disorder behavior in persons with type I diabetes (Stancin et al., 1989). To date, there is no scale or screening tool developed specifically to measure adherence to insulin regimen. This suggests the possibility of a broader problem in patient-provider communication, both in general about a variety of mental health issues, and more specifically regarding insulin adherence.

The communication of insulin omission by an individual has two components, broadly conceived as patient variables and medical provider (e.g., physician, nurse practitioner, physician assistant) variables. Engstrom et al. (1999) investigated the prevalence rates of eating disorders and disordered eating in 89 females with type I diabetes and found that none of the females that had disordered eating behaviors or a diagnosable eating disorder had shared their behaviors with “the staff at the pediatric department” (p. 179). Insulin omission (a type of purging behavior) was not specified within this study as the means of purging nor was it clearly eliminated as one possible means of purging. Is this “secretive behavior” of not following and adhering to the diabetes regimen without communication to the physician generalizable to those that engage in insulin omission specifically? Biggs et al. (1994) discussed the honesty of patients with type I diabetes that were omitting insulin and found that they reported significantly more lying to physicians about adhering to their insulin regimen than did non-omitters. Thus, it would appear from the patient’s perspective there may be barriers that prevent reporting insulin omission to a medical provider.

From the medical provider’s perspective, there may also be underlying concerns

regarding asking about or responding to insulin adherence issues such as an inability to assist in the problem. A qualitative study by Tierney, Deaton, and Whitehead (2008) investigated attitudes and practices of 20 health care professionals who treat those with type I diabetes and disturbed eating and weight control (including insulin omission as it has been defined in the literature). Although the purpose of their study was not to investigate practitioners' attitudes and beliefs about insulin omission, it appeared to be a common topic within the four found "themes." Also, it was common throughout the four themes that the professionals felt uncomfortable treating, diagnosing, discussing, and even referring out (to mental health providers) patients with insulin omission behavior. One major *assumption* within the study was that when the practitioners were discussing insulin omission it was being done to manipulate, control, or lose weight, and yet the study did not specifically assess reasons why. Without asking questions and confronting patients they feel are omitting insulin, how would physicians know that the reason for insulin omission is weight loss? The inter-personal factor of the quality of the patient-provider relationship and communication between the two parties has been found to be related to adherence rates; the better relationship and communication, the better the reported adherence rates (Karkashian & Schlundt, 2003). Thus, medical providers should be more direct and clear in communicating about insulin omission in type I diabetes. While previous research points to practical suggestions to decrease insulin omission such as more flexible treatment schedules and decreased frequency of hypoglycemic episodes (Novo Nordisk, 2010) little research has investigated what might improve communication regarding insulin omission between the medical provider and patient. The question from a psychological standpoint then becomes what factors do individuals

with type I diabetes perceive as facilitating open communication between themselves and their physicians regarding insulin omission?

Young Adult College Students as the Population of Interest

Young adult college students were chosen as the population of interest for several reasons. In previous studies, although studied age range was quite broad (ages 11 – 72), about half of the studies were of adolescents -young adults (ages 11-25) (Fairburn et al., 1991; Jones et al., 2000; Peveler et al., 1992; Rydall, Rodin, Olmsted, Devenyi, & Daneman, 1997; Weissberg-Benchell et al., 1995). To add a more in-depth understanding to the quantitative studies done in this area, a young adult age (18-24) appeared more useful than adolescents given the importance of self-awareness and general verbal skills to describe and discuss their experiences. It was thought that a more adolescent population (ages 11-17) might not have the same ability to discuss insulin omission as in-depth as a young adult population.

In addition, young adult college students were chosen as the population of interest due to the rapid changes occurring in their lives and in the environment around them. According to Bronfenbrenner and Evans' (2000) bioecological model, there are many layers of the environment that have an impact on an individual's development. These include the microsystem, mesosystem, exosystem, and macrosystem (Bronfenbrenner & Evans, 2000). Individuals with type I diabetes attending college will experience changes within each of these systems that could affect appropriate insulin use. Multiple system examples include an individual's ability to regulate his/her insulin regimen without parental supervision (microsystem), interaction of a new living place and the individual being comfortable/ uncomfortable sharing a diagnosis of type I diabetes (mesosystem),

understanding of the diagnosis and insulin use by friends of the individual (exosystem), and insurance coverage changes due to age (macrosystem). In combining previous research in the area of insulin omission with an ecological systems view of development, studying insulin omission in young adult college students appears most appropriate. Finally, a third reason for choosing a young adult population was ease of access and availability in a college setting.

Statement of the Problem and Purpose of Study

There is an inadequate literature base on *reasons why* male and female young adults with type I diabetes omit insulin. Because insulin omission has been assumed (and yet not measured reason) to be a weight loss/weight control behavior, insulin omission has been studied more frequently in female populations. It is unclear if insulin omission is (a) an adherence issue, (b) an illness-specific disordered eating behavior, or (c) something completely different that has not yet been explored. Finally, it appears that insulin omission, as a problematic health behavior, is a behavior that both patients and physicians avoid discussing and thus, there is little in the literature to help patients or physicians communicate more effectively regarding this often secretive and easily hidden behavior. Given the gaps noted above, the purpose of the study is to answer the following two research questions. Research Question #1: Why do young adult college students with type I diabetes omit insulin? Research Question #2: What factors do young adult college students with type I diabetes perceive as facilitating and inhibiting (i.e. acting as barriers) open communication about insulin omission with their medical providers?

Method

Participants

A total of 23 college students with type I diabetes (10 males, 13 females) were screened and 13 (3 males, 10 females) admitted to omitting insulin and participated in the study while 10 of the 23 screened reported that they did not omit insulin and therefore were not include in the study. All participants were between the ages of 18 and 24 years old, were fluent in English, attended a public University, and had no other disabilities. The mean age of individuals that admitted to omitting insulin and those that denied omitting insulin were 21.4 and 20.5 years old respectively. The mean age of diagnosis of individuals that admitted to omitting insulin and those that denied omitting insulin were 9.9 and 12 years old respectively. The mean year in school of the 13 individuals that admitted to omitting insulin was 15.3 (Senior) and 100% were Caucasian. Eight of these individuals reported living off campus and five reported living on campus. Three of the individuals reported giving insulin injections while the other ten reported that they were currently on an insulin pump. Each of the 13 participants completed the Telephone Screening Questionnaire and the Semi-Structured Qualitative Interview. Eleven of the thirteen also completed the Eating Attitudes Test (EAT-26), while the remaining two of thirteen participants were unable to be reached via telephone to complete the EAT-26. All participants that started an interview were mailed a \$20 gift card for their participation. All participants completed the full qualitative interview.

Researchers

The research team consisted of four graduate students from the same program (Counseling Psychology) and university. The principal investigator was diagnosed with type I diabetes in 1985 and none of the other research team members had diabetes. Research team members were all Caucasian but varied in age (23-39 years old), sex,

theoretical orientation (Feminist, Cognitive-Behavioral, Adlerian, Narrative), research interest areas (health psychology, qualitative data analysis, eating disorders/body image), religion/faith, SES background, and year in training (second year masters, completed masters, first year doctoral student, doctoral candidate). Considering that sex and theoretical orientation are often demographic characteristics that biases arise from (Hill et al., 2005; Hill et al., 1997), it was important to have variations of these variables especially within the research team for the proposed study. The auditor was a doctoral candidate from a different program of study (Clinical Psychology) and a different university. She has several previous experiences with analyzing data from qualitative studies, identifies her theoretical orientation as eclectic, and has research interests in women's issues.

Team members' initial biases. Team member's biases surrounding insulin omission and communication of this to their medical team were discussed and recorded during the initial training meeting. Biases discussed around reasons for insulin omission included personality style, rebellion from parents, not for weight loss, for weight loss, inconvenience, and embarrassment/stigma. Biases discussed around communication of insulin omission to the medical provider included that participants will report poor communication regarding this behavior to medical providers, feel unheard/misunderstood by medical providers, worry about reprimand, and to report "socially-desirable" behavior (i.e., insulin adherence).

Procedure

Recruitment. Participants were recruited through an email sent out at a mid-sized, Midwest public University through the Communication Center and the Disabled

Student Development (DSD) office (Appendix A). Each participant that responded to the recruitment email was sent a contact form (Appendix B) and informed consent form (Appendix C). Once the contact form and informed consent were returned, the participant was contacted and scheduled for a time to complete the Telephone Screening Questionnaire. Participants that met the inclusion criteria and agreed to participate and be audio-recorded for the full semi-structured qualitative interview were then scheduled for a time to complete the interview. After the completion of the interview, each participant was contacted again and asked to complete the EAT-26.

Measures. *Telephone Screening Questionnaire.* Developed by the research team, the Telephone Screening Questionnaire was used to gather demographic information and be sure that the participants met the inclusion criteria. The Telephone Screening Questionnaire also included three screening questions about omitting insulin: a) *In the past 10 days, have you missed an insulin dose?*, b) *Do you sometimes take less than you know you should?*, c) *Do you sometimes not take insulin when you know you should?* Participants were included in the study if they endorsed any of the three questions. The questions are altered versions of questions that authors have previously used to assess for insulin omission (Goebel-Fabbri et al., 2008; Polonsky et al., 1994; Weissberg-Benchell et al., 1995). (Appendix D).

Semi-Structured Qualitative Interview. The 12 item, semi-structured interview was developed based on a review of the literature on insulin omission, contacting members of the target population (e.g., those with type I diabetes that admit to engaging in insulin omission), and the principal investigator's personal experiences with diabetes and taking insulin. The semi-structured interview was initially developed and pilot tested

on two individuals with type I diabetes that admitted to omitting insulin, for length and clarity of the questions, and to allow the principal investigator to practice using the semi-structured interview. The questions were reviewed by the research team and appropriate revisions were made (i.e., ordering of questions, dividing up two barreled questions). The final interview questions focused on living with type I diabetes and taking insulin, insulin omission, and communication of insulin omission to one's health care team (Appendix E).

Eating Attitudes Test (EAT-26, Garner et al, 1982) – modified. The EAT-26 is a self-report measure of concerns and symptoms characteristic of eating disorders. It is not meant to diagnose, but is a screening measure used to assess “eating disorder risk.” It includes a demographic portion (Part A- 7 items), frequency of thoughts, behaviors, and emotions related to eating and weight gain using a 6-point scale (*Always to Never*) (Part B- 26 items), and behavioral questions also on a 6-point scale (*Never to Once a day or more*) (Part C- 5 items). Each participant's body mass index (BMI) was also calculated using his/her current weight in pounds and height in inches (World Health Organization [WHO], 2012). On the EAT, a participant is defined as “at risk” for an eating disorder if he/she meets one of three criteria, a) a total score > 20 on Part B, b) endorsed bingeing 2-3 times a month or more, purging more often than never, or exercising once a day or more in Part C, c) or has a BMI that indicates that he/she is currently underweight. Item 3 under Part C states “In the past 6 months have you ever used laxatives, diet pills, or diuretics (water pills) to control your weight or shape?” This question was modified in this study to “In the past 6 months have you ever used laxatives, diet pills, diuretics (water pills), or insulin to control your weight or shape?”

Interview and EAT-26 procedures. Interviews were audiotaped and conducted over the telephone by the principal investigator who shared prior to the interview that she was diagnosed with type I diabetes at the age of two. The participants were told that the purpose of the study was to explore the experience of those with type I diabetes and using insulin and that the goal of the study was to advance the understanding of the experience of living with type I diabetes and taking insulin. Interviews ranged from 13 minutes to 39 minutes with a mean interview time of 25 minutes ($SD=7$ minutes). The audiotaped interviews were transcribed by members of the research team besides the principal investigator and the principal investigator then reviewed all transcripts for accuracy against the audiotapes. Each participant that completed an interview was called at a later time by the principal investigator and asked to complete a follow-up questionnaire, the modified EAT-26. Eleven of the thirteen participants were able to be reached via telephone and all agreed to complete the modified EAT-26 over the telephone.

Data analysis. The qualitative interviews were analyzed using consensual qualitative research (CQR) methodology (Hill et al., 2005; Hill et al., 1997). Each member of the research team was trained by the principal investigator in the use of CQR and read the above works of Hill and colleagues. A training meeting was held and initial biases were recorded and discussed during this initial meeting. A presentation was given by the principal investigator on how CQR works and questions and concerns that the research team members had were addressed. Research team members were also asked to develop and sign a contract agreeing to discuss their opinions freely, minimize power differentials, and discuss problems openly throughout the research project given that consensus and equality of power are essential components of the CQR process (Hill

et al., 2005).

Initially, each member of the research team coded the same interview for domains and core ideas and the team met to discuss the coding process, difficulties, and suggestions. All domains were developed from the transcripts. Once a consensus was met for this first interview, each interview was coded for domains and core ideas by two members of the research team individually, and then agreed upon a final coding consensually. Categories were then created across cases and how frequently the category applied to the whole sample was reported using Hill et al.'s (2005) modified labels of *general* (all or all but one), *typical* (more than half but less than general), and *variant* (two cases but less than typical) . An external auditor was used to provide feedback for the domains, core ideas, and cross-analysis of categories.

Validation strategies. Consistent with Hill et al.'s (1997) recommendations, coherence, representativeness to the sample, and trustworthiness were all used to evaluate the data obtained from using CQR. Coherence of the results refers to the idea that the results make logical sense to a reader and are presented so that a reader could understand how the research team came to their conclusions. Coherence is shown through answering the research questions in a logical way that accounts for all of the data along with supporting our findings with direct quotes from our participants to further illustrate categories within each domain (Hill et al., 1997). The representativeness of the results to the sample is evaluated. This was done through the labels of *general*, *typical*, or *variant* as discussed earlier. If a result only applied to one case, it was dropped because it was considered not representative of the sample (Hill et al., 1997). Trustworthiness of the findings was achieved through a consensual process of data analyzation, open discussion

of biases, and frequent dialogue regarding the CQR process.

Results

Six domains emerged from the data regarding insulin omission and communication of insulin omission to one's medical provider. These included a) reasons for insulin omission, b) predominant reason for insulin omission as reported by each participant, c) motivators to give insulin as prescribed (i.e., adhere), d) overall communication of insulin omission to medical providers, e) factors facilitating communication regarding insulin omission to medical providers, and f) barriers inhibiting communication regarding insulin omission to medical providers. Hill et al.'s (2005) recommended labels were used to describe how representative each category was for the sample. *General* describes categories that applied to 12-13 participants, *typical* applied to 7-11 participants, and *variant* applied to 2-6 participants. Categories that applied to one participant were not reported. In this data set, no *general* categories emerged. See Table 1 for the typical and variant categories that emerged from the data during the analysis of insulin omission and communication of insulin omission to one's medical provider. Typical categories are discussed in detail under each domain and variant categories are mentioned separately under each domain.

Table 1

Six Domains and Their Typical and Variant Categories

Domain	Typical (7-11)	Variant (2-6)
Reasons for insulin omission	<ul style="list-style-type: none"> • Forgot/delay and forgot (11) • Worry of hypoglycemia and its social implications (8) • Situations where limited access to food/medical supplies (7) 	<ul style="list-style-type: none"> • Difficulties with acceptance of diabetes and the need for insulin (5) • Other's lack of understanding about insulin (5)

	<ul style="list-style-type: none"> • Plan to be physically active (7) • Unsure of carbohydrate count (7) 	<ul style="list-style-type: none"> • Expense of supplies (2) • Stress/depression (2) • Other non-adherence that makes giving correct insulin difficult (2)
Predominant reason for insulin omission ^a		<ul style="list-style-type: none"> • Forgot (5) • Avoid hypoglycemia (4) • Difficulties with acceptance of diabetes and the need for insulin (4) • Expense of supplies (2)
Motivators to give insulin as prescribed (i.e., adhere)	<ul style="list-style-type: none"> • Future health and preventing long-term diabetic complications (10) • Relational motivators (7) 	<ul style="list-style-type: none"> • Avoiding immediate physical side effects (5) • Lower HbA1c (2) • Thoughts of future family life (2)
Overall communication of insulin omission to medical providers	<ul style="list-style-type: none"> • Non-disclosure (7) 	<ul style="list-style-type: none"> • Direct disclosure by patient (4) • Indirect disclosure via technology (4)
Factors facilitating communication regarding insulin omission to medical providers	<ul style="list-style-type: none"> • Patient-centered approach to treatment (10) • Empathic, non-judgmental interpersonal style of the medical providers (9) 	<ul style="list-style-type: none"> • More time with medical providers (3) • Knowledgeable medical providers (3) • Decreased patient behavior of insulin omission (2)
Barriers inhibiting communication regarding insulin omission to medical providers	<ul style="list-style-type: none"> • Disease-driven, medical approach to treatment (7) • Non-empathic, judgmental interpersonal style of the medical providers (11) 	<ul style="list-style-type: none"> • Lack of adequate time with medical provider (3) • Switching from pediatric to adult medical providers (3)

Note. Frequencies for each category are provided in parentheses.

