

**A Young Woman's Life with an Invisible Disability:**

*It was the young woman, with the syringe, in the stomach*

An honors thesis by:

**Tara Lyle**

A thesis submitted in partial fulfillment of the requirements for the degree of  
Bachelor of Arts, Honors in Sociology

April 28<sup>th</sup>, 2014, Halifax, Nova Scotia

This honors thesis is approved by:

Dr. Audrey MacNevin

Honors Supervisor

Dr. Russell Westhaver

Department Chair

Saint Mary's University

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## **Abstract:**

### **Invisible Disability:**

*It was the young woman, with the syringe, in the stomach*

This thesis analyses the lived experiences and realities of a young woman living with an invisible disability. More specifically, it debates the advantages and disadvantages of disclosing type 1 diabetes, drawing on the conceptual-theoretical insights of symbolic interaction, including discreditable stigma and impression management strategies. Data for this thesis consist of findings from research studies on the topic, complemented with first-person insights modelled on a biographical-narrative approach. Taken together, this evidence suggests that it is not always smart to disclose an invisible disability and that disclosure brings positive and negative experiences, depending on when and to whom you disclose.

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I would also like to extend my gratitude to the Saint Mary's Criminology and Sociology Department, staff, and secretaries. My appreciation goes out to the honours family members, who were there as we supported one another along the way. I want to acknowledge my friend and classmate, Loretta Saunders, may she rest in peace. My voice will speak the truth, even if it is shaking, thanks to you.

I must also recognize those individuals who live with invisible disabilities like type 1 diabetes and applaud them for their efforts to live fully and to embrace their abilities in this world. Without their experiences, as well as my own, this thesis would not be what it is today.

I also extend a special thanks to Dr. Banting and Dr. Best for the discovery of insulin. It now grants many people living with diabetes a way to live a long and healthy life.

Last, but certainly not least, I would like to say a special thanks to my friend and "my person", Faith. She has been there at some of the most difficult times and helped me realize that life may have its challenges but there is nothing we cannot achieve if we just believe in ourselves; in other words, to have "faith".

# Table of Contents

Abstract	3
Acknowledgements	4
Introduction	6-7
Methodology	8
Modifications of the Definition for Type 1 Diabetes	8-9
Literature Review	10
<i>A. Defining Invisible Disability</i>	10-11
<i>Experiences of living with Invisible Disability</i>	11-14
<i>B. Defining Impression Management</i>	14-16
<i>Symbolic Interaction: The Works of Erving Goffman</i>	16
<i>Experiences with Impression Management</i>	16-17
<i>C. Defining Stigma</i>	18-20
<i>Experiences of Stigma</i>	20-22
<i>D. Defining Disclosure</i>	23
<i>Experiences of Disclosure</i>	23
Experiences in My Life	24-27
Discussion	27-30
Conclusions	30-31
References	32-35

## Introduction

Halle Berry declares, "Diabetes turned out to be a gift," she says. "It gave me strength and toughness because I had to face reality, no matter how uncomfortable or painful it was" (Wilson, p. 51, 2009).

"I don't have a pump yet... I give myself the shot, and I don't mind... it's like sitting down to the makeup table, and you've got this eye makeup you're going to put on, a drink of coffee... it's part of your routine" (Mary Tyler Moore on CNN Larry King Live, July 1, 2005).

"Diabetics are the only people who take drugs to avoid getting high" (tweeted by diabetesdigest.com).

To disclose your disabilities sets you up for others to define your abilities (Lyle, 2014).

When the numbers 4, 5, 6, 7, 8, and 9 come to mind, some people might feel lucky if these numbers mean they have won the lottery. Individuals like me, however, feel lucky for a different reason. The choices I make in terms of daily carbohydrate intake, physical exercise, and accurate monitoring of my blood sugar potentially put me on the track of winning my own kind of lottery. The right choices put my blood sugar between the acceptable numbers for adults as promoted by the Canadian Diabetes Association (CDA). I was diagnosed with juvenile type 1 diabetes, insulin dependent, at the age of three years. This thesis topic is therefore more than an interest of mine; I live, eat, breathe, and inject it every hour, of every day of my life. There is still no cure for this chronic illness. Therefore the diagnosis has no expiry date and the life expectancy of it is forever, or at least until a cure is found.

Unlike individuals who win the monetary version of the lottery and must disclose their identities to the media, disclosing an invisible disability to others is a personal choice. Lingering stereotypes and stigma go along with having a disability, and no one

knows what comes along with living with a disability until he or she experience it first-hand. While support from others might be helpful, often it takes the form of non-diabetics telling you what you should be doing to manage the illness, and if you fall off the wagon, telling you how awful you are doing too. Those who win the lottery have the new-found finances to go on vacation if they choose, but living with an invisible disability like type 1 diabetes means that one can *never* take a vacation from his or her illness. The closest to it one can hope for is to choose not to disclose at all or to disclose only to those few one can trust not to throw it back in your face or use it against you.

The subject of this thesis is the tactical disclosure of invisible disability. Through a synthesis of scholarly research findings cast against the experiences of a young woman living with type 1 diabetes, this thesis considers the pros and cons of disclosing one's invisible disability. The theoretical position taken within respect to this topic draws from symbolic interaction because it concerns issues surrounding construction of the self and impression management strategies (Goffman, 1959). Is disclosing a discreditable stigma tactical? Is it in a young woman's best interest to disclose to others the fact that she has type 1 diabetes?

What follows is a brief discussion of the methodology adopted to address these research questions, followed by introductions to relevant concepts such as invisible disability, impression management, and stigma. The essay concludes with a statement of general conclusions and some discussion of directions for further study.

## **METHODOLOGY**

This essay considers the pros and cons of disclosing a disability. The data consist of scholarly sources on the subject synthesized with a collection of autobiographical passages pertaining to living with type 1 diabetes as a young, Caucasian woman. In this project, the biographical narrative is used to identify similarities and differences with the secondary scholarly literature in the areas of women and disability.

