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## Dealing with the devil: weight loss concerns in young adult women with type 1 diabetes.

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## **Abstract**

**Aim:** To examine the weight loss concerns of young adults with type 1 diabetes (23-30 years of age).

**Background:** Eating disorders are prevalent in young women with type 1 diabetes, particularly those aged 18-22.

**Design:** Qualitative.

**Methods:** Semi-structured interviews with 35 young adults with Type 1 diabetes and 13 healthcare professionals.

**Results:** Most female interviewees were concerned about the difficulties of losing weight when having diabetes. The men who took part in the study were unconcerned about weight. A minority of female interviewees developed severe eating disturbances. These women initially regarded their disturbed eating behavior positively, and engaged in weight loss activities intermittently. However over time they lost control of their behavior and it came to dominate their lives. Family conflict often intensified disordered eating behaviors. Eventually all of these women managed to transition away from their behavior, though this process took some of them several years. Healthcare professionals felt that eating and weight-related issues often went undiagnosed and undocumented in young adult women with Type 1 diabetes.

**Conclusion:** Many young women with Type 1 diabetes are worried about their weight, but will not engage in risky weight loss activities because of concerns about their health. A minority of young adult women will develop more severe eating related disturbances. These eating disturbances may last a significant amount of time before clinicians become aware of them. These women may also have disordered weight loss impulses for sometime after clinical interventions.

**Relevance to clinical practice:** There is a need for clinicians to screen young adult women with Type 1 diabetes for eating disorders, and also monitor young adult women who have developed eating disorders over the longer-term. There may be a need to provide asymptomatic young women with diabetes with information about the potential risks of insulin omission.

**Key words:** Young adult; weight; dieting; diabetes; type 1; eating disorder; diabulimia; insulin omission; qualitative.

## **Dealing with the Devil: Weight loss concerns in young adult women with Type 1 diabetes.**

### **INTRODUCTION**

Young women with Type 1 diabetes are twice as likely as their non-diabetic peers to develop clinical eating disorders (Jones *et al.* 2000). Sub-threshold eating disorders are even more common in this group (Jones *et al.* 2000, Peveler *et al.* 2005, Colton *et al.* 2007, Peyrot *et al.* 2010). Even young women with Type 1 diabetes who do not have eating disorders are often preoccupied by their weight and body shape (Balfe 2007, Peters *et al.* 2011). A number of diabetes specific factors may encourage the development of disturbed eating in young women with diabetes, such as the fact that insulin use is often associated with weight gain (Bryden *et al.* 2001, Peveler *et al.* 2005).

Eating disorders are of concern in this group because they are associated with poor outcomes (Peters *et al.* 2011). Peveler *et al.* (2005) followed-up 87 young women over a twelve year period and found that of those who developed serious microvascular complications, 21% had a probable eating disorder, 47% had a history of disordered eating behavior and 48% had a history of insulin misuse. Eating disorders also appear to increase mortality risk in young women with diabetes by a factor of up to three (Nielsen *et al.* 2002, Goebbel-Fabbri *et al.* 2008).

Although the past fifteen years have seen the publication of a number of innovative studies on disordered eating in women with Type 1 diabetes, there remain several

gaps in our understanding of this group. We lack a sufficient understanding of the natural history of disordered eating in young women with Type 1 diabetes, in particular what leads them to develop disturbed weight loss behaviors and what leads them to desist from these behaviors once they have developed them (Goebbel-Fabbri *et al.* 2008, Young-Hyman and Davis 2010, Powers *et al.* 2012). We also lack an understanding of non-disordered weight loss concerns in young women with Type 1 diabetes more generally (Balfe 2007). We sought to address these questions/research gaps by using a qualitative approach, which diabetes researchers have argued is particularly suitable for gaining a better understanding of young women's perspectives on these issues (Goebbel-Fabbri *et al.* 2011).