^a As reported by each participant in response to the question, “If someone asked you the predominant reason why you omit insulin, what would you say?”

Reasons for Insulin Omission

Typical categories.

Forget/delay and forget. The most common reasons for insulin omission reported by participants was forgetting to give insulin or purposely delaying and then forgetting to give insulin. Four participants noted both as a reason that they omit insulin, while three reported just purposely delaying and forgetting and four reported just forgetting. Explanations for forgetting to give insulin included being busy, distracted, or on the go. Many of those that reported delaying and forgetting, reported taking insulin at some point when they remembered, but often hours later than it should have been given. See Table 2 for sample quotes.

Table 2

Sample Quotes about Forgetting/Delaying and Forgetting as Reasons for Insulin

Omission

- | | |
|----------------|---|
| Participant #2 | Being diabetic so long, it's like, "Oh, yes, when I eat something I have to take insulin," but sometimes you just space it.....it's one of those things where you have a thousand things on your mind, and of course, the ones that are routine are the ones that slip through sometimes. A couple of weeks ago I grabbed a piece of cake, and then I'd be out the door. A half hour later I'd think, "Oh yea, this is why I feel bad.".....Usually when I forget it's because I have something else on my mind. It's just something that you've lived with your whole life, so it's like really second nature, but easy to forget because it's there all the time. |
| Participant #4 | Occasionally I'll eat something and I'll forget to put it into the insulin pump...usually it's just absentmindedly I ate and wasn't thinking about it and forgot..... There have been a few times that I'll eat something and feel like I have to keep working or keep focused cause I don't want to interrupt class, and so I'll wait until there's a break to give myself insulin, but sometimes that break won't come or sometimes I'll forget then as well. |
| Participant #7 | [Sometimes when I wake up low and eat first without giving insulin] I get to watching TV or working on something else and completely forget to take insulin for the food I ate. |
| Participant #8 | Sometimes when I'm at work and I'm eating, I just totally forget to take the bolus because I have something come up. Or I'm at school and I need to get to my next class and I'm eating a bag of pretzels and I'm sitting in class the whole time "Did I take it? Did I not take it? Well I don't want to take it again."I just completely forgot. I just get busy doing something else and it was a situation where I didn't |

know for sure if I had done it or not, and I didn't want to over-do it, so I just didn't.

Participant #12 Your surroundings catch up to you and they overtake your thoughts and just completely blind-side you from what you should be doing. On the go situations, diabetes accidentally gets overlooked, so you just take your food and diabetes is completely forgotten.

Worry of hypoglycemia and its social implications. More than half of the participants noted that worry/fear of hypoglycemia and/or its social implications were reasons that they omitted insulin. Worry and fear about hypoglycemia included being easier to correct high than low blood sugar levels and avoiding "passing out" because of hypoglycemia. Social implications of having hypoglycemia that lead to insulin omission included inconveniencing others, feeling awkward asking for something one would need to treat hypoglycemia, not wanting others to have to take care of hypoglycemia, and "not freaking anyone out." See Table 3 for sample quotes.

Table 3

Sample Quotes about Worry of Hypoglycemia and its Social Implications as Reasons for Insulin Omission

Participant #2 Because I don't want to drop. I think that would be the worst part of it, low blood sugar. Because I get really confused and people get really concerned and me, so that's what I try to avoid the most [by not giving insulin]..... because you're going to have to stop, go take care of it, do all that, so it's like alright, I might cut back [on my insulin]. ..I fear embarrassment. The last thing you want to do is pass out in front of anybody because then they're going to be like freaked out every time they see you. That and just, it's kind of always in the back of your mind, like "I'm starting to feel funny, what, diabetes-wise is going on with me right now?"..... low is the most noticeable effect. People can't really tell when your blood sugar is high but they can definitely tell when it's low.

Participant #7 It's just the effects of the insulin that kind of get to me, like they hypoglycemia..... I'm afraid of being low. Like if I'm out with friends, I'll probably back up my dose cause on my mind, I've realized its better for me to be on the high side than on the low sideif I'm not the one driving anywhere, I don't want to have to be an inconvenience to someone to stop and get something.

- Participant #9 If I dose too much [insulin] when I have a job set in front of me, it would be too irresponsible. I wouldn't be able to shrug that off at work or in class. I would have to fix it and I don't want to fix it on someone else's time. Don't want to inconvenience them.
- Participant #10 The only time I really don't give myself enough insulin is if I'm afraid, before I go to bed, that my blood sugar will go low. When I wake up and my blood sugar is low, I feel horrible and then you have to wake up, get up, and go get a juice or whatever.....sometimes my blood sugar is low and it doesn't come up for some reason. A couple of weekends ago when I was in Ohio, I was staying with a bunch of friends and I didn't know the people that we were staying at their house, so sometimes I feel awkward life if I had to ask for something [to raise my blood sugar]. But, I didn't give myself enough insulin before I went to bed just because I think I'd be uncomfortable if I'd have to ask for juice or something.
- Participant #11 I'll take less [insulin] than what I think I need so that I cannot worry about going low and passing out. Actually today I had a presentation to do in one of my classes and I knew I didn't want to go low but I had just eaten lunch. So I took maybe about two units less than I normally would, just because, when I feel low blood sugar and I have something important to do, like speak, I freeze up. Even if my blood sugar is fixed in time, I still feel like "All hope is lost for this situation." It's hard to recover from the low blood sugar psychologically. So, I took less insulin so that I would feel more confident in my presentation that I wasn't going to have any problems with low blood sugar.

Situations where limited access to food/medical supplies. Over half of the participants mentioned that one reason for omitting insulin was being in situations with limited access to food and/or medical supplies. Situations that participants identified as having limited access to food included the beach/camping, laboratory/class, and work. Several participants mentioned having limited snacks with them, such as juices boxes or glucose tabs, but a concern that these may run out, thus gave little or no insulin. A few participants mentioned not having back up insulin, their blood glucose meter, or their primary insulin with them and thus all of these prevented them from giving insulin as needed. See Table 4 for sample quotes.

Table 4

Sample Quotes about Situations where there is Limited Access to Food/Medical Supplies as Reasons for Insulin Omission

- Participant #1 Went out to the beach and didn't have much food around, just water and pop, so I didn't give myself as much insulin as I should. That's about the only time I don't take as much insulin, if I'm going out like the beach, picnic, anywhere where I can't just come back home right away and get food. I assume it's [blood sugar] usually pretty high, like during the time that I do this.
- Participant #2 I'm a biologist, so I spend a lot of time in the lab and when you start a project, you know you are going to be in there for awhile. No real access to food in there. So it's like alright, I may be done for the next 6 hours. I don't want to take too much [insulin] for lunch so I might cut back more than I should.
- Participant #7 Sometimes I leave the house and I forget like my sugar tablets or forget my meter. I kind of get a little worried or anxious that my sugar is going to go low and I don't have anything with me, so I back off insulin. Yesterday when I went out to get fast food and made a detour to work without my bag with my meter and sugar tablets. I ate Arby's and took, I'm not sure how much less, but I was definitely more conservative with my insulin dose.
- Participant #10 I always have juices with me, but if you know I'm somewhere and I only have three juices with me and no other food, I want to make sure that my blood sugar doesn't get low, so I'd take less [insulin].
- Participant #11 I can figure out whether or not I should run the risk of going high and leave my insulin at home or should I take it with, so that I know my blood sugar's going to be okay, but then run the risk of leaving it and not have it when I need it. So, sometimes, it can be a hassle just to take it along with me places, so I'll leave it [at home], rather than risk losing it. ... or if I'm not going to be able to easily access something to raise my blood sugar if it goes low, then I'll kind of take less than what I think I need.

Plan to be physically active or unsure of carbohydrate count in food. Over half of participants noted that they omitted insulin or gave less insulin when they planned to be physically active or exercise and a few of these participants (two) noted that it was to prevent low blood sugar after physical activity/exercise (i.e., adherence to appropriate insulin use). Over half of the participants stated that insulin was difficult to give as prescribed because it is difficult to count the amount or carbohydrates that one is eating,

and therefore, difficult to calculate the correct amount of insulin to give. Themes here included underestimating the amount of carbohydrates consumed, eating out at restaurants where it is difficult to know carbohydrates in a meal, and certain foods that are difficult to calculate (i.e., pastas, buffets). Given that participants reported adjusting insulin for physical activity and adjusting insulin for the amount of carbohydrates as honest attempts to manage and regulate blood sugar, these themes do not appear to imply insulin omission as it is being studied in this article and appear to be appropriate self-changes in insulin due to external factors.

Variant categories. Five variant categories emerged in the domain of reasons for insulin omission (See Table 1). The most common variant category was participants that expressed difficulties with acceptance of diabetes and the need for insulin. Given the surprising nature of some of the participants' responses that were coded in this variant category, quotes have been included from each participant below in Table 5.

Table 5

Quotes that Imply Difficulties with Acceptance of Diabetes and the Need for Insulin as Reasons for Insulin Omission

Participant #5	I struggle with insulin because I find myself having the attitude that other kids don't have to do this so I shouldn't either.....insulin represents diabetes to me.....If I'm in a hurry, I might look at where I keep my insulin and be like "I don't have time for this right now." Gosh, it's so bad but I guess I don't place enough importance on it [taking insulin] and I just think, I'll do it later if I remember.....Sometimes it's like my protest against diabetes, it's that I don't feel like taking my insulin, so I'm not going to.
Participant #8	I went through a period where I refused to take insulin, because I didn't want to be sick..... I mean it was only for like two weeks but I just really didn't want to mess with it. I didn't want that responsibility because it's such a big responsibility for a person.....I didn't want to be type I diabetic anymore. I just wanted it to go away.

- Participant #9 It's not something that anybody should have to do. The fact that it's a hormone that everybody else has and that I have to physically inject it, it just doesn't sit right with me.....I don't even know what it [insulin] is.....I just get sick of being diabetic and so I just stop. Like stop testing my blood sugar and stop dosing insulin, because it's how it used to be. Where I didn't have to do anything before a meal. [Not taking insulin] In the moment, it's like a stand against diabetes.....Not giving myself insulin just feels like a bit more freedom.....insulin is ruling your life and you're not in control of it. That's probably one of the biggest reasons that I don't take insulin when I'm supposed to. Because insulin is in control of me.
- Participant #11 Giving myself the shot feels so abnormal....Sometimes it feels like it was mechanical or robotic and it just seems so unnatural to give myself a shot. Sometimes taking a shot feels like "I'm not supposed to do this" and sometimes it might even feel like, maybe I was meant to die instead of doing this for the rest of my life. Maybe if I have a disease, it's just because I was meant to have the disease and experience it until I die from the disease.
- Participant #12 It's been really hard to try to fit diabetes in....Trying to remember "Oh I have to check my blood sugar and take insulin for whatever I eat." It's just much easier to get out of soccer practice, eat a couple of crackers, and then go to band practice, and just kind of completely skip the other steps that your doctor really wants you to do. It's easier just to eat the food and kind of ignore the diabetes....I'm a teenager and want to be a normal teenager. It feels normal [to not take insulin]. It's kind of like, well, this is what everyone else is like. I'm just one of them and I'm just eating, can walk away from my food, and do what they're doing. I don't stop to take my insulin. So, it's like my pancreas works, till I feel bad later.

Other variant categories that emerged in the domain of reasons for insulin omission included others' lack of understanding about insulin, insulin being financially difficult to acquire, stress/depression, and other non-compliant behaviors that make giving a correct insulin dose difficult. Several participants noted that a lack of understanding from others about insulin has delayed them or prevented them from giving insulin at some point in time. As Participant #11 explained:

At a restaurant I feel discouraged from taking insulin. I actually used to wait tables. There would be someone who would take insulin at their table, and then other people would complain to me about it, you know, ask me to make them stop

taking insulin. So, I don't take insulin shots in a restaurant anymore [and sometimes forget when I get home].

A few participants mentioned that insulin was very expensive and they had insurance limitations or difficulties in getting the appropriate amount of insulin to meet their insulin needs, therefore would omit insulin as needed to "ration it" [Participant #11] or "to make it to the next paycheck, I won't take, or maybe take less, until I know we have money for it." [Participant #8]. A few participants stated that stress and/or depression caused them to omit insulin. Participant #9 stated "When I'm unhappy, I just feel like having freedom would make me happier, so taking away any routine [including insulin] makes me feel freer." Finally, a few participants mentioned not adhering to other self-management behaviors (i.e., testing blood glucose or changing the insulin pump site as prescribed) that make it difficult to give insulin as prescribed.

Reason not mentioned for insulin omission. Omitting insulin for the purpose of weight loss or weight control was not mentioned by any of the participants. In fact, only one participant mentioned anything about omitting insulin for weight loss. Participant #2 stated, "When I was in middle school, I learned that if you didn't take insulin, you could lose weight. It didn't affect me at all. I understood why some girls would do that. Especially being diabetic, it's harder to lose weight."

Recency of insulin omission. All 13 participants reported that they omitted insulin in the past two weeks. Of the 13, 4/13 (30.7%) had omitted in the past day, 7/13 (53.8%) in the past week, and 10/13 (76.9%) in the last 10 days. Looking at the entire population of individuals with type I diabetes that were screened for the current study (n =23), 10/23 (43.5%) did not admit to omitting insulin, 4/23 (17.4%) omitted insulin in the

past day, 7/23 (30.4%) omitted in the past week, and 10/23 (43.5%) in the last 10 days.

Predominant Reason for Insulin Omission as Reported by Each Participant

Typical category. There were no typical categories that emerged in this domain.

Variant categories. Towards the end of the interview, each participant was asked “If someone asked you the predominant reason why you omit insulin, what would you say?” Four variant categories emerged as the predominant reason why the individual omitted insulin (See Table 1). Some participant’s answers were included in two variant categories. Forgetting was the most common predominant reason noted by participants. Participant #2 stated, “I forget, just being on the go. If I’m grabbing food at a vending machine and I go back to what I’m doing, I may forget to take it [insulin] for something like that.” Avoiding hypoglycemia was noted as the predominant reason for insulin omission by a few participants. This included avoiding the low blood sugar, worrying about others having to take care of them or may not know what’s going on, and being in an uncomfortable situation or not having access to immediate sugar. As Participant #1 explained:

[I omit] so I don’t have to worry about being too low and having other people take care of me. There’s some of my friends that know how to take care of me but they’ve never done it before, and if I go low, I’d be worried that they wouldn’t know what to do. I passed out once when I was little when I was low, and I’ve never passed out from being high. I can usually take care of myself when I’m high.

Difficulties with the acceptance of diabetes and the need for insulin was also a variant category. These statements included hopelessness about the effectiveness of insulin,

wanting to be normal and not have diabetes, feeling that one does not need insulin, and behaving as one did before the diagnosis of diabetes. Participant #12's predominant reason for omitting insulin was:

I get caught up in life. I don't want diabetes to be the number one thing on my mind all the time, every day. I want to be like everyone else, who goes out places and has fun and then goes to work and studies and they don't have to worry about stopping and thinking about diabetes. I don't want to either, but it's part of my life and I have to, just sometimes it gets overlooked, and for a brief second, I'm just like everyone else.

Participant #5 stated that "I felt like insulin is ineffective and that my blood sugar is still going to be high anyways, so why take it." Finally, a few participants mentioned the cost of insulin and testing strips as the predominant reason that they omit insulin. These included insurance coverage of insulin not matching up to insulin needs and not being able to afford blood glucose testing strips so not being able to know what blood sugar is or how much insulin to take.

Motivators to Give Insulin as Prescribed

Typical categories.

Future health and preventing long-term diabetic complications. Many participants indicated that motivators to giving insulin as prescribed included wanting future health and preventing long-term diabetic complications and avoiding/delaying death. Seven participants mentioned overall future health as a motivator. Prevention of specific long-term complications was also mentioned by several participants. These included avoiding vision problems/blindness (3), amputations (2), heart problems (1),

kidney damage (1), nerve damage (1), and internal organ damage (1) (number of participants reported in parentheses). Three participants also mentioned avoiding and/or delaying death as a motivator to take their insulin as prescribed. See Table 6 for sample quotes.