## **DEFINITIONS OF TYPE 1 DIABETES**

### **MY DESCRIPTION**

As someone who lives daily with this illness, my experience of the illness is as follows:

Every morning you wake up wondering whether you are alive or still dreaming because you are awaking to the haze affect of comatose. Your first thought is of a number. You wonder whether you are cold because it is early morning, and the heat has not yet kicked in or if you are dipping down into the blood temperatures nearing zero degrees.

The question of whether or not I am alive is often one of my first thoughts if I wake in the wee hours of the morning. When others are dreaming of sugarplums in the month of December, the best I can hope for is orange juice.

It brings that line to mind that people say when looking at you: "You can't eat sugar?" Really, sugar is what I need the absolute most every time my blood sugar level is low. At that moment, sugar actually keeps me alive. Diabetics therefore have a hate/love relationship with sugar – too much or too little can kill us.

What most people do not know is that with type 1 diabetes you have high and low blood sugars. The goal is to keep your sugars at a normal level, between a value of 4 and 9. Having varying blood sugar levels is similar to a roller coaster ride. You go up, then you go down, and you do that a couple more times and think you have the hang of it. Then right in the middle, when you start to go back up from the bottom and before you start to climb back up that mountain of unwanted adventure, you feel like you are floating on a cloud. You have achieved the height requirement for this ride, a value between 4 and 9.

After a while you have no choice. It's like you work at the carnival and you have only a one-way ticket on that roller coaster ride. Bypass the cotton candy and candy apple stands because on that ride you want to feel the wind on your face without having to



vomit when you have had too much sugar. Then that ride starts to get easier and easier to handle. You take one day and each ride one at a time.

You have not played any of the fair games, but you have won a prize, one that you consider your life lottery, one you make worthy to want to live this roller coaster lifestyle and love it too. Along with all the other things life throws your way that any other person deals with, you have the luxury of winning your life back each time you wake up and get back on that ride.

## **CANADIAN DIABETES ASSOCIATION'S DEFINITION**

According to the Canadian Diabetes Association (CDA):

“Diabetes mellitus is a metabolic disorder characterized by the presence of hyperglycemia due to defective insulin secretion, defective insulin action or both. The chronic hyperglycemia of diabetes is associated with relatively specific long-term microvascular complications affecting the eyes, kidneys and nerves, as well as an increased risk for cardiovascular disease (CVD). The diagnostic criteria for diabetes are based on thresholds of glycemia that are associated with microvascular disease, especially retinopathy” (CDA Clinical Practice Guidelines Expert Committee, 2013).

## **JUVENILE DIABETES RESEARCH FOUNDATION'S DEFINITION**

According to the Juvenile Diabetes Research Foundation (JDRF):

“Type 1 diabetes occurs when the body's immune system attacks and destroys certain cells in the pancreas, an organ about the size of a hand that is located behind the lower part of the stomach. These cells — called beta cells — are contained, along with other types of cells, within small islands of endocrine cells called the pancreatic islets. Beta cells normally produce insulin, a hormone that helps the body move the glucose contained in food into cells throughout the body, which use it for energy. But when the beta cells are destroyed, no insulin can be produced, and the glucose stays in the blood instead, where it can cause serious damage to all the organ systems of the body. For this reason, people with type 1 diabetes must take insulin in order to stay alive. This means undergoing multiple injections daily, or having insulin delivered through an insulin pump, and testing their blood sugar by pricking their fingers for blood six or more times a day. People with diabetes must also carefully balance their food intake and their exercise to regulate their blood sugar levels, in an attempt to avoid hypoglycemic (low blood sugar) and hyperglycemic (high blood sugar) reactions, which can be life threatening” (JDRF, 2014).

## Literature Review

### I. INVISIBLE DISABILITY

Many persons with invisible disabilities such as type 1 diabetes do not disclose their illness to others because they want to be seen by them as normal (Driedger, 2008, p. 7; Charmaz as cited by Dietz, 1994, p. 1; Twohig & Kalitkus, 2004, p. 139). Driedger (2008) finds that being seen as *sick* is viewed as the ultimate devaluation in society; however, through this struggle those with sickness can choose how to live their lives. Twohig et al (2004) found that living with a disability is less about the illness and more about how lives have been disrupted by illness. Often, society puts this burden on those living with a disability, visible or invisible, such that those with a disability cannot embrace illness as normal. Invisible disability can include symptoms such as debilitating pain, fatigue, dizziness, weakness, cognitive dysfunctions, learning differences and mental disorders, as well as hearing and vision impairments. These are not always obvious to the onlooker, but can sometimes or always limit daily activities, ranging from mild challenges to severe limitations that vary from person to person” (Invisible Disabilities Association, 2013, para. 6).

Rasmussen et al.’s (2007) study states, “trying to pass as “normal” if you have an invisible disability causes stress because the individual is worried about being found out as guilty of “calculated cheating” or “caught in a lie” (Thorne, Paterson, & Russell, 2003, p. 1345). Mullins & Preyde (2013) provide unique insights into the experiences of having an invisible disability at a university from the perspective of students. The authors illustrate that the university experiences of individuals with invisible disabilities are

dynamic and complex. Furthermore, they confirm that having a disability that is invisible can make it easier for student participants to be treated normally; it also means, however, that the validity of the disability can be questioned and that others may not understand the full extent of their limitations. Secondly, the authors assert that their study makes a valuable contribution to the literature by providing insight into how individuals with invisible disabilities believe they are perceived within the university context. The authors hope that their study enhances the understanding of lived experiences of having an invisible disability, and provides both individuals with and without disabilities strategies to facilitate an open and accessible university environment.