## **METHODS**

### **Design**

We used a qualitative approach for this investigation. The study was conducted in Ireland.

### **Sample**

Interviewees were recruited from a young adult diabetes clinic (n=3) and through advertisements placed on the Facebook page of Diabetes Ireland (the Irish version of Diabetes UK or the American Diabetes Association) (n=32) (twenty nine women and six men). Six women were either diagnosed as having had an eating disorder, or considered themselves to have had an eating disorder, in the past. Twenty-three women did not consider themselves to have had a history of disordered eating. Our recruitment advertisements did not state that we wanted to talk to young women with eating disorders, only that we were looking to talk to young adults with Type 1

diabetes who were between 23 and 30 years of age. We also interviewed thirteen diabetes healthcare professionals (diabetes nurse specialists n=10, consultant endocrinologists n=3). Healthcare professionals were sampled so that each one was recruited from a different diabetes center. Recruitment continued until we reached data saturation.

### **Data Collection**

The first author conducted all interviews. Interviews lasted between 15-20 minutes (healthcare professionals) and one hour (young adults). Interviews with the study participants who did not have eating disorders focused on barriers to diabetes management in the young adult period, with a specific sub-set of questions focusing on their weight loss activities (if any). As noted, six young women had had eating disorders in the past; interviews with these young women focused more explicitly on their eating disorder behaviors.

### **Data analysis**

The interviews were analysed using standard qualitative thematic analysis (Tierney *et al.* 2008). All interviews were read through and analysed by the first and second authors, with the remaining authors commenting on their analysis. The first two authors began by 'open coding' the interview transcripts, that is by giving each section of a transcript that addressed a particular issue a descriptive tag or 'code' (for example a section of a transcript could be labelled 'concern about shifting mentality'). These codes were then compared and contrasted with one another in order to determine if some of them could be subsumed under high level concepts or 'categories' (for example all posts labeled with the descriptive tags 'concern about

shifting mentality' and 'physical damage as a result of disordered eating' were placed the higher level category 'impact of eating disorder'). These categories became the organizing themes of the article (such as 'general weight loss concerns'). The themes were developed until all authors agreed that they provided a good description of the data collected (Tierney *et al.* 2008). Following Tierney *et al.* (2008), quotations were chosen so that they avoid reporting the views of one person.

## **RESULTS**

### **General weight loss concerns**

Male interviewees were unconcerned about their weight. Most of the female interviewees who did not have a history of disordered were somewhat concerned about their weight. These interviewees often felt that they gained weight easily as a result of taking insulin, and that losing weight was especially difficult with diabetes. Despite these women's general concerns about losing weight, however, most of them were adamant that they would not engage in 'harmful' weight loss activities.

Whenever I've had to go on a diet I've always been healthy. (27<sup>1</sup>).

How people can go on diets that self-induce ketosis I will never know. Sorry, it's crazy. (30).

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<sup>1</sup> This number refers to the interviewees' age.

Most interviewees were concerned about avoiding risk, and did not want to engage in any activities that would harm their diabetes control. They also felt that risky weight loss activities would make them feel ill.

I don't understand why you'd not take insulin because I feel so shit when I'm high. (23).

### **Eating disorders**

#### *Development of an eating disorder*

We interviewed six women who engaged in more disturbed weight loss activities. All of these women no longer considered themselves to have eating disorders, though they did occasionally have troubling weight loss impulses. Five of these women described becoming increasingly concerned about their weight in their mid- to late-teens, with one young woman becoming concerned in her twenties. All six of these women had omitted insulin in the past in order to control their weight. It was notable that all of these interviewees described stumbling across insulin omission as a way to lose weight in a somewhat accidental fashion. They had never consciously sat down and worked out that insulin omission would lead to weight loss. Four interviewees came across this information either through the media, friends or some other informal source.

I found out that if you didn't take your insulin you could lose weight by reading it in a magazine. I was like, this sounds brilliant. (23).