Table 6

Sample Quotes about Future Health and Preventing Long-Term Complications as

Motivators to Taking Insulin as Prescribed

Participant #1	Every time I go to the eye doctor, he always says if my blood sugar is not kept right, my vision will start to get worse and my diabetes doctor always says it takes a long term toll on my body if I don't keep it [blood sugar] in the right area. Those are motivators.
Participant #2	My overall health. The long term effects of diabetes are very scary. I don't want to go blind when I'm 50 or have something amputated or have heart problems. I think that's my motivation for trying to stay as healthy as possible and take my insulin. Because of diabetes I have these extra complications heading my way, so I better take care of myself now. I know that's going to pay off in the long run. My father was diabetic as well and when I was in elementary school, he got a low blood sugar and hit a tree and died. So it's like- diabetes is real- it can do bad things to you.
Participant #4	[Not taking insulin] adds to the worry I have about the future. I need to be taking better care of myself and keeping my blood sugars under better control and not doing things like that. I worry about the effects it'll have long term on my body. Like even if I can control diabetes, I worry that I'll run into complications associated with type I diabetes and that I won't live as long. The desire to stay health and keep diabetes under as good of control as I can motivates me to take my insulin.
Participant #10	My health motivates me [to take insulin as prescribed]. Just for like, my insides, my internal organs I don't want to have my arms or legs amputated when I get older.
Participant #11	Other motivators [to take insulin] are just overall good health. Just realizing more and more as I get older that what I do now will definitely carry over into older ages and will affect how I live my life in the later stages.
Participant #13	Being healthy, 'cause I'm trying to avoid the results of having-related issues from not taking insulin and everything. So that would be the main motivator [to take insulin]. Avoid long-term problems with your eyes, the normal things that people have problems with in late-life diabetes.

Relational motivators. Over half of the participants indicated that other people, their relationships with other people, or their interactions with other people act as motivators to take their insulin as prescribed and not omit. Themes within this category included not worrying others (especially parents and significant others), meeting others' standards and expectations, having a positive impact on others/acting as a role model, and using others (friends, family, significant others) as practical and emotional motivators to take one's insulin as prescribed. See Table 7 for sample quotes.

Table 7

Sample Quotes about Relational Motivators to Taking Insulin as Prescribed

Participant #2	I had low blood sugar, probably like 3 years ago and passed out and it's the only time I've ever had anything like that. So for probably a month after that, my mom called every morning, asking how my blood sugar was. You know, so not scaring her is also a main motivation to stay as healthy as possible and take my insulin as I am supposed to.
Participant #3	Recently my dad has been diagnosed with type II diabetes so I'm kind of put myself in a race with him, like who can have the better blood sugar. So, I'm trying to do that and maybe show him that I can have good blood sugar so he can't do that if I'm not taking my insulin.
Participant #5	There's always been some times where they've [friends] been like "Hey, did you check your diabetes/give your insulin" and I'll be like, oh year I better do that thanks. Also, if I talked to my family about it [diabetes] recently, because I don't like the amount of stress that it ups on my parents in particular. They don't want me to have long term complications and they worry I will. I think they are more convinced that its [complications] going to happen to me than they should, but at the same time I'm probably not worried enough about it. I do just try to put their minds at ease if I've talked to them about it recently, so I'm more motivated after that.
Participant #7	My family motivates me to take my insulin as I am supposed to because they want me to and expect me to. And the boyfriend and friends. I guess trying to meet other people's standards on what I should be doing, meeting other people's expectations.
Participant #11	My fiancée has been really good about it. I started living with her last year and she could see what I was doing and knows when I eat, so she can kind of remind me "Hey, you need to take your insulin." She's a motivator in herself and then she

reminds me of other motivators [children, future].

Participant #12 I want to continue being a good diabetic, to prove to others that diabetes isn't a disease that holds people back. A lot of people know it as the "fat man's disease" and they can't do things because of that. That's not really my disease and I can still do everything else that everyone else can. I may have to take a couple of steps back every once in a while, to take care of it, but I'm still out there at the same pace with everyone else.

Variant categories. Three variant categories emerged as motivators to take insulin as prescribed (See Table 1). One of the motivators to taking insulin as prescribed that was reported by over a third of the participants was avoiding immediate physical side effects that result from hyperglycemia (thirsty, sweaty, vomiting, nausea, headache) and knowing that one will feel better, healthier, and in a better mood when insulin is taken correctly and accurately. As Participant #6 stated:

What motivates me is just knowing how I feel when my blood sugar is not stable. I think- "God this is miserable." So I think that motivates me to make sure that I'm taking my insulin correctly and doing my corrective doses right because I don't want to feel like that. I think that alone is probably the sole motivator. When my blood sugar is high, I can't do anything, so it'll ruin whatever I have going on at the moment.

Participant #7 also noted that avoiding the immediate physical side effects was a motivator; "When my sugars really high, it makes me sick like vomiting and gives me a really bad headache. If that didn't happen I'm pretty sure I'd be less diligent in taking care of myself." Participant #10 mentioned other immediate physical side effects that motivate him/her- "It's really funny because the people around me know if my blood sugar is high, they can tell. So that kind of motivates me, because I don't want to be

moody. I don't want people around me to realize that.”

The two other variant categories that emerged as motivators to take insulin as prescribed were lowered hemoglobin A1c (HbA1c) and thought of future family life.

Participant #11 noted both motivators:

I need to be alive when my children are growing up, I have to take this seriously.

That nothing is as important as taking my insulin, even if it doesn't seem like it in the moment... A newer motivation for me is wanting to lower my HbA1c and I've had a lot of success in that in the last six months or so. It's going down so that feels good and it's a motivator. Having success in dropping my HbA1c levels to almost normal levels makes me want to keep going in that direction.

Overall Communication of Insulin Omission to Medical Providers

Typical category.

Non-disclosure of insulin omission. Non-disclosure about insulin omission and reasons for omission were reported by over half of the participants. Reasons for non-disclosure included not feeling as if insulin omission was important to discuss with the medical provider, fear of embarrassment or distrust from provider, and not wanting to admit that insulin omission is a problem. See Table 8 for sample quotes.

Table 8

Sample Quotes about Non-Disclosure of Insulin Omission to Medical Providers

Participant #5	...gosh, this is bad..... I downplay how much of an issue it is that I forget [insulin], because I'm embarrassed and I don't want him to think badly of me. It seems like other people don't have as much trouble with it [taking insulin] as I do.
Participant #6	...What we communicate about is like the big problem....I don't really talk about missing doses [of insulin].....it's just kind of seems irrelevant to me.
Participant	I don't think I've ever said anything to them [medical providers] about it [insulin

#8 omission]. It's almost like-after I do it- I don't want to admit it. Because my doctor trusts me to the point that I can just call them and be like, "Hey, this is what's going on, can you write me a prescription for an antibiotic....or write me a doctor's note, because I had to miss class." So they have a lot of trust in me and I don't want to break that. So, I don't say anything to them about it [insulin omission].

Participant #11 I haven't mentioned anything about not taking insulin for any reason.....Basically, I felt like if I didn't bring that up, then she [provider] wouldn't bring it up.

Variant categories. Overall communication about insulin omission to one's medical providers fell into two variant categories (See Table 1). Several participants reported direct, honest, and opened communication about insulin omission to their medical providers. A few participants (#4 and 10) stated that they admit to omitting insulin when confronted about a high blood sugar in their blood sugar log. Participant #4 stated that:

I went to see my doctor, there were really high blood sugars I had written down, and she asked about them. I just told her that I had forgotten,...That I had eaten something and then I just forgot to give insulin for it.

Participant #10 mentioned something similar, "I've just told him [provider] about it [insulin omission], because they wanna know- he'll say "That's weird, you had high blood sugar right here, did you not give yourself enough insulin?" He was definitely open to hearing about it." Other participants (#1 and #9) noted that they tell their medical providers about insulin omission without being asked about recorded high blood sugars. Participant #1 stated that "I tell her pretty much everything [including insulin omission] when I am there," while Participant # 9 stated "...when I say that I don't dose insulin sometimes, it's a complete shock to them."

Several participants reported that their medical providers know about insulin

omission because of high blood sugars noted on their continuous glucose monitors or the insulin pump noting missed insulin injections, lowered doses, or higher entered blood sugars. As Participant #12 stated:

She [provider] usually always catches it [insulin omission]. I track everything on my pump, and she'll usually kind of give me that look of, "You know you forgot it, and you know you shouldn't do it, so let's not try and do that again." And I feel like I let her down... but it's a natural part of life to make mistakes and forget things. I just know I shouldn't forget as much as I probably do.

Participant #2 stated:

I have the USB-thing that connects the pump to the online thing. So when I go in, they print out like my last three weeks of blood sugars and what insulin I gave...he'll be like "Why did you take lower amounts of insulin here?" ...usually it's because I know I was going to be in lab that day and didn't wanna drop [hypoglycemia], but I just tell him I ate something and forgot, really I did it on purpose so I didn't go low.

Factors Facilitating Communication Regarding Insulin Omission to Medical Provider

Typical categories.

Patient-centered approach. Most participants mentioned some component of a patient-centered approach that does or would facilitate communication regarding insulin omission to their medical providers. Themes within this category included acknowledging the patient as a whole person with preferences and using a strengths-focused, collaborative, supportive approach to treatment and treatment recommendations.

Acknowledging the patient as a whole person with preferences included the medical provider(s) being aware that diabetes is part of one's life and not one's whole life, being treated as a human first- not just someone with diabetes, talking about other aspects of life besides diabetes related issues, and respecting the needs and preferences of the patient. A strengths-focused, collaborative, supportive approach to treatment and treatment recommendations include having support and encouragement from medical providers, talking about what the patient is doing right, being a collaborative problem solver, and open medical provider initiated communication about various aspects of treatment. See Table 9 for sample quotes.

Table 9

Sample Quotes about Patient-Centered Approach Facilitating Communication about

Insulin Omission to Medical Providers

Participant #1	As long as my blood sugars right, she thinks I am doing the right thing and she encourages me to keep doing what I'm doing. Makes me feel more confident and like I can tell her when I mess up [omit insulin].
Participant #4	It makes it [insulin omission] easier to talk about when they [providers] make it clear that diabetes it's only one part of my whole life.
Participant #6	I think that a lot of times, doctors are attacking when the patient has done something wrong. In the past, I have had doctors who are like "You are doing X, Y, and Z wrong." I'm a social work major, so I know all about the strength based perspective and talking about what people are doing right. So maybe I would feel more comfortable [talking about insulin omission with my provider] if it would be easier for her to highlight things I was doing right instead of things I was doing wrong.
Participant #7	I think talking to someone in the psychology department vs. like the MD department would be really helpful. Just to talk it out with someone. If someone has a background in psychology maybe they could have a different perspective, kind of like how you are feeling about things [insulin omission, low blood sugar], that might help.
Participant #7	I don't really know what would make me more comfortable [communicating about insulin omission to providers]. I guess if I knew that the advice they would

give me would be helpful and work for me...And if we talked about anything besides just my basal rates.

- Participant #8 Maybe if they would be like very upfront with me and tell me that I wouldn't lose their trust or they wouldn't think of me differently. You know, a kind of "Let's get everything out on the table" conversation.
- Participant #10 Tell me what and why I need to fix something, makes me feel like I can talk to them [providers] about anything. For the most part, I'm comfortable [discussing sometimes not taking my insulin]. We [patient and providers] have really good communication I think.
- Participant #12 Me and my doctor are very open. She'll have casual conversations with me all the time. She gave me her cell phone number, so I can call her at any time. So I feel comfortable talking to her about situations like "Yeah, I did miss my insulin, I'm sorry, I'm working on it." She is very open and treats me with respect as a diabetic and as a human being...She's seen me grow as a person and as a diabetic. She's just always been there throughout my life, so it's nice knowing that she does know me. I walked into the office and she was like "Hey, how was your trip to Australia?" I am happy that she remembered, I only see her once every three months so that was kind of cool.

Empathic, non-judgmental, interpersonal style of the medical providers. More than half of the participants noted that an empathic, non-judgmental interpersonal style facilitated or would facilitate them communicating about insulin omission to their medical providers. This included if the medical providers were friendly, non-judgmental, expressed empathy and understanding, and avoided assumptions about and negative reactions to insulin omission and other non-adherence issues and management difficulties. A few participants (Participants #2 and #4) also noted that they would be more opened to discuss insulin omission with their medical provider if their medical provider was diabetic themselves or had a close family member that was diabetic. A few participants (Participants #2, #4, and #7) discussed feeling more comfortable in communicating with their nurse or nurse practitioner than their physician. See Table 10 for sample quotes.

Table 10

*Sample Quotes about Empathic, Non-Judgmental Interpersonal Style Facilitating**Communication about Insulin Omission to Medical Providers*

Participant #2	I really like the nurse practitioner that I see. I think she said her sister is diabetic- or someone close to her- so I think she understands a little bit better what it's really like to live with diabetes. She's more supportive and realizes it's tough. I think it's a fine balance with having to deal with diabetic patients.....I'd be more comfortable to talk about insulin omission if, well I know every diabetes doctor can't be diabetic, but maybe if they could realize and spend a longer time, maybe a week or something, with a diabetic and realize that even if we do take [insulin] exactly what we are supposed to, it doesn't always work perfectly. You know, your blood sugar sometimes jumps for, really, no reason. So if they can understand that it's a really giant trial and error process. If they could get in the mindset of as a diabetic, I might tell them more. Maybe for them, listening to them, talking to them and understand what it's like.
Participant #4	There was one instance where I was talking to a nurse and she was very understanding about not taking insulin. She said "You're a teenager, you have a life, and these things aren't always going to be perfect, but eventually you need to be able to take care of it [diabetes]. I could tell she was very understanding about it so that makes it easier to talk about the problems If they can relate to the experience that you aren't always going to be perfect. I've been to see some doctors who were diabetics themselves, so just them talking about their own experiences or just communicating that they've had to cope with similar things and they understand it's not always easy to take perfect care of yourself. Just expressing that common ground would make talking about insulin omission easier.
Participant #7	My new doctor has a nurse practitioner that also works with me, and I find her really helpful. She is just a really nice woman, warm personality, kind of like a motherly figure, caring and empathic. She is really easy to talk to. I would talk to her about omitting insulin before my physician.
Participant #10	They ask about and were opened to talking about why I might have missed insulin. They don't really lecture me, and when they do it's not in a demeaning way or anything. They actually talk to me and not down to me. They are really nice about it.
Participant #11	I would feel more comfortable talking about not taking insulin with my current physician than my previous physician. She is a lot more personable and it seems like she really wants to see me beat diabetes. She legitimately wants me to do well.
Participant #13	[Because of my continuous blood glucose monitor] she can see the trends and where I missed a dose and we usually talk about it. She asks why and I try to

remember back, what happened during that particular time. It helps that she is friendly and always in a good mood.

Variant categories. When investigating factors that facilitate communication regarding insulin omission to medical providers, three variant categories emerged (See Table 1). A few participants noted that longer and more frequent appointment times would make them more comfortable to discuss insulin omission with their medical providers. As Participant #12 stated:

I would feel more comfortable to be open about insulin omission if I saw her [provider] more often. I only see her once every three months, so it's kind of like a great-grandma that lives in a different state; you only see them every once in awhile. They're family, and you still like them, but it's a little bit awkward just because you don't see each other enough.

Participant #8 stated that she [provider] just comes in the room, "Hi how are you? Okay, let's go." It's like, I'm kinda just in and out, when would I talk about insulin omission? More time would help have the opportunity to do that." A few participants noted that having a knowledgeable medical provider helps facilitate communication about insulin omission. Participant #11 noted:

I would feel more comfortable talking about not taking insulin with my current physician...I know that she knows a lot about diabetes- my first meeting with her she saw me down and showed me all these ways to look at having diabetes and regulating your blood sugar, so I know that she knows a lot about diabetes.

Support from someone who is an expert, is really encouraging for me to just be open and honest.

A few participants also mentioned that they would be more comfortable to discuss insulin omission with their medical providers if they took their insulin as prescribed more often than they currently do. Participant #13 stated, “I would be more comfortable to discuss not taking my insulin if I didn’t miss as much insulin. It’s more like myself, I screwed up and it’s embarrassing”.

Barriers Inhibiting Communication Regarding Insulin Omission to Medical Providers

Typical categories.

Disease-driven, medical approach to treatment. Over half of the participants mentioned that a disease- driven (in this case diabetes driven), medical approach treatment made them less comfortable in discussing insulin omission with their medical providers. Themes within this category included depersonalized appointments and a non-collaborative, disease-driven, problem focused approach to diabetes treatment and treatment recommendations. See Table 11 for sample quotes.

Table 11

Sample Quotes about a Disease-Driven Medical Approach as a Barrier to Communication about Insulin Omission to Medical Providers

Participant #2	He [provider] does not “get me” as a person, only sees me as someone with diabetes. It is like he is looking at my life on paper [where blood sugars and insulin doses are recorded]. We don’t talk about the day-in and day-out stuff [like insulin omission].
Participant #3	I’m kinda just in and out. I’m kind of a number, I suppose. She doesn’t take the time to listen to things like why I’m not taking my insulin. We don’t communicate about those small things.
Participant #6	Some of the characteristics of doctors’ approaches makes me uncomfortable to talk about it [insulin omission]. I know that is their job to solve problems and to make you healthy. I think that a lot of the times they focus too much on the

problem and they go through everything that's wrong and it's depressing. That can be kind of overwhelming, you feel defeated and in turn don't do anything to change it.

Participant #11 [I am less comfortable talking about insulin omission] When I feel like the physicians were running a business and if at any time they decided like I was not a good patient, they could decide just to not see me anymore. It was the physician that Medicaid wanted me to use... so why even bother telling them thing that they don't really care about [insulin omission].