Livneh, Martz, & Wilson (2001) perceive invisible disability to inspire high levels of anxiety. A person who perceives his or her disability to be invisible can resort to denial to further reduce the condition's potential discovery. Thus, the persistent fear associated with the impending discovery serves to increase anxiety. In sum, the authors assert that it is plausible that some forms of denial are more readily associated with invisible disabilities, whereas other forms of denial are more closely linked to visible disabilities.

## **EXPERIENCES LIVING WITH INVISIBLE DISABILITY**

Living with an invisible disability involves choosing who gets to know about our illness and who does not. A common response from others when they find out that I have type 1 diabetes is "You don't look diabetic". Some of my experiences and my reactions to these experiences living with an invisible disability include the following:

### **On the subject of disclosure:**

There is a difference between accepting one's diabetes and disclosing it to everyone. I think positively about my diabetes. I would not have some of my closest friends if it were not for my diabetes. Disclosing it to everyone is *not* always the best thing to do. That does not mean I am hiding that I have it. Just think about it for a second. Do you tell everyone everything personal about your life? No. Therefore, those individuals who do not live with an invisible disability should stop telling those of us who do what is best for us, i.e. that we should disclose to everyone. You can embrace it and you can decide to whom to disclose. Having an invisible disability might make you feel as though you should hide your illness, but think about those who live with a visible disability. I can assume they wish they had an invisible one sometimes and might even think that those living with an invisible one are somewhat lucky. However, invisible or visible, the negative connotations associated with disability of any kind in society are unacceptable."

By choosing to share my invisible disability at my job interview with the Diabetes Clothesline I got the job as a Promotional Assistant, and the boss told me I got the job because I am diabetic.

You strive to keep your disability invisible, to appear as normal and to be independent and not use it as an excuse because then others look down on you when you get special treatment. If you can keep it invisible people deem you as normal and they will accept you. There are people who help you, but you do not want to be seen as someone who needs assistance always from others, because that can become a burden to them and take away your freedom.

### **On joining others with similar illnesses:**

There is no one to go to at the university I attend. I was asked to join a disability group and it was supposed to be kept completely confidential. However, there was a mistake that occurred where the coordinator was sending out emails to the entire group and that made me feel uncomfortable. Plus, I like to embrace my 'abilities' rather than be in a group for 'disabilities'. There should be a group of diabetic students who can compare their university experiences with each other and be a form of support for one another.

I have formed my own close group of friends who have invisible disabilities like me. We can relate to each other the kind of life we live, different from all the rest.

### **The pros and cons of the illness:**

Dealing with an invisible condition can have both incredible positives as well as numerous negatives. The negatives include going to the hospital numerous times a year and having to explain yourself constantly. Also, there is inner battle one faces

when it comes to knowing how to prioritize your life around fluctuating energy, sugar or brainwave levels. It is the delicate balance of knowing how to incorporate healthy lifestyle choices and knowing when to let drugs do the work. A sense of not belonging socially can also be something that many face on a constant basis. That can be a very isolating condition, even among others like you. There are many positive attributes as well, from understanding one's own mortality at a very young age and learning how to not take certain things for granted, even something as simple as taking a breath. Relishing and embracing things such as independence, health, laughter, support, love and above all else a sense of learning how to live in the moment and taking every day one at a time. It teaches you about transparency, where health is concerned. It is incredibly important to be honest at all times. Even though truth can cause pain at times, it can also save your life. That discretion is up to you. It reminds you every single day to have discipline in all you do as your choices can and will greatly impact your life with greater consequences in the end; especially, when it comes to staying on top of self-care in order to live longer. This illness gives you perspective on life, emotionally, psychologically, ethically, etc. All in all, it gives you an extra kick when it comes to life and living and taking each day with a great deal of faith in yourself and looking at life as a constant blessing.

#### **On attempting to pass when you feel ill:**

Feeling like the world around you is moving in slow motion and you're not a part of it? Many thoughts and more happen within one minute, which puts you in a panic mode that you cannot breathe. How do I channel these emotions without drawing attention to myself, yet quietly keeping calm, pretending to be normal? You find ways to cope because sometimes, not everyone wants to be dependent on medication. Therefore, we find holistic ways to work around it, which to me, makes me feel like I am in control of my disability. The preference to stay to myself in silence, makes one realize that this can look odd in a public setting; therefore, ones finds ways to tolerate the social setting. You develop a seventh sense, to be engaged in the conversation and atmosphere enough to be normal; however, the whole time your living in your head.

#### **On self-motivation:**

A lot of people joke when they say, "I didn't want to get up this morning". Waking up is an accomplishment, getting out of bed is a milestone, getting showered is a victory, eating is triumph, and getting something completed for work or school, heck, you just won the lotto! I refuse to let my disability define my character. It is up to me when and to whom I disclose. Only to those I trust completely and wholeheartedly because it can either work against you or work in your favor. Sometimes it is not worth discovering the answer.

**On managing social life:**

When you are around others frequently, there is a constant need to explain yourself. Sometimes you allow your control over the illness to fail because no one is perfect, but then others see your imperfections.

Some people say that they don't want to be normal... they want to live outside the box, but they don't understand what it entails to be unique – it's f\*\*king hard work! People who have disabilities, all we ever want to be is "normal". We don't like the struggle of waking up in the morning, being medication dependent, altering our behavior, not being ourselves, having to explain ourselves, and living our lives around our disabilities forever. We just want to be sad, happy, angry, and tired when we need to be, without being questioned, with no explanations necessary.

We act as normal as possible in public, but when alone, the invisible disability is very visible to us. You see, to us, invisible disabilities are private; you can conceal it, act like it does not exist, but when you're alone, you cannot run from it or tell yourself that you don't have it because your disability reminds you that it is a part of you and you are a part of it, forever.

When people around you know of your disability it can be deemed your personal failure. It's a struggle for you every day – they can (1) treat you like you're incapable, (2) act indifferent towards you, or (3) hold it against you. You are constantly judged by it; your past mistakes are because of it, and your future possibilities are limited by it.