The remaining two interviewees stopped taking their insulin because their injections hurt them. They also quickly noted that insulin omission led them to lose weight.

It stung, so I didn't take it [injection]. And then I started to lose weight. I thought that was great (23).

#### *A positive experience*

These women initially regarded insulin omission as a positive experience. They quickly lost weight without experiencing any noticeable side-effects, and additionally often received a number of admiring comments from their family members and friends; their behavior was therefore positively reinforced via a number of sources.

A Was losing weight quicker than you were expecting?

B Yes. It was in about 2-3 weeks. My family had noticed. They just thought I was doing a lot of exercise.

A Were you exercising at the time?

B Not really. I just hadn't been taking the insulin.

A Did it feel good to actually lose weight at the start?

B It did, yeah. (25)

Insulin omission was accompanied by a feeling of mastery, which stemmed both from interviewees' feelings of control over their bodies, and also from a sense that they had figured out a secret way of controlling their weight that other people did not know about.

I realised that I was getting thinner from doing that and I could manipulate it quite easily. It was like this brilliant trick I had (23).

Interviewees' sense of mastery was partly fueled by a lack of knowledge about their behavior. As they often stumbled across their behavior by accident that they were unaware of the possible long-term consequences of what they were doing. It is unclear whether these young women genuinely did not believe that there would not be any longer term consequences stemming from their behavior, or whether they did have some concerns but squashed them.

I thought it was just something that I'd discovered. There couldn't be any possible long term effects of this, I'll just do it and it will be grand. (23)

### *Escalation*

These women, at the beginning, engaged in disordered weight loss activities intermittently. They appreciated the control that their weight loss activities gave them, but these behaviors were viewed primarily as short-cuts to achieving greater goals rather than objectives in and of themselves. Interviewees usually felt in control of their behavior during this initial period.

If like there was an event coming up I'd be prone to letting my bloods run high and fit into my dress. (23).

One interviewee remained an intermittent insulin ommitter until she eventually managed to bring her behavior to a halt.

It went on a year maybe. It wouldn't have been every week I was doing that, just if there was a big thing coming up. (23).

The other five interviewees' disordered behavior gradually escalated. They became habituated to what they were doing. These women also became locked-in to their behavior, realizing that if they started to take insulin again properly they would gain back all of the weight that they had lost by omitting insulin.

It got easier gradually. I just got used to it. I just kept doing it. I found it very difficult to start taking insulin again because I knew I was going to put weight back on. (24)

As weight loss came to assume a more and more central role in these women's lives, eating-related problems often began to extend beyond insulin omission. Beginning to move away now from any initial feelings of mastery, these women began to feel more and more out of control of their weight loss behaviors.

I was eating constantly and didn't take insulin. I ate a weeks normal person calories in a day I was so bad. Then I might take my insulin and I'd wake up and be like, oh my God, I'm putting on weight. And I'd be like, I'm not taking my insulin today. It went on and on and on. (24).

*Impacts of disordered behaviours*

Day-to-day life for these women became increasingly organized around food and weight loss. Two of these women were in college at the time, and felt that their course-work suffered because of their disorder.

I do think if I was being careful I might have done a bit better in college. (23).

This woman was also particularly unlucky in that she was the only interviewee to experience serious diabetes-related complications as a result of her eating disorder, though two of the other women reported ending up in hospital at various points because of their disordered eating.

I'm getting laser treatment done as there's blood vessels forming at the back of my eyes. I get pains in my legs. I had dental problems. I lost a lot of hair. But I still didn't want to take care of it. (23)

Overall, it seems clear that disordered eating began to seriously impact interviewees' lives. However disordered weight loss behaviors occupied such central and controlling positions in their lives that they were often unable to alter their behaviors even when faced with the risk of diabetes problems.

Small patches I might be like, I'm going to do this, I have to take care of my diabetes. But it wouldn't last. (23).