Participant #12 [It makes me less comfortable talking about insulin omission] because I haven't found a doctor that I like because when you do see them, they want a perfect diabetic- and that's fine, everyone should try to become a perfect diabetic, but that's not natural human life. It's natural to make mistakes and do wrong things. So, they should be more opened and responsive to the mistakes and to how I want to treat my diabetes, not the textbook way to treat diabetes....It's just small things that they want done correctly, and it's kind of impossible because when you get low blood sugar, you just want to eat the entire refrigerator....They've kind of outlined it in this picture-perfect frame and I'm working towards that, but I feel like it's taking forever to get there. It's just hard and you want to make them proud and show them who you can be. When you make small mistakes like forgetting to take your insulin, it's like taking one step back, after you just took two steps forward.

Non-empathic, judgmental interpersonal style of the medical providers. Most participants reported some type of cold, negative, non-empathic interpersonal style of their medical provider does or would act as a barrier to communication about insulin omission. This included feelings of a cold, distant interpersonal style and feelings of a judgmental stance including a lack of empathy and understanding and negative interpersonal reactions to the participant or to insulin omission. See Table 12 for sample quotes.

Table 12

Sample Quotes about a Non-Empathic Interpersonal Style as a Barrier to Communication about Insulin Omission to Medical Providers

Participant #2 Um, he's [provider] not a diabetic...I don't think he can fully understand what it's like, and how hard it really is. As much as technology has gotten better it's

still not easy to try to watch it [blood sugars] all the time. So he gets on me, which is good, you need someone to get on your case about if you have highs or lows, but he's more hurtful when trying to motivate me.he makes me feel really bad [for omitting insulin], so then I just get nervous and fell guilty about it.... In regards to omitting insulin, I just don't think he [provider] understands that you also forget things. Like diabetes isn't on the forefront of my mind at all times, which he [provider] thinks it should be.

- Participant #4 If they [providers] were not at all understanding and really critical of times when I messed up, I think that would make me very uncomfortable to bring it [insulin omission] up. To admit that I had made a mistake to them [providers] and then have them be very critical of the mistakeThey are knocking things out and not really focusing on the needs of the patient.
- Participant #5 If he [provider] acted really judgmental when I tell him about insulin omission, like if he said "It's not that hard, other people do it" type of attitude.
- Participant #8 When they [providers] confront me in a cold, super direct manner, I'm likely to be dishonest. If they were like "Look we know you sometimes don't take insulin that you should" it would make me feel more like, "No, I always take my insulin," and I'd almost be offended, even though I know it's true that I sometimes don't.
- Participant #9 I say I've missed a dose [insulin], and they [providers] go straight to disappointment. They don't ask why I've missed the dose or how I was feeling when I missed the dose. They just go straight to me being irresponsible, instead of maybe it's not my responsibility but something else. They should ask about the context of missing it [insulin]. I mean I'm just as disappoint with myself when it happens, so disappointment [from them] doesn't really encourage me to solve anything. Disappointment from them isn't motivating.
- Participant #12 I had on doctor that every time I saw her, I knew she was going to scold me and give me that dirty look. She was just so cold and bland and I actually traded doctors. I felt like I couldn't tell her anything, especially when I messed up [insulin omission].

Variant categories. When investigating barriers to communication regarding insulin omission to medical providers, two variant categories emerged (See Table 1). A few participants mentioned a transition from their pediatric endocrinologist to an adult internal medicine or endocrinology clinic was a barrier to their communication about insulin omission to their medical providers. Participant #10 stated, "I use to go to (pediatric clinic) and they just now kicked me out, so I have to go to a grown up doctor

now. Might be harder to talk to them about stuff like this.” Participant #13 mentioned a similar experience:

It’s a big switch [from pediatric to adult endocrinology]. They treat me a whole lot different- they treat me like an adult now, where before it was kind of like, step me through everything. It was a little bit weird the first time...the newness of having a new doctor made it uncomfortable to communicate about insulin omission in the beginning.

A few participants mentioned the lack of availability due to limited appointment hours and being busy as barriers to communicating to their medical provider about omitting insulin. Although more time and greater frequency of appointments were noted above in factors that facilitate communication regarding insulin omission, different participants noted a lack of time as a barrier. As Participant #3 indicated:

If their hours were a little bit better and I could have a little more time, I guess it would be easier to discuss things like that [omitting insulin]. I’m kind of a number I suppose. A little more time would make me more comfortable to talk about insulin omission.

Similarly, Participant #13 stated, “...she was obviously busy, it is kind of an awkward situation-that really doesn’t help me to communicate really well about anything including not taking my insulin.”

EAT-26 Findings

The mean score on modified Part B of the EAT-26 was 9.36 (SD=7.72) with a range of scores from 1 to 29. Based on these scores, one participant was considered “at risk” for an eating disorder (score = 29). In Part C, all 11 participants denied using insulin

in the past 6 months to control his/her weight or shape (modified question). Overall in Part C, 8 of 11 participants did not endorse items that would consider them “at risk” for an eating disorder. However, 3 of the 11 participants endorsed a 2-3 times per month or more frequency of “In the past 6 months, have you gone on eating binges where you feel that you may not be able to stop?” These three participants are also considered “at risk” for eating disorders (one was the same participant considered at risk based on the Part B scores). Upon further qualitative inquiry around the reason for these binges, all three participants indicated that they binge ate when blood sugar levels were low. The following are quotes from each of the three participants that endorsed bingeing 2-3 times a month or more and explained the context of their binge eating. Participant #3 stated “Especially when I am alone and low, I get scared that my blood sugar won’t go up fast enough, so I eat, and eat, and eat, until I am so full my stomach hurts.” Participant #8 stated “Sometimes when my blood sugar is low, it feels like I can’t stop eating, even though I know I don’t need all of that.” Finally, Participant # 6 stated “When I am going low and trying to get it [blood sugar] up, it feels like my appetite is out of control. I overcorrect because it feels like what I need to do.” Based on participants BMI scores, none were “at risk” for eating disorders. Mean BMI was 24.73 (SD= 4.11) with a range of 19.0 to 35.1. Eight participants were normal weight, two were overweight, and one was obese class I based on their BMIs.

Discussion

Of the 23 college students screened for insulin omission, 13 (56.5%) admitted to currently omitting insulin. This qualitative study of 13 young adults (ages 18-24) used consensual qualitative research (CQR) to explore reasons why they omitted insulin and

what they perceived as factors that facilitated and acted as barriers to communication of this behavior to their medical providers. Results indicated that participants omitted insulin for a variety of reasons, surprisingly none of which included weight loss/control purposes. Results of earlier studies on insulin omission were not replicated in the current study possibly for several reasons. First, this study used an exploratory, qualitative approach, the first one known to date to investigate insulin omission and did not include an assumed reason for insulin omission in the screening question as some studies have in the past (Biggs et al., 1994; Bryden et al., 1999; Herpertz et al., 1998; Jones et al., 2000; Peveler et al., 1992; Rydall et al., 1997). Second, previous studies have used a single item measure of insulin omission (Goebel-Fabbri et al., 2008; Polonsky et al., 1994), while this study used a three item screening measure, which may have included a broader population of individuals that omits insulin than those in previous studies (including men). Previous studies have used measures or criteria that may not apply to those with type I diabetes as they do to those in the general population, such as DSM diagnostic criteria for eating disorders, the Questionnaire for the Diagnosis of Eating Disorders, or the Diagnostic Survey for Eating Disorders (Herpertz et al., 1998; Rydall et al., 1997; Stancin et al., 1989), which may have artificially categorized individuals with type I diabetes as having problems with disordered eating or a diagnosable eating disorder. For many of the studies mentioned above, insulin omission was studied in the context of eating disorders and this study did not. Finally, while other studies have included males, those that reported prevalence rates sorted by gender found very low prevalence rates of insulin omission in males ranging from 0% - 0.006% (Bryden et al., 1999; Fairburn et al., 1991; Herpertz et al., 1998; Peveler et al., 1992). This study screened a total of ten men

with three admitting to omitting insulin. Thus other reasons for insulin omission besides weight loss may have emerged given a higher percentage of male participants than in previous studies. Thus, it is concluded that past studies on insulin omission were not replicated in this study because of a) the more exploratory nature of the current study, b) use of a multiple-item screening measure to identify those that are omitting insulin, c) intentionally not studying insulin omission in the context of disordered eating or clinical eating disorders, and d) the identification and inclusion of more male participants than in prior studies.

Each participant in the current study noted at least two reasons for insulin omission and many reported more than two. More than half of the participants noted that they had no communication of their insulin omitting behavior to their medical providers. Barriers to communication included a disease-driven, medical approach to treatment and a non-empathic, judgmental provider interpersonal style. Facilitators of communication included a patient-centered approach to treatment and an empathic, non-judgmental provider interpersonal style.

Prevalence Rate and Recency

Medical providers have been found to “dramatically overestimate compliance in teenagers” and young adults (Gordon & Mansfield, 1996, p. 320; Peyrot et al., 2005). While the prevalence rate of insulin omission in the population with type I diabetes is difficult to estimate given the variety of ways that it has been studied and measured, a prevalence rate of 56.5% (13/23) was found in this study with 43.5% (10/23) admitting to omitting insulin in the last 10 days. In Weissberg-Benchell et al.’s (1995) investigation of adolescent (ages 11-19) with type I diabetes, they found that 25% of adolescents

admitted to missing insulin injections in the past 10 days. Two factors must be considered when trying to draw any type of hypothesis about the difference in the results of these two studies. One, technology to deliver insulin (i.e., the insulin pump) has improved since 1995 with progressively more adolescents on insulin pumps. Two, the age of the participants in these two studies differs (ages 18-24 vs. ages 11-19), thus one has to wonder if the prevalence rate of insulin omission is higher in those that are older adolescents or young adults, than children or younger adolescents. Important to note about the measurement of insulin omission in the current study, asking participants about omitting insulin in the past 10 days identified 10 of the 13 participants that admitted to omitting insulin. A time frame of two weeks would have identified all of the participants that admitted to omitting, thus may be a better specific amount of time to use when providers are asking about insulin omission to young adults.

Reasons for Insulin Omission and Motivators to Take Insulin as Prescribed

The most common reasons that participants in this study reported for insulin omission were forgetting, delaying and forgetting, fear of hypoglycemia and its social impact, or being in situations where there is little or no access to food/medical supplies. No participant mentioned omitting insulin for weight loss/control, even though a few participants were at risk for eating disorders based on their EAT-26 results. The most common reason for insulin omission noted by participants was because they forgot or purposely delayed giving insulin and later forgot. Similar results were found in The Global Attitudes of Patient and Physicians in Insulin Therapy (GAPPtm) survey by Novo Nordisk (2010). This survey found that the main reasons cited by both patients and physicians for patients missing a dose of insulin were change in normal routine, being too

busy and forgetting, or simply forgetting to take insulin. While participants in the current study mentioned forgetting due to distractions such as school, work, and a social life, it could be hypothesized that there might be some psychological reasons for insulin omission related to forgetting or even delaying and forgetting, such as non-acceptance of diabetes and the need to take insulin, underestimating the importance of insulin, or psychological resistance to the idea of taking insulin regularly (i.e., psychological insulin resistance). Psychological insulin resistance (PIR) is “a psychological opposition towards insulin use in both people with diabetes and their prescribers” (Brod, Kongso, Lessard, & Christensen, 2009, p. 23). There may be lack of insight into more accurate psychological reasons for insulin omission that is being labeled “forgetting” by the individual.

Other reasons for insulin omission were worry about hypoglycemia, hypoglycemia’s social implications, and being in situations where the individual had little or no access to food/medical supplies (appears to be related to fear of hypoglycemia as well). Fear of hypoglycemia has been discussed in the literature as a barrier to giving appropriate amounts of insulin and there is evidence that it has a negative health impact on metabolic control and diabetes management (Wild et al., 2007). The Global Attitudes of Patient and Physicians in Insulin Therapy (GAPPtm) found that 67% of patients on insulin were fearful of hypoglycemia and 74% reported that they would adhere to their insulin regimen more closely if they didn’t fear a major hypoglycemia episode (Novo Nordisk, 2010). Also noted in the literature is the difficulty in distinguishing symptoms of hypoglycemia and anxiety (Green, Feher, & Catalan, 2000). While both can be problematic, there are typically more immediate physical health dangers associated with hypoglycemia. Finally, fear of hypoglycemia has been noted as one of the most

common diabetic side effects that leads to psychological insulin resistance (Brod et al., 2009). Thus, intentional or unintentional insulin omission may be participants' attempt to decrease fear/worry of hypoglycemia and prevent hypoglycemic episodes or psychologically resist the need to take insulin or even have diabetes.

Some reasons for insulin omission reported can be considered appropriate methods to control blood glucose given specific situational variables. Many participants noted that they gave less insulin when they planned to exercise, be physically active, or when they were unsure of the amount of carbohydrates in the food they were eating. In general, these are considered appropriate methods, even though they involve insulin omission. Giving less insulin prior to planned exercise/physical activity is often recommended by medical providers (Mayo Clinic, 2012) and adjusting insulin for carbohydrates can often be challenging and underestimation can easily occur (especially when not preparing your own food, eating in restaurants, etc). These reasons for omitting insulin were seen as attempts by the participants to manage their blood glucose levels appropriately, honestly, and with their best effort.

Other reasons for insulin omission were reported by five or fewer participants. These included difficulties with acceptance of diabetes and the need for insulin, other's lack of understanding about insulin, expense of supplies, stress/depression, and other non-adherence (i.e., not testing blood glucose, not changing pump site) that make giving the correct amount of insulin difficult. Participants all noted several reasons for insulin omission. This supports the idea that medical providers, whether medical or psychological, need to ask about the environmental, behavioral, and psychological context of insulin omission and be open to patients' explanations of why they engage in

the behavior. As Rapaport, Cohen, and Riddle (2000) stated “Our goal should be to view this as “intelligent non-compliance” and take time to identify the person’s underlying personal motivation. We can ask nonjudgmental questions, such as: “People often change their medications for one reason or another. What about you?”” (p. 204). It is only after an individual understanding of reasons for insulin omission is gained that appropriate, idiosyncratic interventions can be collaboratively developed between the patient and medical provider to improve insulin adherence. These will be further discussed below.

Participants were each asked to note the predominant reason why they omit insulin and the top three included forgetting, avoiding hypoglycemia, and difficulties with acceptance of diabetes and the need for insulin. Forgetting insulin and avoiding hypoglycemia were also found to be primary reasons for insulin omission in the global survey by Novo Nordisk (2010). Interesting to note, that although many participants reported physical activity and being unsure of carbohydrate counts in foods as reasons for omitting insulin, no one noted these as the predominant reason they omitted insulin. Individuals may be aware of some of the psychological reasons that impact how they give their insulin, if only we directly ask about them and are willing to listen to the answer.

Motivators to take insulin as prescribed included future health, avoiding long-term complications, and relational motivators, such as relationships with others and others as motivators themselves. Although most participants reported thinking about their future health and trying to avoid long-term diabetic complications (i.e., blindness, amputations, kidney problems) as motivators to give insulin as prescribed, each of the participants in this study reported *not* giving insulin as prescribed. As reported in much of the literature on health behavior change of high risk behaviors, knowledge (of long-term

health complications) does not always equal positive behavior changes or improved outcome (such as giving insulin as prescribed) (Bazata, Robinson, Fox, & Grandy (for the SHIELD Study Group), 2008)). Over half of the participants also noted that others' support, encouragement, and reminders helped motivate them to take insulin as prescribed. In a letter from a patient published by Kadohiro in a 2000 article in *Diabetes Spectrum*, an adolescent stated, "...the best treatment for dietbetes is having friends, parents, doctors, and even strangers supporting you, helping and always being there..." (p. 81). Interestingly, only a few participants mentioned lowering HbA1c as a motivator to take insulin as prescribed. One participant had already lowered his/her HbA1c close to a normal level and one was in a contest with his/her father to have the lower HbA1c. Clinically, I have observed medical providers attempting to use lowering HbA1c as a motivator to improve adherence and improve diabetes care management, without much success. Maybe this could be used as an external secondary motivator once initial improvements in HbA1c have been documented rather than a primary or internal motivator to increase long-term insulin adherence. In a review of other health behavior change (e.g., quitting smoking, losing weight, starting an exercise program), young adults are eager to start and initiate behavior changes but have more difficulty with the maintenance of these positive health change behaviors (Baumeister, Heatherton, & Tice, 1994). If behavior changes in regards to insulin omission are similar, then an external secondary motivator, such as a noticeable drop in one's HbA1c, might be helpful to maintain positive behavior changes in adhering to an insulin regimen once initial behavior change occurs.