**II. IMPRESSION MANAGEMENT**

Goffman (1959) contends that each social interaction is like a performance - a presentation of self in which the individual seeks to create specific impressions in the minds of others in the attempt to present oneself in a particular way. He terms this process impression management, an insight that is especially useful when considering whether or not to disclose one's disability to others. Research findings on how individuals with disabilities want to portray their illness publically (Mullins & Preyde, 2013, p. 147; Balfe, 2009, p. 128; Sandstrom, Martin, & Fine, 2010, p. 122). Mullins et al. (2013) generally agree that hiding a disability is motivated by the desire to be treated normally, but that not

disclosing fails to acknowledge the limitations the person with the disability might truly have.

Similarly, Balfe (2009) views young people with disabilities as especially torn between being healthy and being perceived as normal. Another view by Sandstrom et al (2010) is that self-esteem plays a key role in one's self-conception, especially to an individual with a disability. There is also a clear gendered dimension to living and coping with social life as a person with an invisible disability. Media pressure in contemporary Western culture especially targets young women to conform to narrow standards of beauty and femininity, while young men are subject to the demands of masculinity, which include such traits as strength, independence and rationality.

Tsečlon (1992) mentions that according to Goffman (1959) "the actor has a repertoire of 'faces' each activated in front of different audiences, for the purpose of creating and maintaining a definition of the situation. He also states that techniques of emphasis and dramatism are mostly to conceal irrelevant information, not some real truth. For individuals with an invisible disability, withholding disclosure can simply be about eliminating any further questioning. It is therefore not about being dishonest, but rather about saving themselves and others the trouble that comes along with disclosure. But the consequences of failing to achieve a balance between being healthy and being perceived as normal as Balfe (2009) states are sometimes life threatening. For example, some students in his study living with type 1 diabetes were involved in binge drinking, even knowing the disastrous affects it can have on their blood sugar levels. The reward, however, of performing as normal is a positive and sometimes surreal experience. It involves a feeling of powerful independence that is easily taken away once the disability is disclosed.

The effort and discipline that is required to pass as normal is substantial, however. Balfe (2007) quotes Shilling (2003), “The acceptance of having to discipline their desires to be disciplined was emotionally difficult. Body projects are always unfinished, meaning that an individual needs to constantly work at them.” Applied to managing a chronic disability, more specifically type 1 diabetes, this insight is especially relevant.

### **SYMBOLIC INTERACTION: THE WORKS OF ERVING GOFFMAN**

The works in sociological theory that guide this essay are drawn from the symbolic interactionist perspective. Goffman (1963) analyzes the stigmatized persons’ feelings about themselves and their relationship to “normal. He also explores the variety of strategies stigmatized individuals employ to deal with the rejection of others, and the complex sorts of information about themselves they project.

### **EXPERIENCES WITH IMPRESSION MANAGEMENT**

When my blood sugar is high it feels as though there is a hand grabbing my heart and squeezing it. I have to stop myself from putting my hand over my heart in a hope to ease the pain. Sometimes I cannot help from doing it, but it makes others ask what is wrong with me.

People look at me funny when I’m buying a lot of batteries. I usually respond that “I do I have a lot of vibrators” but, in fact, I buy batteries for my insulin pump like they are going out of style. It’s my insulin pump that needs them to vibrate; the batteries are not for my sexual pleasure.

It’s hard work hiding it to seem normal.

My mom would always try to protect me from others who might judge or stigmatize me by saying, “go to the washroom to test your blood and take your



insulin.”

I choose to be happy because no stress equals no extra insulin. The stress of school can get you down sometimes – but I refuse to let that happen. When I am stressed or negative that is not me. When my blood sugar goes high I am grumpy at times, but when my blood is normal I feel happy and my mood is wonderful. However, people think something is wrong with you when you are happy all of the time. Usually people who are not happy with their lives or having a bad day want to take your happy away. I usually get “whatever she is on I’ll take some of that” and my response is always “insulin”. There are the people who are educated or think they are better than you who think being happy is dreadful and not supposed to happen as much as I possess it. I had one of my friend’s moms get me a t-shirt that said “You can’t make everyone happy, try making yourself happy”. When you have a day where you are not happy, like everyone can have, you get the “what’s wrong? Why are you not the happy you?” I am human and I can have a bad day just like anyone else. Then you get the suggestive question of whether you use “the sunny side persona” to make up for your disability or the assumption of “does she not care about school, is this her last priority, or was she out drinking the night before” if I had not told my professor that I was diabetic she might think these other things; when all I do is dedicate my life to school work. These things can be frustrating.

When asking for nutritional guides at restaurants, some have them and some don’t. Some tell me to go online to get it, which is inconvenient. Plus, I feel like a burden when asking for them. Also, going to a fast food restaurant means that I get comments like “getting a diet coke with a big mac meal defeats the whole purpose.” Really, I can only get fries, diet coke and a small soft serve ice cream so I don’t exceed the number of carbs allowed for my largest meal of the day. Otherwise it would cause my blood sugar to go through the roof or cause me to take double, even triple the amount of insulin to control my blood sugar after eating so many.

## DEFINING STIGMA

### III. STIGMA

In the following passage, Goffman (1963) colourfully and succinctly traces the evolution of the term stigma:

The Greeks, who were apparently strong on visual aids, originated the term *stigma* to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier. The signs were cut or burnt into the body and advertised that the bearer was a slave, a criminal, or a traitor – a blemished person ritually polluted, to be avoided, especially in public places. Later, in Christian times, two layers of metaphor were added to the term: the first referred to bodily signs of holy grace that took the form of eruptive blossoms on the skin; the second, a medical allusion to this religious allusion, referred to bodily signs of physical disorder. Today, the term is widely used in something like the original literal sense, but is applied more to the disgrace itself than to the bodily evidence of it.