Interviewees felt that as their eating disorder became more and more entrenched their perspectives and attitudes began to shift, with weight loss becoming the core principle

in their lives that all other considerations were assessed against. Any consideration that was felt to interfere with weight loss activity was deemed irrelevant or threatening, and ignored or avoided. Interviewees felt that their minds had shifted into quite an alien way of thinking at this point.

I only realise it now... I just thought it was normal. I wasn't in a good head space at all. (24)

My head wasn't screwed on at the time. (28).

Interviewees also became increasingly distressed by their weight loss activities, with depressive episodes becoming common and some experiencing suicidal thoughts. The following extract is quite interesting because it captures something both of the out-of-control dimension of this interviewee's thinking and also its calm, matter-of-factness ('that was ok').

When I was a teenager 15-16 I suffered with bulimia and then that led to depression. I remember sitting there after trying to slit my wrists and not taking insulin for a week, about to jump out the window. If I had to die from it I had to die from it and that was ok. (28).

### *Family support*

Families were described as imperfect supports. One interviewee noted that her mother actually encouraged her to omit insulin. This is revealing as it says something about some parents' lack of knowledge about the potential risks of eating disordered

behavior in their daughters, and also something about parents' lack of knowledge about diabetes.

I said it to my mum, look, I'm not taking my insulin and I'm losing loads of weight. She was like, that's brilliant, I wish I could do that. (23).

Interviewees who had eating disorders seemed in general to have quite conflicted relationships with their parents, particularly if they continued to live at home. Interviewees' parents were understandably very worried about their daughters' behaviors, but did not seem to be able to act on their concerns in ways that they did not alienate their daughters. There seemed to be high levels of expressed emotions in interviewees' family lives, and constant arguments over food. Interviewees sometimes used weight loss behaviors as a tool to get back at their parents and demonstrate independence from them. A range of complex emotions and impulses striated weight loss activities at this point.

My parents, we'd be fighting and shouting in the house. It nearly drove me to it more by then trying to stop me. I kind of felt like I was really rebelling in ways. They hid food. I was like, what age am I that you're hiding food from me. It made me feel even worse. I hated them because of it and then I'd eat everything. My mum would ask, how can we help you? Do you actually want us to put a lock on the fridge at night? (23).

*Moving away from disturbed eating behaviour*

All interviewees eventually moved away from their eating disorder behaviors. There were three main factors associated with this transition process, with some interviewees experiencing multiple factors. The first was the interviewee experienced a catastrophic event, typically one that destabilized their diabetes control to such an extent that they became seriously ill; interviewees often became truly conscious, perhaps for the first time, of the long-term risks of their weight loss behaviours during these events. The second was that something happened to make interviewees realize that they were not the only ones to engage in extreme weight loss behaviors. Seeing other young women with diabetes who had eating disorders often served to break through interviewees' solipsism and present them with an understanding that their behavior was abnormal and serious and that they were in need of help. Medical intervention was the third reason (in all of these interviewees' accounts medical intervention occurred after a catastrophic event). Interviewees seemed to find it easier to open up to medical professionals who they considered to be 'nice', and who they had developed some kind of trust with in the context of a long-term supportive relationship.

B I ended up in ICU for a few days, it was that badly controlled. And now I want to get it more under control.

A Why's that? What's changed?

B Complications. I don't want to get them. (25).

I was in college with the girls and I was watching tv and it happened to come up on some programme. I just remember listening to it in the background and had this shock of realisation that that was what I had. (24).

The doctors were very good but I find it hard to open up and to talk to strangers. I just couldn't tell them what was wrong and why because I didn't know them. I'm that type of person that wouldn't just open up to anyone about those things. (23).

However while interviewees often wanted to desist from their eating disorder behavior, doing so proved more difficult. Just as the period when their eating disorder first began was characterized by intermittent insulin omission, the period when their disorder began to end was characterized by intermittent desistance. Interviewees needed to work hard to change their thought patterns and pay careful attention to their behavior in order to identify triggers of weight loss impulses; they also had to accept that they were going to gain weight, and they were going to lose some of the rigid control that they had established over themselves.