Interventions for Insulin Omission

As recommended by Schechter and Walker (2002), when thinking about approaches and interventions to improve adherence, it is important to think about the type of adherence to be improved (in this case taking insulin as prescribed) and the type of interventions being considered. After a review of the literature on adherence, interventions can be divided into three categories: educational/informational, behavioral, and affective (Roter et al., 1998; Schechter & Walker, 2002). Educational/ informational, behavioral, affective, and psychological interventions to improve insulin omission behaviors will all be discussed further. Interventions discussed are those thought to be most applicable, appropriate, and potentially effective given the reasons for insulin omission reported by participants in this study

Educational/informational interventions. Educational/informational interventions are meant to provide knowledge, information or skill that may improve adherence. For example, a few participants in this study noted that their medical providers gave them information about their risk of diabetic complications and its association with higher HbA1c levels. These few participants noted that lowering their risk of long-term diabetic complications was a motivator for them, especially when directly discussed in the medical appointment. An appropriate education/information intervention recommended to decrease insulin omission is blood glucose awareness training (BGAT), training specifically designed for individuals with diabetes to increase awareness of symptoms of blood glucose changes and the factors associated with extremes in glucose readings (Cox et al., 2001). Cox et al. found that blood glucose training resulted in a reduction in severe hypoglycemia, improvements in worry about hypoglycemia, and improved recognition of hypoglycemia even at a 12-month follow-up.

Effectiveness of educational/informational interventions appears to be less dependent on the intensity of the program and more dependent on the patient's willingness to incorporate and integrate the new information (Touchette & Shapiro, 2008).

Educational/informational interventions to improve adherence to insulin regimens could also include the family in diabetes education/ psychoeducation (Denham, Ware, Raffle, & Leach, 2011).

Behavioral interventions. Behavioral interventions are widely cited in the adherence literature (Bazata et al., 2008; Fielding & Duff, 1999; Schechter & Walker, 2002; Silverstein et al., 2005; Touchette & Shapiro, 2008). These include self-monitoring, goal setting, behavioral contracts, problem solving, using memory aids, reminders (cues), skill building, and rewards as reinforcements (Delamater, 2006; Schechter & Walker, 2002; Touchette & Shapiro, 2008). Interventions that could be used to decrease forgetting and delaying and forgetting include setting an alarm on a cell phone or on one's actual insulin pump that is not dismissed until the insulin is taken. Practical behavioral interventions such as carrying glucose tabs and a blood glucose meter may also decrease fear of hypoglycemia and therefore decrease the frequency of insulin omission.

Affective interventions. Affective interventions have been defined as facilitating and providing emotional support and encouragement to improve adherence. This could be through the patient-provider relationship (which will be discussed later) or as medical providers, including the family, significant other, or spouse in appointments to increase accountability. Family support has been noted as an important affective intervention to help young adults adhere to long-term goals and prevent burnout that often comes with

maintaining a chronic health condition such as diabetes (Gordon & Mansfield, 1996; Kay, Davies, Gamsu, & Jarman, 2009). For both adolescents and adults, diabetes-specific social support was found to be associated with better adherence to appropriate insulin use, while for adolescents only general social support was found to be associated with better adherence to appropriate insulin use (McCaul, Glasgow, & Schafer, 1987).

Psychological interventions. While currently not specifically mentioned in the adherence review literature as a category of interventions, psychological interventions appear to be very relevant to insulin omission as they are to many other health behaviors (i.e., smoking cessation, weight loss, HIV/AIDS prevention). Whatever the reason(s) for insulin omission, patients may need help examining and clarifying their values and life goals and accepting diabetes and the need to take insulin (Gregg, Callaghan, Hayes, & Glenn-Lawson, 2007; Heisler, & Resnicow, 2008; Schreiner, Brow, & Phillips, 2000). This could be done through a variety of psychological interventions that have been suggested to be helpful in producing behavior changes in those with diabetes including motivational interviewing (MI) (Heisler & Resnicow, 2008), acceptance and commitment therapy (ACT) (Gregg et al., 2007), and use of the Transtheoretical Model (TTM) of change (Ruggiero, 2000). To date, this author was unable to identify any of these psychological interventions that directly focus on decreasing insulin omission in those with type I diabetes, although some studies may have included this behavior in targeted behaviors to change. Many of these psychological interventions have been found effective in working with individuals with type II diabetes with a focus on weight loss/management, improved adherence to medical nutrition therapy, increasing exercise, and improved medication (pill) management (e.g., Gregg et al., 2007; Ruggiero, 2000).

In summary, there is no single, gold standard intervention to improve adherence to insulin regimens for those with type I diabetes. As noted by Touchette and Shapiro (2008), even effective interventions appear to have minimal impact on positively changing poor adherence. It is important to classify interventions into educational/informational, behavioral, affective, and psychological given that Schechter and Walker (2002) concluded their review by stating that “applying several approaches drawn from different modalities tends to produce better results than any single modality” (p. 174) and other have made similar recommendations in the past (Roter et al., 1998). This makes sense for the non-adherent behavior of insulin omission and is supported by this study’s results of various reasons reported by each participant, and by the group as a whole, for insulin omission. It would appear that at least for the participants in this study, insulin omission is a multifaceted behavior which would respond most effectively to multi-component interventions. So, the question becomes which interventions to use.

Selecting interventions using the Health Belief Model.

McKenzie, Neiger, and Thackeray (2009) make the argument that all health promotion interventions, even on the individual level, should be planned using some type of theoretical frame work. When looking to change health risk behavior (such as insulin omission) and promote health, several theories of behavior change have been developed and studied. One of these is the Health Belief Model (HBM) (McKenzie et al., 2009). HBM was originally developed in the 1950s to explain preventative health actions (such as getting a vaccine) but has since been applied to compliance with general medical regimens (see Janz & Becker, 1984 for a review) and more specifically compliance to diabetes regimens and self-care behaviors (Becker & Janz, 1985; Charron-Prochownik,

Becker, Brown, Liang, & Bennett, 1993; Harvey & Lawson, 2008). Originally developed by Rosenstock (1966), HBM suggests that health-related actions depend four beliefs that combined can predict health behaviors. These include a) perceived susceptibility to the disease (e.g., belief in the diagnosis, susceptibility to further disease/disability because of insulin omission), b) perceived severity of the disease/disability (e.g., leaving the condition untreated), c) perceived benefits of health-enhancing behaviors, and d) perceived barriers to health-enhancing behaviors (e.g., financial costs of insulin, dangerous to mental and psychological health, injections unpleasant, time consuming to give insulin).

A number of factors can serve as action triggers or motivational cues for initiation of behavior change and these can include both internal cues (e.g., a hypoglycemic event) or external cues (e.g., seeing your insulin pen, reminder from significant other to give insulin) . In addition to these components, recent studies have used an Extended Health Belief Model (EHBM) (first proposed and tested by Aalto and Uutela (1997)) in adolescents and young adults with type I diabetes (Charron-Prochownik et al., 2001; Gillibrand & Stevenson, 2006; Wdowik, Kendall, Harris, & Auld, 2001). EHBM includes all aspect of HBM and four others including a) locus of control (i.e., high or low internal locus of control), b) self-efficacy (i.e., general and diabetes related), c) health value (i.e., value put on physical and mental well-being), and d) social support (i.e., general and diabetes specific social support) (Aalto & Uutela, 1997). No study to date has specifically applied HBM or EHBM to insulin omission as the target behavior for change. Using the EHBM to guide selecting interventions for insulin omission for an individual, all factors above must be considered and appropriate interventions matched.

For example, imagine that you are working as a medical provider for a young man with type I diabetes that admits to you that he regularly omits insulin. He describes a low perceived susceptibility to getting any type of medical complication (e.g., neuropathy, retinopathy) and says that he does not feel that missing insulin doses is a serious problem. He reports often “just forgetting, I am busy and I got other important things to do like school assignments and spend time with my significant other (who was with him as this appointment).” His value of health is low and he reports a poor relationship with his parents because of his poor control of his diabetes. This patient reports more perceived barriers to giving insulin (i.e., financial, social, and situation) than perceived benefits (i.e., feels a little better physically when he gives insulin as prescribed).

Appropriate interventions to try to help decrease the behavior of insulin omission might include: a) providing educational information about his risk of physical complications as his HbA1c increases (*educational intervention*), b) helping him set up more external cues as reminders to take his insulin (e.g., placing his insulin pen on the table prior to eating any meal) (*behavioral intervention*), c) encouraging his significant other to provide general support and diabetes specific support surrounding giving insulin appropriately (*affective intervention*), and d) collaborating with the patient to do a cost-benefit analysis (grounded in the Transtheoretical Model) of changing the behavior of insulin omission (*psychological intervention*). As one can see, using the EHBM of behavioral change combined with specific interventions, an individualistic plan can be collaboratively developed by the patient and provider to help decrease insulin omission and increase appropriate insulin use.

Communication of Insulin Omission to One’s Medical Provider: Impact of Multiple

Sources and Technology.

Over half of the participants in this study reported that they had not shared or discussed insulin omission with their medical providers, while four reported disclosure of insulin omission only after some type of diabetes medical technology (i.e., insulin pump, continuous blood glucose monitor, blood glucose meter) identified the omission or high blood glucose readings. As noted previously, appropriate use of insulin is one essential component for glucose control. Intense glucose control has been seen to increase quality of life and delay and even prevent diabetic complications that are associated with diabetes (i.e., neuropathy, retinopathy, and nephropathy) (Lachin et al., 2008; Rubin & Peyrot, 1999). Type I diabetics who report omitting insulin have also been found to have higher rates of mortality (Goebel-Fabbri et al., 2008). Goebel-Fabbri et al. found that of the 26 women who passed away during their 11-year follow-up, 10 had reported insulin omission at baseline and 16 had reported appropriate use of insulin. In comparing the two groups that had passed away, they found that those that had reported insulin omission had died younger than those that had reported appropriate use (mean ages of 44 vs. 58 years old). Insulin omission been found to be associated with higher risks of diabetic complications and mortality, so new approaches to identifying, communicating about, and training medical providers to empathize and understanding the difficulties someone may have regarding insulin omission will be discussed.

Ogles, Lambert, and Fields (2002) have written on evaluation of outcome assessment in psychotherapy and in assessing insulin omission/insulin adherence, it is helpful to borrow from their model. Ogles et al.'s model includes measuring, monitoring, and managing outcome; in this case insulin adherence. Measuring insulin adherence

could be one of the most difficult steps given that patients' self-report of insulin omission is not always accurate or forthright and there is currently no specific measure of insulin adherence available. Clinically, it would be helpful to have additional sources of data to supplement the patient's self-report (Ogles et al., 2002). Devices mentioned above, such as the insulin pump, could be helpful to document times that individuals did not give insulin as prescribed. Given the ability of some of these technologies to download information to a website or computer, the frequency of collecting this data from patients could be frequent and convenient. If the use of such devices is not possible due to the high cost or lack of insurance coverage for such a device, it is recommended that medical providers get a report from another individual (i.e., family member, significant other, spouse) that could comment on daily insulin use. But, caution should also be used here, given that like medical providers, others tend to overestimate compliance in teenagers and young adults (Gordon & Mansfield, 1996). Typically, lower estimates of adherence have been found when recall-independent behavioral measures are used (Schechter & Walker, 2002) and it has been recommended that multiple measure of adherence be used to gain the most accurate understanding of any behavior (Patton, 2006). Gathering other information (whether from technology or others' report) may help medical providers bring up the topic of appropriate and accurate use of insulin more easily. Monitoring insulin adherence would involve collecting data over time and might include measures of insulin adherence, other's report, and HbA1c. Managing outcome would involve using the monitored outcomes mentioned above to decide when to add, alter, or change interventions to help increase insulin adherence and decrease insulin omission. Given the significant negative impact that insulin omission can have on HbA1c levels, risk of future

complications, and quality of life in general, improving patient-provider communication regarding this behavior is essential.

Barriers and Facilitators to Open Communication

Barriers and facilitators to open communication about insulin omission are closely related and will thus be discussed jointly in this section. Many participants noted that a barrier to communicating with their medical provider was a disease-driven, medical approach to treatment and treatment recommendations. Such barriers included depersonalized appointments and a non-collaborative, problem focused approach to treatment. Marvel, Epstein, Flowers, and Beckman (1999) found that patients' initial statement of their problem to their physician was interrupted in an average of 23 seconds, while 25% of patients reported that they were unable to express their concerns at all. A few participants in the current study noted the lack of time and the perceived busyness of the medical provider as a barrier. In a 2008 survey of more than 4,700 physicians, 28.6% of specialist physicians (including endocrinologists) reported that they did not have adequate time to spend with their patients during their office visits and 27.8% reported that this lack of time limited their ability to provide high quality care (Center for Studying Health System Change, 2009). Thus, patient and providers may both be noticing the limitations of short, solution focused medical appointments.

Many participants noted that a more patient-centered approach, including acknowledging the patient as a whole person with preferences and needs (not just a diabetic) and using a strength-focused, collaborative, supportive approach to treatment and treatment recommendations would help facilitate their communication regarding insulin omission to their medical providers. A more patient-centered, collaborative

approach to patient care that recognizes the patient's autonomy, preferences, and personal goals has been suggested previously to improve patient adherence to diabetes management activities (Delamater, 2006). This recommendation for those with diabetes is fairly consistent with the Institute of Medicine's (2001) suggestion that to improve the 21st century health care system, reduce the burden of illness, and improve health, health care should be patient-centered, defined as "care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" (p. 40). Patient-centered care was one of six major recommended goals for improving the quality of health care, while other one was timely care. A few participants in this current study indicated that more time during appointments would help facilitate communication of insulin omission. Research that has looked into patient-provider communication and enhancing health outcomes is very prevalent (see Bonvicini, Iwema, & White, 2011 for Institute for Healthcare Communication annotated bibliographies). The impact that effective communication and the interpersonal style/approach of the medical provider has on adherence to treatment regimens can be found within this broader patient-provider literature.

Hausman (2001) found that open, collaborative, active communication by both the patient and the provider positively affects compliance behaviors. Others have also supported that, especially in diabetes care settings, patients are active participants and patient-centered collaborative goal setting and communication be used (Glasgow et al., 2001; Golin, DiMatteo, & Gelberg, 1996; Skovlund, Msc, & Peyrot (on behalf of the DAWN International Advisory Panel), 2005). In a meta-analysis of patient preference in studies published after 2000, a majority of patient preferred to be involved in shared

decision making with their medical providers in 71% of the studies reviewed (Chewning et al., 2012). The first implication of the DAWN study included medical providers needing to promote active patient self-management and medical providers being sure to take into account patient's needs, preferences, resources, and circumstances when creating treatment plans with the patient (Skovlund et al., 2005). Safran et al. (1998) investigated seven elements of primary care patient-provider relationships and found that physician's knowledge of the "whole person" was most strongly associated with adherence. They found that adherence rates were 2.6 times higher among patients that rated their physician as knowing them as a whole person than patients that rated their physician as not knowing them as a whole person.

Enhancing and improving overall communication, specifically communication regarding non-adherence behaviors like insulin omission, will take active involvement from both the patient and the medical providers (Skovlund et al. 2005: Dam, Horst, Borne, Ryckman, & Crebolder, 2003). Patients should be encouraged to take responsibility of their own care and express their own medical, support, and psychological needs to their medical providers (Skovlund et al. 2005). Dam et al (2003) found that while there has been a shift towards a patient-centered, collaborative model, medical providers have a difficult time changing their style from the more medical model and to do so need "intensive and continuous support" (p. 21).

Clinical recommendations based on the above studies and previous research include medical providers taking a more patient-centered, collaborative approach to appointments and treatment recommendations. This is proposed to facilitate more open and frequent communication about insulin omission. If medical providers are unable to

do this due to limitations in time or resources in particular settings, it is encouraged that these medical providers consider including providers of psychological services (who are familiar with diabetes, its psychosocial implications, and behavior change principles) into each medical appointment or at least on a consultation basis. Research supports an interdisciplinary approach in working with individuals with diabetes, which ideally would include a behavior change specialist, psychiatrist, or psychologist (Dahan & McAfee, 2009; Delamater, 2006; Lorenz et al., 1996; Tierney et al., 2008). The American Diabetes Association suggests that a behavioral specialist and/or mental health professional be available for referrals and screenings related to adjustment, psychiatric disorders, and non-adherence to self-management issues, like insulin omission (Silverstein et al., 2005). Results from the DAWN study concluded that medical providers believed that difficulties with adherence were consequences of patients' psychological problems, thus providers of psychological services might be the most well trained to assess and deliver appropriate interventions to improve adherence, including insulin omission (Peyrot et al., 2005). One of the recommendations from the DAWN study was to enhance psychological care to individuals with diabetes (Skovlund et al., 2005). Clinical experience in an adult endocrinology clinic, suggests that patients with diabetes respond very well to being told what they are doing *right*, appear to enjoy working collaboratively to help move towards improving areas of difficulty, and seem more self-efficacious when small goals are met. Adding a psychological provider may also help patients feel like they have more face-to-face time with providers in general. This may afford the patient the extra time needed to disclose struggles, such as insulin omission, that may be affecting his/her overall health and quality of life. One study that

compared male and female internists physicians on many factors found that female physicians conducted longer appointments and obtained more relevant medical information than their male counterparts during “routine medical visits” (Hall, Trish, Roter, Ehrlich, & Miller, 1994, p. 386). While gender is obviously a confounding variable to the more time- more medical information association, longer appointments in-and-of themselves may facilitate more opened, honest communication of relevant medical information, like insulin omission.