The above quotation shows the long history of the concept of stigma, and the evolution of the term to the contemporary connotation of stigma as a mark that socially shames the bearer. It also points to the persistent tendency among social groups to establish various means to encourage conformity and discourage non-conformity among its members.

With respect to its relevance to invisible disability, Rasmussen et al. (2007) state from their study that, “The women who have diabetes feared stigmatization and discrimination if they disclosed. If they did not disclose, on the other hand, they feared they would be blamed for “telling a lie” should their diabetes become apparent. They felt more at risk by nondisclosure, because their colleagues might not be able to assist them should they need it: for example, if they developed a “hypo” (a hypoglycemic reaction or low blood sugar).

Rasmussen et al.’s (2007) study also states that, “There is definitely a good-bad girl association. You know, if your blood glucoses are good you are good, and if your

glucoses are bad, you are bad. This study also found, “One consistent source of frustration, and a dimension of being in the grip of Blood Glucose Levels (BGLs), was other people’s ignorance about diabetes. Women in this study usually responded by “cutting them out” of their networks, for example, when people became “food” police: “I can say, ‘Look, I can have it [chocolate cake], leave me alone’. By selectively drawing on supportive people, the women felt they had a higher degree of control, which enhanced stability in their lives. The women needed to trust other people and sometimes to maintain anonymity to manage transitions well.” The extensive study by Rasmussen et al shows that at certain times women with diabetes do not disclose to eliminate the need to educate others on the topic of diabetes self-care procedures. In my own experience, living successfully with type 1 diabetes also involves surrounding oneself with supportive people.

Similar to this view, Gardner et al (2005) state that social interactions that involve unfulfilled expectations cause the individual to lay claim to his or her own interpretation of self and/or disability. Therefore, if an individual with a disability allows others to label them, this is how he or she will then be viewed. This often draws upon and perpetuates pre-existing cultural themes, which may often address troubling social conditions. Stereotypes that are enforced by society, culture, and popular media cause additional ignorance surrounding those with disabilities. This then establishes stigmas that are then naturally formed after stereotypes are developed.

The study by Rasmussen et al. (2007) quotes Charmaz (1991) who, “noted that individuals with chronic illness attempt to control stigma by being highly selective about the individuals to whom they reveal their condition and rely on them to withhold the information from others.” I agree with this claim because disclosure takes away one’s

sense of independence. The authors emphasize “the importance of maintaining autonomy and staying anonymous about diabetes until the women chose to disclose it.”

### EXPERIENCES OF STIGMA

I tried to get the insulin pump three times – either my blood sugars were too good, or too bad, or they literally do not get back to you after the three month trial to show how regulated you can keep your sugars. If you do not have insurance you have to pay out of pocket for a \$5000-\$8000 dollar insulin pump, unless you have a common law wife status, which means the insurance pays eighty percent of the insulin pump and saves you some money on such an expensive piece of equipment that will make your life easier. It is not fair that you have to be the ‘right’ kind of diabetic to be approved to be a suitable pump user or that the insulin pumps are not provided to all diabetics for free. We did not ask for this illness, nor should we have to suffer through it and have to pay for what will keep us alive.

You have to disclose to get support, which is not always the best choice because then people can use that against you. However, if other people know then they will know what to do if something goes wrong, and how to help you.

Once you turn 18, you are officially an adult. You move from the IWK to QEII hospital, and the experience is completely different – you get treated like you are the forgotten group, and stigmatized as though you are a type 2 diabetic, and not type 1 diabetic, which is the kind you get as a juvenile, and keep with you until you die. So yes, throughout the years of adulthood, right on through to senior citizen, when they are reminded of this they just obnoxiously treat you as an adult juvenile.

As I grew up i.e.: in Grade 7, in Personal Development Relations (PDR) class, the teacher states that if a diabetic woman has children she will die. You deal with these kinds of bold statistics all the time telling you that having diabetes cuts your life down by so many years. This made me decide at a young age that I wanted to live a healthy life. I wanted to live a full life.

At day-care, when I was four years old, I played a Halloween game where we were blind folded and everyone got a piece of candy but I got a half of banana.

There is nothing better than being embarrassed and ostracized in public to show off your differences. It is already unfair to have diabetes but why couldn't all the kids get something healthy so I did not have to feel further left out?

Not wanting to be on the pump because that would mean it is always on me, made me think of star wars, and how I would be similar to a cyborg. This would allow more people the chance to see my flaw (disability) and after all my hard work hiding it and being in control of it with no pity from the outside. This would change everything. However, having to take 1 injection every 2-3 days instead of 12 in the same 3 days is nice and I had to ask myself: do I want to live a longer life, and will this help me achieve that? Yes. So I had to recharge my brainwaves into thinking that being a cyborg would not be so bad after all.

Drinking: questions always arise about whether can you drink alcohol and that becomes the topic of conversation. I used to drink more but being able to drink a shit load when your blood sugar is high means the alcohol won't affect you; you can remain sober. I also wanted to prolong my life as much as humanly possible, so I will have the celebratory drinks occasionally, but usually I refrain from drinking. I am already considered not normal so why would I put my health at risk to only get the approval and acceptance of others my age? Why try to fit in with peers, when I can be healthy? I consider myself wise beyond my years – an old soul in a young body. I am able to have just as much fun around my friends when I am sober and they are drinking or having only 1-2 drinks (my fiancé will drink anything extra for me so that I don't have to). People still accuse me of being drunk when I have not had anything to drink or a half a glass of wine. Sometimes that makes me mad because honestly I do not drink a lot, or at all, so that I can be healthy. These are my choices - when I choose to have a drink or a few, that is up to me, kind of like when I want to disclose, I will.