It took a long time to get it where it should be. It took about 3-3½ years. I suppose it was just being conscious of what you're doing. I would actually start questioning, I'm getting an urge not to take my insulin. Why am I getting it? I found it very difficult to force myself to think about it. It took a long time of conscious effort. (24).

Although interviewees no longer considered themselves to have eating disorders, many of these interviewees continued to struggle with weight loss impulses, particularly when they experienced stressful life-events such as becoming unemployed, experiencing relationship difficulties and so forth.

I've been tempted. The bulimia is always there. It's not something you get rid of. (28).

A Do you have to fight yourself sometimes?

B Yes.

A And would it just kind of come into your head sometimes or would it be a constant battle?

B It would be a constant battle.

A Do other people know this?

B No. I haven't said anything to anyone. (25).

### **Eating disorders- a hidden problem**

Interviews with healthcare professionals supported young adults' accounts. Healthcare professionals felt that weight loss concerns were prevalent in young women with diabetes who were in their early to late **teens**.

The girls may conceal it a little bit but they're very weight conscious. (Nurse).

Young women with eating disorders were of concern to all of the healthcare professionals who took part in the study. Most healthcare professionals felt that eating disorders were more likely to be concentrated in young women in their late teens to early twenties, becoming less common as they moved into their mid- to late- twenties.

A Would there be any sub-groups of young adults who you would be particularly concerned about?

B Well the first group that come to my mind and we have a few of them, are people with eating disorder (Nurse).

Eating disorders, in the early twenties in particular, is a huge risk (Nurse).

Healthcare professionals felt that healthcare services were misdiagnosing (or not diagnosing at all) many young women with serious weight loss problems, particularly young women who did not quite meet the full diagnostic criteria for an eating disorder. They felt that young women were often reluctant to open up and discuss their eating problems with doctors and nurses, and that doctors and nurses in turn were often either unable to encourage young women to open up and talk about their problems, or unsure about what to do on the occasions when they did open up. Specialist psychological support services for young women with eating disorders were often either absent or had very long waiting lists.

I know the term diabulimia has been coined by some people and I do think it's a real entity. We do not diagnose it very often but I suspect it is in there, particularly with those young women with persistently high A1Cs or recurrent DKA. (Consultant).

I'd put my hand up and say that as a clinician I think we're missing eating disorders, some clinical eating disorders, or abnormal eating patterns. I also

think we're poor at managing the psychology of our patients, services for which are poor (Consultant).

Some professionals felt that young women who disclosed eating problems were easier to treat than women who kept their eating problems to themselves, as disclosure indicated a state of mind that was receptive to assistance. These professionals felt that young women who did not disclose their problems were generally more resistant to treatment, and as noted, would often remain undiagnosed by healthcare professionals.

When we realise it's an eating disorder, it's obviously going on a while. The ones in early stages will verbalise it so they're already looking for help. Those ones you can help. But the ones who don't even mention it are the harder ones to help. (Nurse).

## **DISCUSSION**

This study addresses calls from researchers to investigate the natural history of eating disorder behavior in young women with Type 1 diabetes (Goebbel-Fabbri et al. 2008), particularly the events that lead to the behavior being developed and, ultimately, discontinued. It also addresses the lack of research into more general weight loss concerns in 'older' young adult females with Type 1 diabetes. We found that most of the women in this study were concerned about their weight, but would not engage in disordered weight loss activities as they did not want their diabetes control to suffer. A minority of interviewees developed highly disturbed eating behaviors (though mainly when they were younger), and these conditions extracted a heavy physical and mental price from them over time. Findings in this study that we have not seen

previously reported include: the accidental way in which young women can develop insulin omitting behavior; their lack of knowledge about the consequences of this behavior; the positive feelings that they have towards insulin omission at the beginning; and the halting, extended nature of the transition away from eating disorder behavior. These findings indicate the utility of taking a qualitative approach with young women with Type 1 diabetes (Hillege *et al.* 2007).