Most participants reported that a non-empathic, judgmental interpersonal style is a barrier for them in communicating directly about insulin omission to their medical providers. This included medical providers not understanding what it’s really like to have and deal with diabetes on a daily basis and medical providers being judgmental about the participants not being the “perfect diabetic.” In this study, medical providers that were diabetics themselves or who shared that they have a close relative with diabetes were perceived as more understanding and empathic than those medical providers that did not. For medical providers that are going to work with individuals with diabetes that take insulin, experiential training might be extremely helpful. For example, this could include shadowing a diabetic for a day, attending a diabetes camp, or even testing one’s own blood sugar and giving saline injections with the amount based on blood sugar, given scale, food intake, exercise, and stress. This might be beneficial in aiding medical providers with empathy and understanding of the impact that being diabetic and taking insulin on a daily basis has on you as a person. To date, nothing found in the literature could support this idea. Experiential training was discussed with several medical providers that treat those with type I diabetes. One of the providers stated, “That sounds

like a great idea that might occur during medical school, residency, or fellowship, but I wouldn't have time for that now, I'm too busy." When pointed out that not everyone that has diabetes feels like they have time for that either, he stated "Good point, I never thought about that. Man that would be hard." So, even a discussion of this experiential experience provided some evidence that empathy and understanding for those with diabetes could possibly be increased using this type of training.

Limitations and Future Research

As with any study, limitations warrant sufficient discussion. The above results, discussion points, and clinical suggestions are based on a one time data collection of qualitative interviews and brief eating disorder screening measures. The research team included one male, three females, and a female external auditor and all were Caucasian. Gender and/or racial biases and beliefs may have influenced the coding/interpretations of results found. Also, the principal investigator of the study has type I diabetes, takes insulin, and currently works in an adult endocrinology clinic doing psychological consults, all of which could have influenced the coding, interpretation, and write-up of the results. Other limitations include those of qualitative research in general and CQR specifically. The CQR method attempts to control for biases, yet each individual member of the research team has a "lens" in which they view the world, which could have impacted the interpretations of the data. Thus, a potential limitation of the study is that biases were not filtered through the consensual research team approach. An additional limitation of the study includes the generalizability of the results to a broader population other than young adult, Caucasians individuals with type I diabetes attending a public Midwest University. It is unknown how generalizable the results are to other men and

women, races, age groups, those non-college bound, or individuals with type II diabetes.

Due to the unknown generalizability of the results, it is essential that researchers continue to study insulin omission with a focus on understanding the *why* of the behavior in these various groups along with finding ways to improve patient and medical provider communication regarding this dangerous and potentially deadly behavior (Goebel-Fabbri et al., 2008). While it is known that there are some individuals that may choose to omit insulin to lose weight and weight loss may be a physiological side-effect of frequent insulin omission, further research is needed to understand why other individuals may engage in insulin omission if not for weight loss/control purposes. Ideally, future research would also include a more concrete and descriptive definition of insulin omission (including frequency and duration) and the development of a screening measure that medical providers could use to assess for insulin omission and further understand idiosyncratic reasons for insulin omission.

Conclusion

According to the Global Attitudes of Patient and Physicians in Insulin Therapy (GAPPtm), more than one in three patients with diabetes fail to take their insulin as prescribed, including skipping doses (Novo Nordisk, 2010). Medical providers cannot make the assumptions that the reason for insulin omission is for weight loss/control, even if a patient appears at risk for disordered eating or an eating disorders. Reasons for insulin omission appear to vary by person and are multifactorial, therefore interventions should also contain multiple intervention components. Patient-provider communication about insulin omission is fair at best, with over half of the participants in this study failing to disclose this behavior to their medical providers. Yet the improving technology of the

insulin pump and continuous blood glucose monitor may allow medical providers a way to identify and discuss insulin omission more routinely. Participants noted that a more patient-centered, collaborative, empathic, non-judgmental approach would help facilitate communication about insulin omission to their medical providers. As Schechter and Walker (2002) stated, “Managing one’s diabetes is a complex task that touches nearly every important aspect of daily life, and we providers might marvel that any individual manages to do it at all,” (p. 170). We must first listen to patients, understand the idiosyncratic reasons for insulin omission, and then collaboratively work on developing interventions to decrease the frequency of insulin omission. This will ultimately help improve quality of life, delay/prevent complications, and decrease chances of early mortality in individuals with type I diabetes.

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Appendix A

Initial Letter

Dear potential participant,

My name is Jill Sullivan, M. A. and I am currently a doctoral student in the Counseling Psychology program at Ball State University, Muncie, Indiana. I am writing to inform you of an opportunity to participate in a research study that involves exploring the use of insulin in those individuals with type I diabetes. To be eligible to participate in the study you must meet the following criteria:

- be diagnosed with type I diabetes for at least the past year
- be ages 18-24 years old
- currently attend Ball State University, Purdue University, or Indiana University
- currently not live at home with parent(s)/guardian(s)
- be fluent in English
- have no other physical disabilities

If you believe that you meet the above requirements, please consider being involved in the current research study.

The purpose of this study is to explore the experience those with type I diabetes have using insulin. The goal of the study is to advance the understanding of the experience of living with type I diabetes and taking insulin and would like to consider interviewing you in order to achieve this goal.

By participating in this research, you will have the opportunity to discuss your personal experience of type I diabetes and taking insulin. No studies to date have specifically explored this issue in those with type I diabetes. This research could be especially useful for professionals that work with individuals (especially young adults) and assist them in a better understanding the experience of being type I diabetic and taking insulin.

Whereas you have self-identified as being a potential candidate for this study, I would like to explain further what participation in the study would entail. The study would involve a 30-60 minute taped, telephone interview, given that this may be more convenient for you than a face-to-face interview.

After an agreement to participate in the study, your initial questionnaire will be screened and a decision will be made if you are an appropriate candidate for the study. I will then contact you to set up a time that is convenient for you to complete the interview over the telephone. Prior to beginning the interview, I will again briefly introduce the study, remind you of the information that was presented on the consent form, and answer any questions you may have before beginning the interview.

There are no foreseen risks involved in the study, however, you will be provided with referral information to your college counseling center should any psychological distress come from the interview. I have included in the email an informed consent for you to review and sign. For your participation you will receive a \$20 gift card to Walmart, Target, or BestBuy.

If you are interested in participation in the study, you may complete the informed consent form, initial questionnaire, and the contact form so that I may contact you about the interview. If you have any questions regarding the study or the procedures, you may contact me via email at jesullivan@bsu.edu or by phone at (419) 239-9205.

I am looking forward to learning more about the personal experience of type I diabetes and using insulin and hope that you will consider being an essential part of this research project. I am interested in this topic area as a researcher, but also have a personal interest in the topic given that I was diagnosed with type I diabetes at the age of two. I am passionate about this area of research and hope that with your help, we will gain a better understanding of having type I diabetes and insulin use.

I look forward to hearing from you and thanks for considering being a participant in this study!

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Appendix B
Contact Form

Name: _____

Please contact me by:

Email: _____

If yes then what email address: _____

Phone: _____

If yes then what number: _____ and best time of day to reach you _____

Electronic Signature: _____

Please email back the **contact form** with the **signed consent form** and **screening questionnaire** to Jill Sullivan, M.A. at: jesullivan@bsu.edu

THANK YOU!

Appendix C

Informed Consent

STUDY TITLE: Type I Diabetes and Insulin Use.

Purpose of the Research:

The purpose of this research is to explore the experience of using insulin, by those with type I diabetes. The goal of the study is to advance the research fields understanding of the experience of living with type I diabetes.

Rationale:

No studies to date have specifically explored the personal experience of having type I diabetes and taking insulin. This research could be especially useful for health care professionals who work with individuals (especially young adults) with type I diabetes.

Inclusion Criteria:

To be eligible to participate in this study, you must be between the ages of 18-24, have been diagnosed with type I diabetes for at least one year, and attend Ball State University. You must also be fluent in English, not currently live at home with your parent(s)/guardian(s), and have no other disabilities.

Explanation of Procedures:

For this study you will initially be asked to fill out this informed consent and a contact form and email these back to the principal investigator. This should take approximately 5-10 minutes. A brief (5 minute) phone screening will then be set up with the principal investigator or a member of the research team. If after this screening you are found to meet the requirements to be involved in the study, you will participant in a 30-60 minute telephone interview that will be set up at a later time that is convenient for you.

Audio Tapes:

For the purposes of accuracy, with your permission, the interviews will be audio taped. Any names used on the audiotape will be changed to pseudonyms (fake names) when the tapes are transcribed. The tapes will be destroyed after they are transcribed and the transcriptions will be kept as password protected files on the principal investigator's computer for three years and will then be deleted.

Confidentiality:

Any and all information that is shared with the principal investigator and the research team is private and confidential. Names and other identifying information will not be used in the reporting of the data. Written data will be saved on the principal investigator's computer for three years and will then be deleted. Only members of the research team will have access to the data.

Risks:

Participation in the proposed study would include minimal risk to you. Minimal but disturbing psychological distress could occur while discussing your personal experience of living with type I diabetes, taking insulin, and communicating to your physician. Counseling services are available to you through The Counseling Center at Ball State University (765-285-1376) if you develop uncomfortable feelings during your participation in this research project. You will be responsible for the costs of any care that is provided [note: Ball State students may have some or all of these services provided to them at no cost]. It is understood that in the unlikely event that treatment is necessary as a result of your participation in this research project that Ball State University, its agents and employees will assume whatever responsibility is required by law.

Benefits:

The current study may directly benefit you by allowing you to have a safe environment to talk about your experiences (positive and negative) of living with type I diabetes and taking insulin. This study could also help researchers better understand the experience of living with type I diabetes and taking insulin and help physicians gain a better understanding of what might facilitate better patient-physician communication regarding the omission of insulin.

Compensation:

If you are found eligible after the brief screening telephone questionnaire to participate in the study and begin an interview, you will receive a \$20 gift card to Walmart, Target, or Best Buy. In other words, if at any point after you begin the interview you decide to end or withdraw from participation, you will still receive the gift card.

Withdrawing from the Study:

Participation in this study is completely voluntary and you are free to discontinue participation at any time without question from the investigator.

Cost of Participation:

There is no cost to participate in this study. The only exception to this might be if you give the principal investigator a cellular telephone number to call for the telephone interview, then you are responsible to pay for any minutes used on your personal cellular telephone.

Questions:

If at any time you have questions regarding your rights as a subject, please contact The Office of Research Integrity, Ball State University, Muncie, IN 47306, (765) 285-5070, irb@bsu.edu.

If at any time you have questions regarding the research, Jill Sullivan, M.A., please contact Dr. Donald Nicholas, Ph.D. at (765) 285-8040 or dnichola@bsu.edu.

Additionally, you may ask Jill Sullivan, M.A. at (419) 239-9205 or jesullivan@bsu.edu

any questions before, during, or after the telephone interview. Please also contact Jill Sullivan, M.A. should you have questions to research-related injury.

Do you wish to have the results and explanation of the study sent to you via email at the conclusion of the study? No _____ Yes _____

Consent

I, _____, agree to participate in this research project entitled, "Type I Diabetes and Insulin Use." I have had the study explained to me and my questions have been answered to my satisfaction. I have read the description of this project and give my consent to participate. I understand that I will receive a copy of this informed consent form to keep for future reference.

To the best of my knowledge, I meet the inclusion criteria for participation (described on the previous page) in this study.

Participant's Signature (Electronic)

Date

Researcher Contact Information

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Appendix D

Telephone Screening Questionnaire

Please fill in, check, or highlight the appropriate answer

1. Age (in years) : _____
2. Sex: **MALE** **FEMALE**
3. Age (in years) when diagnosed with type I diabetes: _____
4. Race:
 - ___ Black or African American
 - ___ White or Caucasian
 - ___ Asian
 - ___ American Indian or Alaska Native
 - ___ Native Hawaiian or Other Pacific Islander
 - ___ Other, please specify _____
5. Are you fluent in English? **YES** **NO**
6. Besides diabetes, do you have any other disabilities? **YES** **NO**
 If yes, please explain: _____
7. University currently attending:
 Ball State University _____
8. Year in school:
 - Freshman _____
 - Sophomore _____
 - Junior _____
 - Senior _____
 - 5th Year Senior _____
 - Masters Student _____
 - Doctoral Student _____
 - Other _____
9. Current place of residence:
 - Campus dorm _____
 - Off-campus living _____
 - Living with parent/guardians _____
10. In the past 10 days, have you missed an insulin dose (either by injection or pump)?
YES **NO**

-If yes, approximately how many times in the past 10 days? _____

- 11. Do you sometimes take less than you know you should (for example when you ate something, as per your doctor's request, when your blood sugar is high)?**

YES NO

-If yes, how often? _____

- 12. Do you sometimes not take insulin when you know you should (for example when you ate something, as per your doctor's request, when your blood sugar is high)?**

YES NO

-If yes, how often? _____

- 13. Would you be willing to participate in a 30-60 minute audiotaped, telephone interview about your experience of living with type I diabetes and taking insulin?**

YES NO

Pump or injections: _____

Appendix E

Semi-Structured Qualitative Interview

1. Tell me about your personal experience living with type I diabetes and taking insulin.
2. What are your feelings toward having to take insulin on a daily basis?
 - 2b. How do these feelings effect how you take your insulin?
3. What emotions precede not taking your insulin as you should?
4. What thoughts precede not taking your insulin as you should?
5. What makes taking your insulin as prescribed difficult?
 - 5b. What types of things motivate you to take your insulin as directed?
6. What situations make you more likely to not take your insulin as you should (omit insulin)?
 - 6b. What situations make you more likely to take your insulin as you should?
7. In the initial question, you stated that you (insert question that they said yes to from initial questionnaire), can you tell me more about this?
8. Tell me about the most recent time you omitted your insulin?
9. If someone asked you the predominant reason why you omit insulin, what would you say?
10. Tell me about your communication of restricting or omitting insulin to your doctor(s)?
11. What would make you more comfortable to discuss sometimes not taking your insulin with your medical providers?
 - 11b. What currently makes you or might make you less comfortable to discuss sometimes not taking your insulin with your medical providers?
12. Is there anything about your experience as an individual with type I diabetes and taking insulin that we did not discuss but you feel is important for us to know?

Appendix F

More Complete Literature Review

The purpose of the current chapter is to review the literature in regards to insulin omission along with a critique of the literature, in order to propose a qualitative study that would fill in the current gaps within this literature base. Review studies and meta-analyses have attempted to summarize the empirical studies to date that have investigated the prevalence rate of eating disorders and disordered eating in females with type I diabetes (Crow et al., 1998; Daneman, 2002; Nielsen, 2002; Nielsen & Molback, 1998, Rodin & Daneman, 1992). These reviews have also pointed out the inconsistency and inappropriate use of eating disorder measures and lack of rigor across studies. These differences make it difficult to compare findings across studies. Many of these reviews also conclude that insulin omission and/or restriction is very common among this population and is a common means to control weight for individuals with type I diabetes (Crow et al., 1998; Daneman, 2002; Rodin & Daneman, 1992).

More consistently, elevated levels of insulin omission or restriction, a diabetes-specific way of engaging in purging behavior, has been found across studies that have investigated this behavior, ranging from 5.9%-39% (Biggs et al., 1994; Bryden et al., 1999; Fairburn et al., 1991; Goebel-Fabbri et al., 2008; Herpertz et al., 1998; Jones et al., 2000; Morris et al., 1997; Peveler et al., 1992; Peveler et al., 2005; Polonsky et al., 1994; Rydall et al., 1997; Stancin et al., 1989; Weissberg-Benchell et al., 1995). Ways that insulin omission or restriction were measured varied across each study and the possible reasons for omitting or restricting insulin were either made unclear (Goebel-Fabbri et al., 2008; Morris et al., 1997; Weissberg-Benchell et al., 1995) or focused on the behavior as

a way to lose and control weight and shape, making an accurate estimate of those with type I diabetes engaging in this behavior difficult to obtain. Also, an accurate understanding as to *why* type I diabetics may choose to participate in this behavior is unclear. Given that Type I diabetics that omit or restrict insulin have higher rates of morbidity (diabetic complications) and mortality (Goebel-Fabbri et al, 2008), it appears essential that a more complete understanding of the possible reasons that type I diabetics engage in insulin omission be proposed. The following chapter will critically examine the empirical studies that have investigated insulin omission both in- and outside of the context of disordered eating behavior, review the consequences of insulin omission, and examine the difficulty with communication between patient and professional in regards to this potentially dangerous behavior.