I have said this before: "I am used to getting treated like shit" "I have mastered a way of getting through it, I'm used to it. I can take it. NO ONE should ever have to deal with this kind of SHIT in any situation, NO ONE. I mean being stigmatized, being thrown in with the stereotypical individuals who live with an invisible disability, etc.

In October 2013, I was the happiest I have ever been in my entire life. No, I was not proposed to; that was the month before, which made me very happy too. October was the month I was going to be hooked up to an insulin pump for the first time. I had been waiting for this for a long time. Then, in November 2013, I found out that there was an error with my insulin pump. The diabetes team had not made sure that my basal level was programmed into my pump, which is the unit of insulin my pump releases automatically into my body on an hourly basis. The team became *very* mean and defensive about the serious error (law suit thoughts perhaps) and they blamed me (even though it was my first appointment after getting the insulin pump) for this mistake that could have been prevented. The head manager of the team stated, "Tara, you could have died." However, when the diabetes pump trainer said I could turn my two-hourly check alarms off, I had this

feeling that I should not. I kept it on, meaning my pump would vibrate every two hours, for me to check my blood sugar. If it were not for the Honors Program, and being up most nights, all night, and associating stress with high blood sugar, I very well could have died.

Telling people I went to diabetes camp has its positives but also people laugh or make fun of the fact that you had to go to a camp that was for your illness or they make the analogy of “band camp” from the movie *American Pie*.

Ignorant individuals who are not educated on what diabetes is, and that there are different types of the illness will say really dumb things to us like “Did you get diabetes from eating too much sugar,” “You don’t look like a diabetic,” “You’re not fat,” “Do you have the good kind or the bad kind of diabetes?” “My grandma has diabetes too,” “I hate needles, eww, I could never do that,” “My mom’s friend who had diabetes died,” “DIABETUS: it’s Dia-beet-eeze (we are not going to let this beat us),” “You have this forever,” “Aspartame causes cancer,” and “You can’t eat sugar, you’re diabetic.”

Non-diabetics also assume that the stereotypes they hear on television are all true and they use them when referring to you. But here is how it really feels when you have a high or low blood sugar according to me: The feeling of having a high blood sugar: your body feels numb, like your veins and muscles are tight, and you move very slowly, your palate is dry (need water) to flush sugar out of your kidneys, you feel tired/exhausted, your heart hurts, your eyes hurt, you want to pee a lot, there are aches and pains all through your body (these feelings also occur when you eat potatoes, white pasta, pizza, high glycemic index carbs make you feel like death. With low blood sugar you feel silly, dizzy sometimes, like a little girl, talk like a child, are overly excited and happy, hungry (like you can’t get the juice and food inside of you fast enough) so cold that your teeth chatter and you shake if it gets really bad.

When you are told you are subject to negative physical effects of diabetes like: “You have diabetic damage in your left eye and it is not easy to get rid of it”. That is when I prove to them *I can*. A year later when I went for my appointment they told me I was rid of it completely.

At first with the pump I thought it was like having a colostomy bag (a bag on your side which catches your feces when you are unable to take a bowel movement the original way any longer) on your side because the tubing always has to be tucked in and you need to be careful with it – the catheter. I have experienced stigma so much I am starting to stigmatize myself on a new product for my diabetes, rather than celebrate the fact that the insulin pump will help me live longer.

## DEFINING DISCLOSURE

According to the internet, disclosure is “the action of making new or secret information known”. Goffman (n.d.) says that disclosure is “the means by which we can regulate what others know about us in terms of depth, breadth, and intimacy.”

## EXPERIENCES OF DISCLOSURE

At age twenty, I went to my family doctor and he was not in that day so I was referred to another doctor. I told him I was having difficulty with my diabetes and needed some help. He responded that I should just suck it up and asked if that was all I needed today. This is the type of thing that made me even more on top of my health and independent about diabetes. When you ask for help professionals tell you something like this, which is not helpful whatsoever.

At a friend’s house when I would go over at a meal time the reaction would always be the same – Tara’s coming over, well we need to have a healthy supper because she is diabetic and she can’t have dessert (she is diabetic). I felt like a burden and was constantly reminded that I could not have sugar, when, in fact, I need sugar to stay alive.

Love – before now I would try to impress my boyfriends with how I can be like a normal girlfriend and make sure they are happy. Then I realized that does not make me happy. Therefore, when I started hanging out with my now fiancé I kept him at arms-length. I made sure he respected me, that he knew I had diabetes, and I was my complete self around him. I soon found out that you can be YOU (100%) and when you allow yourself to accept and love yourself (not letting diabetes define you, or society, and believe, embrace, and treat the fact that you having diabetes is NORMAL) then and ONLY then will you allow others to love you for who you truly are (diabetes and all). Don’t hide it from those you love and trust. This does not mean you have to tell or show everyone that you have diabetes, but if you decide to that is ok too. He is my very best friend, who I love more than anything in this whole world, and we would both do anything for one another, we trust each other, and we acknowledge that no one is perfect. Even though sometimes we try to act like perfectionists, the flaws in us are beautiful and that is LOVE.

## EXPERIENCES IN MY LIFE

My brother has been a big support but also a negative role model. When I got older I made him realize that he needed to be a good role model for his kids. I had to help him turn what he was losing control of into something he could control, like the throttle of a Porsche. He loves vehicles, and I just made him recognize how he could associate vehicles with his diabetes and he began and still is controlling the speed of his blood sugars in total control. An example I remember as a teenager, is running down the airport trying to catch him and give him regular pop for his low blood sugar, because when he is low he acts as though he is drunk. It is not nice to have someone who loves you tell you this is what you appear like when having a low. But he had to hear the truth in order to take his life back. For that, he will always be my hero and role model. We can fight this illness together and live our lives to the fullest. A statistic that is well known of diabetics is that only one child from the family gets type 1 diabetes. Although, if you think positively, we are lucky, because both of us got it, and we could be there for each other as we grew up with this disease.