Insulin omission appeared to be a key gateway behavior to full-threshold eating disorders in this study, a finding previously noted (Goebbel-Fabbri *et al.* 2008). However the almost accidental manner in which some young women can begin to omit insulin has not been previously noted. It may therefore be worthwhile for healthcare professionals to provide asymptomatic young adult women with brief information about eating disorders and diabetes and their potential consequences, and also asking screening questions such as ‘are you taking as much insulin as you feel you should be?’ (Goebbel-Fabbri *et al.* 2008). It was evident in this study that healthcare professionals are missing eating disorders in young women with diabetes, especially in the early stages of the illness. Similar problems with detecting eating disorder behaviors in young women with diabetes have been identified in other studies, so these difficulties are not unique to the Irish context (Tierney *et al.* 2009). If healthcare professionals do not proactively identify Bulimia symptomology in young women, this behaviour may last a number of years before these young women seek help, with obvious consequences for their diabetes control and mental health. Parents’ inability to effectively help their young adult children (and knowledge about eating disorders and diabetes) was notable. It may be useful for healthcare workers who are working with a patient with an eating disorder to ask for their permission to talk to

their parents (if there is a lot of conflict in the family home). Healthcare workers could give parents advice about how to handle the situation with their child more productively, in a way that does not increase conflict within the family.

A number of factors (the development of an 'alien' mindset, fear of weight gain) helped to maintain eating disorders once they were developed, until the disorders were eventually brought to a halt. Young women with diabetes' high recovery rate from eating disorders have also been noted (Peveler et al. 2005, Goebbel-Fabbri et al. 2011), though as several interviewees in this study noted, by the time recovery is underway considerable damage may be done. However it is also clear from this study that some young women who stop having an above-threshold eating disorder continue to harbor fears about weight gain, with these fears sometimes lasting for years. This points to a need for diabetes professionals to monitor these young women, or at least the ones deemed to be of particular risk, over the longer-term. Therapeutic intervention may help recovery, but again these services are often lacking for these young women.

Taking a step back, it is worth considering these young women's narratives as a whole. Our analysis indicated that the narratives of the different interviewees with eating disorders who took part in this study had a similar structure; we termed this the 'dealing the devil' narrative. Western cultural history is replete with stories of individuals who seek control over their bodies or the world and want a short-cut to doing so (the classic version of this story is Goethe's Faust); to achieve their goals these individuals often make a deal with the Devil, who grants them what they want in exchange for one or two small favours; these favours usually come with small print

(that is never read) that eventually allows the devil to take their souls. What the Devil gains at the end of these stories is much more valuable than the worldly goods or power that he grants at the beginning. The narratives of the women in this study follow a similar pattern. They all desired power/control over the natural world (their bodies). They discovered a force that they did not quite understand that allowed them to cheat nature and fulfill their desires (insulin omission). They led a charmed existence for a period of time. However the power they used to achieve their desires eventually turned out to be poisoned and ultimately took their 'souls' from them (as they noted they went 'crazy' and 'lost their minds'). Although they regained their souls at the end of the story and escape the Devil's clutches, even then he continues to 'tempt' them.

The main weakness of this study is the small number of women with eating disorder who took part in it, though the sample size as a whole is quite large for a qualitative study (Morse 2000). However the study provides important and needed information about the eating disorder trajectory in young women with Type 1 diabetes.

## **CONCLUSION**

Many young women with Type 1 diabetes who are in their twenties are concerned about their weight, but will not engage in risky weight loss activities out of concern about future risk. A minority will develop more severe eating related disturbances. They will feel initially empowered by their eating behaviors, but there is a risk that these behaviors will end up eating them.

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