Compliance/Adherence to Diabetes Care-Activities, Specifically Insulin Regimens

The rate of non-compliance across chronic disease and life-style changes has remained around 50% for the past two to three decades (Brannon & Feist, 2004). Diabetes self-management involves multiple components of treatment such as checking blood glucose, giving insulin, monitoring food intake, and exercise just to name a few. Non-compliance can occur in any of these self-management activities and compliance in one self-care activity may be unrelated to compliance in other area (Kravitz et al., 1993; Kurtz, 1990, Peyrot et al., 2005), and according to the WHO (2003) adherence to each component should be assessed independently. Delamater (2006) wrote an excellent reviewing on improving patient adherence to diabetes self-management activities. He noted that several factors must be considered when looking to investigate and improve adherence to diabetes self-management activities. He noted that demographic (e.g., low

SES and education level), psychological (e.g., maladaptive beliefs, poor coping, stress), social (e.g., family organization, social support), health care provider and medical system (e.g., support from treatment team, patient-provider relationship), and disease- and treatment-related (e.g. chronic condition, complexity of treatments) factors all be considered.

Given the focus of this study, further literature will be reviewed about adherence to insulin regimens specifically with adherence to other self-management activities noted where relevant. A recent large worldwide study investigated diabetics' compliance rates to many aspects of diabetes care, including medication use (Peyrot et al., 2005). In this study, compliance was defined as "complete success." Of individuals with type I diabetes, 83% reported compliance to their insulin regimens. Insulin adherence rates were somewhat similar to that of adherence to self-monitoring of blood glucose (70%) and adherence to keeping medical appointments (71%) but very different from the self-report adherence rates to diet (39%) and exercise (37%) (Peyrot et al., 2005). Peyrot et al., 2005 found that providers reported significantly better adherence for those with type 1 diabetes than those with type 2 across most domains and their estimates of self-care were lower than patient's report for all behaviors.

Other variables have been considered to be correlates of insulin adherence. These include duration of disease (Jarosz-Chobot, Guthrie, Otto-Buczowska, & Koehler, 2000), age (Morris et al., 1997; Weissberg-Benchell et al., 1995), and self-esteem (Knecht, Keinanen-Kiukaanniemi, Knuutila, & Syrjala, 2001). Jarosz-Chobot et al., conducted a study with both American and Polish children with type I diabetes and found that children that had been diagnosed with diabetes for a longer period of time were more

likely to forget an insulin injection than children that were just diagnosed. Weissberg-Benchell et al. found that older adolescents were more likely to miss insulin injections than younger adolescents and Morris et al. found that adolescents between the ages of 10-20 were significantly more likely to be in the lowest adherence category to insulin than their younger or older counterparts. Finally, Kneckt et al. found that high levels of adherence to appropriate adjustment of insulin doses were related to high self-esteem. Although there is some literature on adherence to insulin regimens outside of the context of disordered eating/eating disorders, there appears to be much more in the literature on insulin omission (i.e., non-adherence to insulin regimen) as a weight loss/control behavior.

Type I Diabetes and Insulin Omission

Currently, omitting insulin, in order to lose or control weight, could be considered to fit into the second criteria of bulimia nervosa in the *Diagnostic and Statistical Manual of Mental Disorders, fourth edition, text revision* (DSM-IV-TR): “Recurrent inappropriate compensatory behavior in order to prevent weight gain, such as...misuse of medications...” (American Psychiatric Association [ApA], 2000, p. 594). Fairburn et al., (1990) cautioned the use of diagnostic criteria that have been seen in general populations, such as those being seen in eating disorder clinics, to other, potentially very different populations (i.e., those with type I diabetes). The prevalence of insulin omission has been studied within and outside of the context of disordered eating and eating disorders.

Prevalence of Insulin Omission

Table 13 is a summary of 13 studies found to date that as part of the authors' studies, examined the prevalence rate of insulin omission in populations with type I diabetes.

Table 13

Summary of Empirical Research on the Prevalence of Insulin Omission

Authors	Year	N	Gender	Ages ^a Range and m(SD)	Duration of Diabetes ^{a,b} m(SD)	ED ^c Yes or No	Percent ^d
Stancin et al.	1989	59	F	18-30 21.5(2.7)	?(?)	Y	39%
Fairburn et al.	1991	100	F and M	17-25 21.5(2.4)	F 9.2(5.2) M 10.1(5.2)	Y	37%F 0%M
Peveler et al.	1992	76	F and M	11-18 15.3(?)	F 8.0(3.7) M 7.2(2.8)	Y	15% F 0% M
Polonsky et al.	1994	341	F	13-60 33.1 (12.4)	15.7(10.7)	N	31%
Biggs et al.	1994	42	F	16-40 ? (?)	? (?)	Y	36%
Weissberg- Benchell et al.	1995	144	F and M	11-19 14.6 (2.3)	5.3 (3.6)	N	25%
Morris et al.	1997	89	F and M	Under 30 16.0 (7.0)	7.0 (4.0)	N	28%
Rydall et al. (follow-up)	1997	91	F	16-22 19.0 (2.0)	11.0 (4.0)	Y	34%
Herpertz et al.	1998	341	F and M	?-? 36.3 (10.6)	13.9 (10.8)	Y	5.9% 19F, 1M
Bryden et al. (follow-up)	1999	65	F and M	20-28 F 23.7(2.1) M 23.9(2.0)	F 16.3 (3.5) M 15.7 (2.9)	Y	19%F 0%M
Jones et al.	2000	356	F	12-19 14.9 (2.0)	6.7 (3.6)	Y	11%
Peveler, et al. (follow-up)	2005	62	F	20-38 A ^e 23.9 (2.0) Y ^f 33.1 (2.9)	A ^e 15.7(2.9) Y ^f 20.8(5.5)	Y	36%
Goebel-Fabbri et	2008	234	F	24-72	28.0(12.0)	N	30%

al. (follow-up) 45.0 (12.0)

Note. M=male, F=female.

^a Years

^b ?= Missing data

^c Did the study investigate insulin omission within eating disorders

^d Percent of studied population that was found to be engaging in insulin omission and/or restriction

^e A= adolescent

^f Y= young adult

The studies reviewed were published between 1989 and 2008 and the number of participants that were included ranged from 42 to 356 with a mean of 156 participants. Six of the thirteen studies included both males and females while the other seven included only females when investigating the prevalence rate of insulin omission. The age ranges covered ages 0 through 72 years old with six of the studies staying within an adolescent-young adult range (ages 11-28). While two studies failed to report the mean duration of the diagnosis of diabetes (Biggs et al., 1994; Stancin et al., 1989), the majority of the studies reported it. The range for mean duration of the diagnosis of diabetes across studies was 5.3-28 years. Interesting, only four of the thirteen studies examined the prevalence rate of insulin omission in those individuals with type I diabetes outside of the context of disordered eating or eating disorders (Goebel-Fabbri et al., 2008; Morris et al., 1997; Polonsky et al., 1994; Weissberg-Benchell et al., 1995). These four studies varied slightly in their proposed purposes yet all were similarly interested in compliance and adherence to insulin regimens. The purpose Weissberg-Benchell et al.'s study (1995) was to examine adolescent diabetes management and mismanagement while the purpose of Morris et al. (1997) was to examine the relationship between poor glycemic control and failure to adhere to one's insulin regimen. Goebel-Babbri et al. (2008) and Polonsky et al. (1994) both investigated insulin omission as a lack of

adherence issue and its relationship to morbidity and mortality and disordered eating, long-term complications, and glycemic control respectively.

The reported prevalence rates of insulin omission and/or restriction, from all 13 studies, ranged from 0-39%. In contrast, the studies that examined the prevalence rates outside of disordered eating (Goebel-Fabbri et al., 2008; Morris et al., 1997; Polonsky et al., 1994; Weissberg-Benchell et al., 1995) reported a much narrower range, 25%-31%. In viewing the studies in which both males and females were involved as participants, three studies reported 0% of males as engaging in insulin omission (Bryden et al., 1999; Fairburn et al., 1991; Peveler et al., 1992), one study reported 0.006% of males engaging in insulin omission (Herpertz et al., 1998), and two studies did not report prevalence by gender (Morris et al., 1997; Weissberg-Benchell et al., 1995). Peveler et al. (2005) appear to have reported the highest rate because insulin omission *and* insulin restriction were both considered. Overall, what can be concluded from the prevalence rates is that insulin omission in those diagnosed with type I diabetes, as it has been measured in the past 19 years, is not uncommon especially in females. This leads to the question of exactly how was insulin omission measured in these reviewed studies.

Measurement of Insulin Omission

Table 14 is a summary of how the 13 studies reviewed measured insulin omission.

Table 14

Measurement of Insulin Omission

Authors (Year)	Measurement of Insulin Omission
Stancin et al. (1989)	Measurement of insulin omission is unclear, but a combination of questionnaires designed to assess eating disorders by DSM-III diagnostic criteria.

- Fairburn et al. (1991) Insulin omission was measured by questions added to the eating disorder questionnaire about “underuse or omission of insulin for the purpose of weight control” (p. 18). No further clarification about the questions was given.
- Peveler et al. (1992) Insulin omission was measured by “taking no insulin during a 24-h period for the purpose of weight reduction” (p. 1357). Insulin underuse was measured by “taking less insulin than prescribed on at least two occasions during the past month for the purpose of weight reduction” (p. 1357).
- Polonsky et al. (1994) Insulin omission was measured by the patients response to the statement “I take less insulin than I should” (p. 1180).
- Biggs et al. (1994) Insulin omission was measured by the patient response to the question that he/she was “intentionally withholding insulin for weight loss within the last 3 months” (p. 1187).
- Weissberg-Benchell et al. (1995) Insulin omission was measured by a question in the diabetes mismanagement questionnaire developed by the authors “In the past 10 days, how often did you miss a shot?” (p. 81).
- Morris et al. (1997) Insulin omission was measured by the amount of prescribed vs. filled prescriptions from the individual’s pharmacy.
- Rydall et al. (1997)^a Insulin omission was measured by questions added to the Diagnostic Survey for Eating Disorders about “omission or underdosing of insulin to promote weight loss” (p. 1850). No further clarification about the questions was given.
- Herpertz et al. (1998) Insulin omission was measured by questions added to The Questionnaire for the Diagnosis of Eating Disorders about “omission of insulin or deliberate undertreatment in order to lose weight” (p. 1111). No further clarification about the questions was given.
- Bryden et al. (1999)^a Insulin omission was measured by asking each patient “if they ever reduced or omitted their insulin in order to lose weight” (p. 1957).
- Jones et al. (2000) Insulin omission was measured by questions added to the eating disorders inventory to “include diabetes related items such as intentional insulin omission for weight loss” (p. 1564).
- Peveler et al. (2005)^a It was unclear how insulin omission was measured, but it appears to be as a bingeing behavior within disordered eating that was reported.
- Goebel-Fabbri et al. (2008)^a Insulin omission was measured by the patient’s response to the statement “I take less insulin than I should” (p. 416).

^a Follow-up study.

As evident by review of Table 14, there does not appear to be any constant way that authors use to measure insulin omission/restriction. Several studies asked about insulin omission/restriction in the context of weight control/loss (Biggs et al., 1994; Bryden et al., 1999; Fairburn et al., 1991; Herpertz et al., 1998; Jones et al., 2000; Peveler et al., 1992; Rydall et al., 1997), while other studies appeared to assess insulin omission in the context of binge eating disorder behavior (Peveler et al., 2005; Stancin et al., 1989), but these two were less clear about specific questions asked to the participants. Other studies used a single question assessment about taking less insulin than the individual should (Goebel-Fabbri et al., 2008, Polonsky et al., 1994) or missing shots within the past 10 days (Weissberg-Benchell et al., 1995). Finally, one study used a behavioral method to measure insulin omission by obtaining the ratio of prescribed verses filled insulin prescriptions from the individual's pharmacy (Morris et al., 1997). It is important to note that all other measures of insulin omission used in previous studies were self-report either in the context of a questionnaire or a single scale item. Morris et al. (1997) note that the objective measure of obtaining the ratio of prescribed verses filled insulin prescriptions for each individual still has its limitations. Given that those individuals on a basal-bolus regimen adjust their daily insulin regimen in response to food intake, exercise, and blood sugar levels, it was difficult to accurately define what the "prescribed" amount of insulin would be although the mean as prescribed by the physician was used (Morris et al., 1997). Morris et al. (1997) also note that they cannot be sure that the individuals were taking insulin as prescribed just because they were filling their prescriptions on time. In summary, an objective measure is often superior to a self-report measure for some

behaviors but even using an objective measure of insulin omission has its limitations and thus is not necessarily a more valid measure of insulin omission.

While several of the authors asked about insulin omission in the context of weight loss/control, four of the studies reviewed above did not specify for what reasons the insulin omission was occurring. If the interest of the studies is to define prevalence rates of insulin omission, then this may not matter. But if the interest of future studies lies in developing a further understanding of insulin omission (e.g., for weight loss) and possible individualistic interventions that could help those with type I diabetes, a better understanding of other reasons for omitting insulin besides for weight loss/control need to be investigated. Given the high frequency in which insulin omission is being reported by those with type I diabetes (especially females), the short-term or more immediate results of omitting insulin and long-term consequences on insulin omission must be considered.

Consequences of Insulin Omission or Restriction

Short-term Consequences

Short-term consequences of omitting or restricting insulin include all symptoms of marked hyperglycemia (high blood sugar) including: slightly blurred vision, weight loss, polyphagia (excessive hunger), polyuria (frequent urination), and polydipsia (increased thirst) (ECDCDM, 2003). Another, more severe short-term consequence of untreated hyperglycemia is ketoacidosis, or a collection of ketones (waste products) (American Diabetes Association [ADA], 2007b). As one's body breaks down fat to use for energy (because insulin is not available to use sugars), ketones will build up to dangerous levels and the body cannot get rid of them, causing ketoacidosis (also known as diabetic coma) (ADA, 2007b). Morris et al., (1997) found that in those patients that

took less insulin than prescribed (28% of patients, as evident by not filling prescriptions as would be needed if they adhered to their insulin regimens), hospital stays for ketoacidosis were negatively related to their adherence index. Since high adherence index meant less insulin restriction or omission, those that were found to be omitting or restricting insulin were found to have more hospital stays for ketoacidosis. Peveler et al. (2005) also found a strong relationship between insulin misuse (for reported weight control) and hospital admissions for ketoacidosis.

Given that diabetes and its related complications are reported as the seventh leading cause of death in the United States in 2007 (Centers for Disease Control and Prevention, 2009), it appears important to know how insulin omission effects the long-term morbidity and mortality of those that are engaging in the behavior.

Long-term Consequences

While complications can occur in any individual with type I diabetes, several studies have found higher rates of complications (besides ketoacidosis) in those that engage in insulin omission or restriction (Goebel-Fabbri et al., 2008; Peveler et al., 2005; Polonsky et al., 1994; Rydall et al., 1997; Takii et al., 2008). While some of these studies investigate complications of having disordered eating or a diagnosable eating disorder (including insulin omission as a purging behavior) (Peveler et al., 2005; Rydall et al., 1997; Takii et al., 2008) other studies have investigated complications of insulin omission or restriction in and of itself (Goebel-Fabbri et al., 2008; Polonsky et al., 1994).

Complications of eating disorder behavior: Including insulin omission.

Peveler et al., (2005) investigated disordered eating habits in 87 female patients with type I diabetes at baseline and 63 of the original 87 patients with type I diabetes during an 8-

12 year follow-up. When looking at the two cohorts combined and the rates of microvascular complications, 48% (11) of those patients that developed serious microvascular complications (defined as “laser-treated or preproliferative retinopathy, renal failure or proteinuria, or peripheral or autonomic neuropathy” (p. 85)) had reported a history of insulin omitting or restricting. Peveler et al. (2005) also found a significant relationship between reported insulin omission or restriction and the presence of at least two serious complications. Within this study, microvascular and other complications were obtained through case notes within the patients’ medical charts.

Rydall et al. (1997) investigated the presence of retinopathy, a microvascular complication to the retina, in 91 female patients with type I diabetes at baseline and follow-up. These females were also questioned regarding disordered eating behavior (including insulin omission or restriction). Rydall et al. found that for females that reported disordered eating behavior at baseline (including insulin omission), retinopathy four years later was associated. The author’s concluded that those type I diabetics with disordered eating behavior have a higher risk of retinopathy, given that 86% of those that identified as having highly disordered eating behavior (defined as “at least twice a week for three months: binge eating, omission or restriction of insulin to produce weight loss, induced vomiting, laxative use” (p. 1850)) had been diagnosed with retinopathy at follow-up. Within this study, the presence of retinopathy was confirmed by an eye examination and dilation.

Lastly, Takii et al. (2008) investigated the factor most closely relating clinical eating disorders in females with type I diabetes with nephropathy and retinopathy. Using multivariate analysis, the authors found that duration of severe insulin omission was

significantly associated with nephropathy and retinopathy and it was more strongly associated than the duration of having type I diabetes for the individuals. Within this study, the presence of nephropathy and/or retinopathy was determined by an examination by a physician and medical testing.