My grampy will forever be my hero. He lived with type 1 diabetes his whole life, until the ripe old age of ninety-three. Before I was diagnosed with diabetes, I used to say "I want diabetes like you, Grampy. You should not have to suffer alone" But he said that he would never wish this upon anyone. But what has stuck with me my entire life is when he said these monumental words: "Sweetie, if you ever do get diabetes, be as happy as you can, never let anything bring you down. Diabetes has this way of taking you up and bringing you down; stay happy and you will remain healthy" and I continue to follow his advice to this day.

My parents are my best friends, because they have always been there for me and always will and I treasure their selflessness and the care they have for my brother and me. They still care, and we talk almost every day and they will check in on me to see how I'm doing with my diabetes. It's not in a way that makes me feel like a child because they just care in a nice way that is not manipulative. Some people may think that would be annoying, but not me. I think it is helpful and I appreciate them for it. I hope I can help them if they ever need it in life too.

My dog can tell when I have low blood sugar. I don't know how, but she can. She will come over to wherever I am and lay beside me or put her head on my leg and low and behold I test my blood and it is low.

My experience of telling one of my classmates, who is now my best friend, my sorority sister, and the maid of honour for my wedding is that when I told her I was diabetic, without hesitation she says "want me to come with you to your car to check you blood?" It was a breath of fresh air.



When I was 3 years old I was sick for a week and they had no idea why. After testing my blood sugar, they discovered that it was 66. I was diagnosed with type 1 diabetes.

What I remember about being first diagnosed is that the baby cage in the IWK hospital had blue bars and that my parents and brother were leaving me. Seeing them outside the window going to their car, I thought they had left me behind and I felt like a prisoner. Also, on that same occasion, five doctors and nurses held me down on a table to give me a needle. It is a traumatic memory that will stick with me until the day I die.

I can also remember that while in hospital one of my very first friends was a little boy who had cancer. His mother said to mine on the day I was released from the hospital that "At least you get to take yours home." My motto for life is therefore "it could be worse."

A short time later, while leaning against the sharp rock in the yard around the corner from the day-care centre I attended I felt like I weighed too much for the day-care teacher to carry me inside. It was my first feeling of "I'm fat" but little did I know that more of that would come along with having diabetes. When you are having a low blood sugar you are literally dead weight.

I remember lying in bed as teenager, wondering why I could not wake up, but knowing that my blood sugar was low. I felt my eyelashes against my cheek, and I crawled out to the fridge to drink juice, pounding on the floor to wake my parents up for help.

When playing sports your body releases extra sugar for energy. When your blood sugar is high you should therefore not exercise because the released sugar makes the blood sugar even higher. You need to drink lots of water, take insulin and wait for it to come down.

Bladder infections are common when you have diabetes. I had so many at one point I figured out how to not suffer until getting the antibiotics. It was to drink cranberry juice.

Having diabetes, and taking insulin makes you want to eat, which makes the ability to lose weight that much harder.

When stressed out I have to take extra insulin to prevent high blood sugar before it happens.

I have a love-hate relationship with purses because I have to put my blood monitor test kit, my insulin pump infusion set, etc. and insulin in my purse. I'm usually the one in the group with the big purse and it can be heavy and the weight of that additional reminder stresses me out. Having to buy luggage-size purses to

fit my meds does not make it easy to have cute little purses. Wanting to go downtown and carry only a little purse does not help my illness.

When my A1c (the average of your blood sugars over a three or six month period) came down from 9.8 to 7.8 (2 whole points) it was a miraculous day. It is supposed to be under 7.

One of the scariest days of my life was finding out that my friend died from diabetes. The cause was a high/low blood sugar while asleep. Falling asleep and never waking up again. It was a horrible event, but it made me pay attention and want to take care of myself so that did not happen to me.

I have diabetic damage on my stomach (from taking too many injections in the same area for a number of years). Taking injections for 24 years means approximately 30,000 injections. The damage looks like small hills, and it makes my stomach puff out. There are bumps, bruises, and tissue there so tough that if I were to take an injection there now, the insulin would not be absorbed. I have been told that I could lose a bit of this, but if I wanted it to look like a normal flat stomach ever again I would need to have skin grafts. Due to the damaged tissue on my stomach, I have been asked if I was pregnant so many times I don't even want to count anymore. That is always a nice confidence booster.

But I keep smiling, genuinely, because you learn to cope having an invisible disability because otherwise you just complain about all the flaws you have and how diabetes has ruined your life and you become a Debbie Downer. Well, I am an Optimistic Olivia. I put on my metaphoric armour every single day before I leave the house JUST IN CASE, because just when you forget to put it on one day someone says something negative or ignorant to remind you how awful it can be. You can always prepare for the shit, that is how you handle it, you get by, you use your positive attitude, and be emotionless, you control and discipline yourself for the shit ignorant people might throw at you and you throw back at them your ability to not be a rude person like them. I was raised with manners and to add other people's ignorance and rudeness on top of the many other tasks you take on in the run of a day is not fair. It's not like you don't have enough to do already i.e.: writing a thesis, plan a wedding, and taking care of your dog. Managing diabetes is just an added bonus; no one needs the bullying ignorance of non-diabetics.

The first day I got my insulin pump I was happy drunk on life. It was a whole new feeling, and my words to my fiancé were "Why would anyone who does not have diabetes ever want to be mad purposely? This feeling is amazing and this can help me have more normal blood sugar levels and that means being happy more often."

The feeling of the insulin pump falling out of the tank-top bra I'm wearing and not catching it feels like it is pulling your insides out from all parts of your body.

I once said when I was still taking injections with syringes: “If my blood sugar was always normal I would be my true self, happy, and kind. My true identity is invisible when my blood sugars are out of control. Hence I am a perfectionist who likes to be in control.

## Discussion

Analysis of scholarly sources compared with my own life experiences shows a very close match. Balfe (2009) was researching university students and their struggles to be normal and how this might affect their diabetes control. This closely contrasts with the many times that I have put off taking insulin or testing my blood sugar levels so that I could pass as normal. As mentioned previously, striving to keep your disability invisible is motivated by the desire to appear normal and to maintain your independence. It is also about not using it as an excuse because others might then look down on you when you get special treatment.

Charmaz (1991) touches on controlling the stigma associated with chronic illness by only disclosing it to a few trusted people. This is what this thesis is all about. There are good and bad experiences surrounding disclosure to others. Now I only disclose to a select group of people who I know and trust to keep it to themselves. Dovey-Pearch et al (2007) discusses the transition, and development, when moving from youth health services to adult health services and how the healthcare teams should react. Similarly, Gee et al (2007) discuss the move of youth with diabetes from pediatric to adult health care and the impact of having diabetes. This is a big issue based on what has happened to me. One of the few times I asked for real help from my doctor I was told to “suck it up” and was sent on my way. As for the impact, at one time I was considering going into the

military, but because of my diabetes I did not qualify. This is also an example of how having diabetes affects our life choices.

Gytten et al's (2006) research looks at the stigma people with multiple sclerosis (MS) have to deal with in their social relationships. This does not relate to my life experiences directly as I do not have MS. On the other hand, as both are invisible disabilities, this research relates closely to my life experiences. On a regular basis I experience the stigma of diabetes from people not educated on the issue and when you do disclose to the wrong people your social relationship can change in an instant.

Rasmussen et. al (2007) consider the turning points and times of transitions in the lives of young women with diabetes. More specifically, they consider how blood glucose levels (BGL's) are affected, the response of others, and the impact the young women with diabetes have on others' lives. These are things I consider on a daily basis. How is an event going to affect my blood sugar? What are people going to think? How do I affect others? Surrounding myself with the right people brings stability in times of change and transition, and unlike many other diabetics, I am always on top of my BGL monitoring.

Livneh et. al (2001) focus their research on college students and how the denial of having an invisible disability can reduce the potential discovery of the illness. At the same time, hiding the condition significantly increases the experienced anxiety of the person with the invisible disability. For all of my university years except this last one I did not want to accept that I had a learning disability. I denied it over and over again even though I knew deep down I should have been diagnosed. Having a learning disability as well as diabetes made me worry about what other people would think. How differently would I be perceived and will the disclosure benefit me or hurt me in the long run?

Pearson et. al (2003) and Madaus (2008) both examine university graduates and the disclosure of their invisible disabilities when entering the workforce. While I was successful in obtaining a paid position with the Canadian Diabetic Association because I was qualified and diabetic, I would not be inclined to disclose my condition to other potential employers owing to the fear that it would most likely work against me.

Some might argue that avoiding disclosure of a disability serves to perpetuate the wide-spread ignorance and stigma associated with it. I would respond that it is not my responsibility to educate those on my invisible disability. Frankly, if I were to take that on I would go blue in the face explaining it over and over again. Surely we should take it upon ourselves to learn about things that do not directly affect us so that if the topic ever does come up we do not offend the person with the invisible disability.

If I were to continue this research, further study would involve the longer-term benefits of disclosing or not disclosing invisible disability to others. It would be interesting to collect primary data with a sample of older individuals, or to initiate a longitudinal study of young women to middle age and beyond to see how their thoughts on disclosing have changed, or not changed.

Most Honors students can research and write their theses and be done with it. Some may move on to graduate school and use it as a starting point for their next research project. This thesis topic is much more significant because I live with mine twenty-four hours of the day, seven days a week, three hundred and sixty five days a year for my whole life. Many other male, female and transgender individuals of all ages live with the same illness. I wanted to research what others have been through to hear their experiences and to use my own to compare the two. Ultimately, I want the voices of the hidden to be heard and not looked at as inferior or different. I want those of us living with an invisible

disability to not be afraid to disclose because of the negative connotations society associate with disability. This topic needs to be researched in more depth, and by researchers like myself who identify as the *other*; someone participants can trust and want to share their stories with because I can relate to what they go through every day.

## CONCLUSIONS

This research confirmed to me one major concept that I had already concluded from my life experiences alone - it is not always smart to disclose. When you do disclose a disability to others, you have to be careful and selective, in terms of who you disclose to and when. Disclosing to the wrong people will result in them looking at you like you have an unforgivable weakness. They may treat you like you are incapable, act indifferent towards you, and hold your disability against you. If they are in any position of power over you they may even hinder your future possibilities. On the other hand, disclosing to the right people at the right times can be a very positive and beneficial endeavour. It does take a lot of effort to pass as “normal” and it can even be life threatening to the person with the invisible disability. This is because to appear “normal” often requires ignoring or putting off medical treatments that are necessary to one’s health.

When the right people do know then the person with the invisible disability does not have to put in the extra effort to appear “normal”. They are already seen as “normal” and need not worry about what these people think. Even though they can never truly hide or take a break from their disability, by disclosing to the right people they can at least not deal with it alone and can be accepted for who they are without the fear of being judged. As much as the support may be wanted, persons with invisible disabilities may feel that

they are a burden when they ask for help. You know you have disclosed to the right people when they don't feel burdened. If anything they will feel honoured that you felt comfortable enough to disclose your invisible disability to them.

Another reason why persons with an invisible disability do not disclose is because of the stigma around it. Many people are ignorant about the many invisible disabilities that exist and by not disclosing, persons with invisible disabilities eliminate the need to constantly explain to others self-care procedures. Some people may also feel that they will lose their independence by disclosing as some people then feel they have the obligation to tell this person how to live their life and judge them when they are not being perfect about their regimen.

As stated above, it is not always smart to disclose. You can have both positive and negative experiences when disclosing depending on if you disclose to the right people at the right time.

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