A strength of the three above studies was their methods of assessing complications, through examination, testing, or by collecting data from the patient's medical chart. More confidence can be put into the findings compared to if the authors' would have used self-report measures of complications. One limitation that is worth mentioning is that all three studies were done only with female patients, thus the generalizability of the findings to male patients with type I diabetes are very limited. Other limitations of these three studies are identified when investigating the direct complications of insulin omission, and not disordered eating or clinical eating disorders. While insulin omission was included in the authors' questionings of disordered eating behaviors, it was not the only factor that could have been influencing the increased rate of complications, given that those with disordered eating may have had other conditions that could negatively impact their physical health (i.e., an eating disorder, depression). Although helpful, less confidence can be given to the results of these studies when attempting to review the complication of insulin omission or restriction itself, outside the parameters of disordered eating or clinical eating disorders. More confidence can be given to those studies that directly examine the complications of insulin omission in and of itself.

Complications of insulin omission. Goebel-Fabbri et al. (2008) and Polonsky et al. (1994) both investigated insulin omission in female patients with type I diabetes and

the morbidity and mortality associated with this behavior, outside of the context of studying disordered eating. Polonsky et al. (1994) asked female patients (ages 13-60 years old) to fill out questionnaires including an item to measure insulin manipulation (i.e., “I take less insulin than I should” (p. 1180)) that was answered on a 6-point Likert scale (1 never-6 always). Any patient that responded other than “never” was considered an “insulin omitter” (p. 1180). Complications of retinopathy and neuropathy were determined by a blind review of the patient’s medical chart and “insulin omitters” were found across all age ranges (Polonsky et al., 1994). Using a chi-square test, those that reported omitting insulin had statistically significant higher rates of neuropathy and retinopathy than those that were categorized as non-omitters.

Goebel-Fabbri et al. (2008) conducted an 11-year follow-up with 234 women (mean age of 45 years old with a range from 24-72 years old) with type I diabetes who were initially and at follow-up, asked about insulin restriction via a single scale item. Data on complications for each participant was gathered by self-report of: nephropathy, foot problems, retinopathy, neuropathy, and cardiovascular complications. Complications of foot problems and nephropathy were more common in those patients that reported insulin restrictions at baseline than those that reported appropriate insulin use at baseline (25% vs. 12% and 25% vs. 10% respectively). Of the 26 women who died during the 11-year follow-up, 10 had reported insulin restriction at baseline and 16 had reported appropriate use. In comparing the two groups that had died, Goebel-Fabbri et al. (2008) found that those that had reported insulin restriction had died younger than those that had reported appropriate use (mean ages of 44 vs. 58 years old).

Thus, insulin omission and restriction has not only been found to be associated with higher risks of diabetic complications than those that do not engage in this behavior, but according to Goebel-Fabri et al. (2008) they also appear to have a greater chance of dying at younger ages than their non-omitting peers with diabetes. Given the above review of complications of insulin omission or restriction, it is important to point out limitations of this body of literature. First, all of the above studies contained female-only patients, thus it is impossible to know if the complications and mortality that could arise out of insulin omission or restriction would look similar in a male population. Also, the added “noise” of examining insulin omission within the context of disordered eating and clinical eating disorders, leaves the reader with an unclear idea about what complications may arise out of insulin omission and which ones may arise from disordered eating behavior in those with type I diabetes. Even so, it does appear that those that engage in insulin omission or restriction appear to have a higher rate of developing some complications and even possibly a higher risk of mortality. Thus, the communication by the patient of insulin omission or restriction to his/her professional care team appears essential in order to take steps to help decrease the patients risk of developing such serious complications or even avoiding death.

Patient-Provider Communication

Cameron et al. (2007) advocate that a mental health screening (including depression and anxiety) be considered as important as complications screenings that are often used with individuals with type I diabetes (i.e., screening for neuropathy, retinopathy, etc.). Yet, to date, no mention has been made advocating for insulin adherence screenings. Given that direct communication is currently being facilitated

regarding quality of life and complications, it is likely that there is less direct communication regarding adherence issues. Patient-professional communication between patients with type 1 diabetes and their health care provider should include communication about adherence, particularly insulin omission.

Patient Communication

One study that investigated the prevalence rates of eating disorders in 89 females with type I diabetes (ages 14-18 years old) found that six of the females had a diagnosable eating disorder (mostly binge eating and purging behaviors). In follow-up, none of the females that had a diagnosable eating disorder had shared their disturbed eating behaviors with their health care team (Engstrom et al., 1999). While insulin omission (a type of purging behavior) was not specified within this study as the means of purging, the question comes to mind, is this “secretive behavior” of not adhering to the diabetes regimen without communication to the physician or care team, generalizable to those engaging in insulin omission or restriction. Biggs et al. (1994) also discuss the honesty of patients with type I diabetes that are insulin withholding for weight loss in sharing this information with their physicians. Women with type I diabetes that reported withholding insulin intentionally (for weight loss) within the last three months were compared with women with type I diabetes that did not reported insulin withholding within the past three months to control weight (non-withholders). Those that withheld insulin, reported significantly more lying to physician about adhering to their insulin regimen than did the non-withholders.

Professional Communication

A qualitative study investigated attitudes and practices of health care professionals that treat those with type I diabetes and disturbed eating and weight control (including insulin omission) (Tierney et al., 2008). Face-to-face interviews were done with a total of 20 professionals (four male, sixteen female) from three different positions (twelve diabetes specialist nurses, six doctors, and two dieticians) in adult and pediatric units. Tierney et al. asked open-ended questions to the participants and found four themes that emerged after analyzing the transcripts. Theme 1 was “defining problematic eating” (Tierney et al., 2008, p. 386) in type I diabetes. Insulin omission was thought to be very common and even natural as a means of weight control in their patients, especially young females. One professional even feared that he or she may prompt the idea of omitting insulin to lose weight, by talking about it.

Professional 8: I do wonder how much of a seed I or other healthcare professionals place...because sometimes I say in routine consultations ‘so you missed your insulin, what happened, how did it make you feel?...Are you purposely trying to lose weight?’ and then you start to focus on that subject and they start to think about it. (Tierney et al., 2008, p. 386)

Theme 2 was defined as “detecting the unmentionable” (Tierney et al., 2008, p. 387). Professionals across the board described feeling that their patients were not open and honest about their activities including insulin omission. One professional expressed that he or she felt guilt or shame may also play a factor in the dishonesty and underreporting of such behavior.

Professional 1: ...we’re trying to go and do one thing and they’re trying to do another and that often drives it [insulin omission] underground...often when you’re talking

about it you can see the barriers being put up...because obviously you're talking about something that has been set down as a cornerstone of diabetes. (Tierney et al., 2008, p. 387)

Within theme two, professionals also mentioned a lack of confrontation with an individual about behaviors that are assumed to be for weight control (i.e., insulin omission and disturbed eating) due to a lack of training, and feeling clumsy and awkward. Themes 3 and 4 were defined by Tierney et al. (2008) as “containing rather than changing” (p. 387) and “accessing additional support” (p. 388) and thus again an expressed lack of training to deal with “eating disorders” and an overall lack of support to deal with the issues if expressed by the patient.

Tierney et al.'s (2008) qualitative study lacks generalizability and external validity, but some interesting observations can be made from the themes and topics themselves. Although the purpose of the study was not to investigate practitioners' attitudes and beliefs about insulin omission, it appeared to be a common topic within all of the themes. Also, it was common throughout the four themes that the professionals felt uncomfortable treating, diagnosing, discussing, and even referring patients with disordered eating or weight manipulation behavior. One major assumption within the study is that when the practitioners are discussing insulin omission that it is being done to manipulate, control, and lose weight. Without asking questions and confronting patients that they feel are omitting insulin, how would they know that the reason for insulin omission is weight loss? The question from a patient standpoint then becomes what types of questions would I be more honest about answering regarding insulin omission, and how could it be addressed within the professional-patient relationship in an open and

honest manner? Given that the inter-personal factor of the quality of the patient-provider relationship and communication between the two parties has been found to be related to adherence rates (better relationship and communication, the better the reported adherence) (Karkashian & Schlundt, 2003), it would appear that professionals might also be interested in improving this patient-professional communication.

Also from a professional standpoint the question is what are some of the other reasons that patients might be omitting insulin besides weight control and would professionals feel more comfortable addressing these issues, if they were in fact, diabetes management or psychologically related more than weight and eating disorder related? The importance of further understanding of these concepts is important because if insulin omission is assumed to be an “eating disorder” behavior, then primary care physicians, endocrinologist, and nursing staff treating the type I diabetic might not address these issues that are affecting metabolic control. If insulin omission could be better understood and patients feel better able to discuss the behavior with their doctors, diabetes management can be discussed and improved within the diabetes care team.

Proposed Methods: Qualitative Research

Limitations in the prior literature result in a number of unanswered questions such as a) why do individuals with type I diabetes omit insulin, b) from the patients’ perspective, what would facilitate better patient-physician communication regarding insulin omission, and c) how can insulin omission best be understood so that a reliable and valid measure of the behavior could be developed. In-depth, semi-structured interviews are needed with individuals that admit to omitting insulin to potentially find answers to these unanswered questions. This calls for a qualitative research design.

Qualitative methodology is used to further understand a phenomenon of interest and allows for the importance of context to be considered and it also provides an in-depth understanding of the individuals' created meaning of their lives and experiences (Wang, 2008). In using qualitative methodology, it is important to use a methodology that fits with one's approach to data analysis and one's philosophies of science, thus this will be reviewed next.

Approach to Data Analysis

My approach to data analysis will be phenomenological with the analytic framework of consensual qualitative research (CQR) (Creswell, Hanson, Clark-Plano, & Morales, 2007; Hill et al., 2005; Hill et al., 1997). A phenomenological approach to research includes attempting to understand the shared experiences that *all* individuals have who experience the same phenomenon (e.g., those with type I diabetes that engage in insulin omission). A phenomenological approach to data analysis includes identifying individuals who are diagnosed with type I diabetes that engage in insulin omission and collect data via interviews (Creswell et al., 2007). According to Creswell et al. (2007), a phenomenological approach to data analysis is a structured approach and they state that there are several models that appear appropriate to do this structured data analysis. Although not specifically mentioned by Creswell et al. (2007), it appears that using the CRQ method of data analysis would be appropriate to use to get at the experience of *all* individuals, using Hill et al.'s, frequency label of *general*- which includes categories experienced by all or all but one participant (Hill et al., 2005; Hill et al., 1997). Using the CQR's method of data analysis will also add more data, given that its focus is on experience felt by all participants or all but one (*general frequency label*), those

experiences felt by at least half of participants but less than all but one (*typical frequency label*), those experiences felt by less than half of participants but more than two (*variant frequency label*), and those experiences felt by one (*rare frequency label*). Thus, to me this is more rich data than just identifying those experiences felt by all individuals which would be a more typical phenomenological approach to data analysis (Creswell et al., 2007).

Using Hill et al.'s (2005) CRQ analytic approach to data analysis involves four steps: developing domains or topic areas, creating core ideas while keeping the developed domains in mind, creating categories for the core ideas within each domain by cross-analyzing the data, and having an external auditor assess to make sure the raw data is reflected in the developed domains and the created core ideas and categories. The creating categories step is the step in which the frequency labels are assigned (e.g., are the categories that were created by cross-analysis: *general, typical, variant, or rare*). Two other important aspects to mention about the CQR data analytic approach is the importance of consensus and the attempt to bracket biases and openly discuss them throughout the data analysis (Hill et al., 2005). Consensus must be obtained within the closed research team about the developed domains, and created core ideas and categories. Also, biases, expectations and experiences with the phenomenon (e.g., insulin omission) will be discussed openly and honestly throughout the data analytic process and this will be especially important given that the author has been type I diabetic since the age of two (Hill et al., 2005). Now that my approach to data analysis has been discussed, my philosophy of science through research paradigms will be discussed in regards to *ontology* (view of the nature of reality), *epistemology* (view of the relationship between

the research and participants), and *axiology* (role values within the research process) (Ponterotto, 2005). Before beginning to use qualitative methodology, a clear understanding of one's personal philosophy must be understood. Ponterotto (2005) noted that most researchers beginning qualitative research do not understand their philosophy of science before they begin. I feel that it is essential for me and the reader to understand my personal philosophy of science in regards to ontology, epistemology, and axiology before describing my specific methodology.

Research Paradigm

A paradigm is a theoretical or philosophical framework or a thought pattern in a discipline. Research paradigms are thought to help one understand his/her own philosophy of science as one undergoes the process of research (Ponterotto, 2005). In reviewing the research paradigms, it appears that I fall within a constructivist-postpositivist research paradigm philosophy of science with a slight lean towards constructivist. I arrived at this conclusion through my review of literature on ontology, epistemology, and etiology. This makes sense to me given my feminist worldview (constructivist) yet having my quantitative methodological training (postpositivist).

Ontology

In regards to my view of the nature of reality, I appear to be constructivist. I believe that multiple, created but equally valid realities exist (Ponterotto, 2005). There does appear to be some debate regarding whether looking for consensus within a team is consistent with a constructivist or postpositivist approach to ontology. Hill et al. (2005) stated that finding consensus within the team is just another one of the multiple, valid realities, while Ponterotto (2005) argued that finding consensus takes away individual

realities. I tend to agree with Hill et al. (2005) that coming to a team consensus within the data analysis is just another valid reality, and while this will become the reality of the team and not necessarily of the participants, this will be acknowledged in reporting the results.

Epistemology

In regards to my view of the relationship between the research and participants, I feel that I fall between a constructivist and postpositivist view. I do not think that the interviewee is a trustworthy reporter just sent to get accurate information from the participant (postpositivist). I do believe, however, that the research and participant *somewhat* mutually affect each other in the process (e.g., the participants by what they choose to share and the researcher by which probes they choose to use) (Ponterotto, 2005). I do not believe that the researcher and participant mutually influence each other so much that it could potentially change the entire meanings of the data collected, especially given Hill et al.'s (2005) recommendations to use previously designated probes for most of the interview and have 8-10 questions within the semi-structured questionnaire.

Axiology

Finally, in regards to the role of researcher values within the research process, I again feel that I fall between a constructivist and postpositivist belief. I do believe that we can attempt to bracket our biases and this should be done (as is suggested by Hill et al., 2005 and a postpositivist view of the value of roles within the research process). However, I do not believe that we can eliminate them from the process and believe that we must acknowledge that even when bracketed and openly discussed, they still affect

the research process (more constructivist approach). Hill et al. (2005) recommends that the researcher should initially discuss biases, expectations, and beliefs regarding the topic being investigated (e.g., insulin omission) and that this should also be done openly and honestly throughout the data analytic process.

In conclusion, it would appear that I fall on a continuum between a constructivist and postpositivist research paradigm (leaning more towards the constructivist side) when I consider my beliefs about ontology, epistemology, and axiology. This was a very interesting conclusion to come to for me, given that Hill et al. (2005) stated that the CQR approach to qualitative methods falls within this same continuum, again closer to the constructivist side. Although others tend to disagree and have stated that the CRQ method developed by Hill et al. (1997) is more postpositivist than anything (Ponterotto, 2005).

CRQ

As stated earlier, a fairly newly developed approach to qualitative research, called CQR (Hill et al., 2005; Hill et al., 1997) will be used as the method of choice to explore the proposed research questions. Given that CQR has been noted to be especially good for “.... studying events that are hidden from public view, are infrequent, occur at varying time periods, have not been studied previously, or for which no measures have been created....” (Hill et al., 2005, p. 204), it appears to be an appropriate qualitative method to further understand insulin omission. Whereas many of the quantitative studies on insulin omission have investigated prevalence rates of insulin omission and the behavior as a purge behavior, little in-depth understanding of the behavior itself has been gathered. Hill et al.’s approach to qualitative research was chosen for several other reasons including the emphasis on consensus within the research team, the constructivist

approach to reality (i.e., each individual has his/her own “truth” as they view it), and the constructivist approach to data collection, with a focus on interactive, non-experimental, naturalistic data (Hill et al., 2005). Lastly, Hill et al.’s (1997) approach to qualitative research was chosen due to its emphasis on examining researcher’ bias. Given that the biases could come out of this researcher’s demographic characteristics (i.e. being a woman with type I diabetes) or her beliefs and values surrounding the topic being investigated, it appears essential that her biases be considered in an open and honest manner throughout the study’s process.

Consistent with Haverkamp, Morrow, and Ponterotto’s (2005) request to ask researchers to think about what role qualitative research could have in advancing the field of counseling psychology, a qualitative approach to investigating reasons for participating in a behavior, may help lead to better developed individual interventions for those that are engaging in insulin omission and/or restriction. It may also help improve communication between patients with type I diabetes engaging in such behavior and the professionals on their care teams. Without knowing the *why*’s behind a behavior, it may be more difficult to develop such individualistic interventions, permanently change the maladaptive behavior, and even communicate regarding the behavior.