2018

Master's Project: Northern Nevada's T1D Women's Community

Celia Grace Johnson
The University of Vermont

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NORTHERN NEVADA’S T1D WOMEN’S COMMUNITY

A Project Presented

by

Celia Grace Johnson

to

The Faculty of the Graduate College

do

The University of Vermont

In Partial Fulfilment of the Requirements
for the degree of Masters of Professional Studies
Specializing in Leadership for Sustainability

October, 2018
ABSTRACT

My aspiration for this project was to create a safe space for women with Type 1 Diabetes (T1D) in the Northern Nevada/Tahoe community to come together and share their stories and connect outside the walls of medical facilities. I was motivated to do this project by by desperate search for a resource like this and feeling constantly alone in my struggles with T1D.

For me it was important the group was created for all persons identifying as female, and that it was an in person experience. Research has shown that women’s spaces are generative in a different way than co-ed spaces (Wolf, 2013). There is an abundance of online communities to turn to for resources and advice, but nothing in Reno that was offering what I and other women I met needed; inperson time with someone who gets it, cares, and understands.

Having someone to laugh with about moments only another diabetic could understand, and just knowing there are others like you, not just behind a computer screen somewhere, but just down the road from you, is enough in moments to not feel quite alone. Isn't that what life's all about? Connecting with others on this great adventure through life.

Keywords: Diabetes, Type 1 Diabetes, T1D, Community, Intersectionality
ACKNOWLEDGEMENTS

For my parents, brother and sister-in-law who through the hardest and best moments in my life never once made me question their love and belief in me. The amount of quiet sacrifices my parents make to help keep me alive and well in a world where school tuition, insurance costs, and medical bills try to drown us little by little, I may never be able to repay this, but I sure hope my dedication and hard work make you proud.

To Eliseo for demonstrating and reminding me how having patience with myself is what I deserve. I have learned so much from you everyday from the moment I met you.

To Eddie, for the endless encouragement and support you provided me even when I was unbelievably stubborn and depressed. I was always listening and more appreciative than I was ever able to let on.

To All of the members of my extended family for exemplifying how having a safe community can make all the difference in the world.

Jenna Ringelheim, when you told me about the MSLS program I nearly fell out of my chair. It was because of you I found my way here and had the strength to choose happiness because of the lessons you’ve taught me.

Karen T-S, you brought a wonderful perspective to my project that I am so thankful for. I learned so much from your guidance and wisdom.

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TwoTrees, the way you move through life inspires me daily. How you have woven your passion for art and social justice into the academic gives me motivation to carry with me your lessons into my everyday interactions.

Shadiin, for your guiding light throughout the process. I am forever grateful.
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“Make your biggest challenge your greatest gift to the world.”

CHAPTER 1: INTRODUCTION

YOU ARE NOT ALONE IN THIS

My Journey

Curling on the dirty carpet of my small midtown apartment, tears streaming from my eyes, shaking, and emotionally beaten down from fifteen years of struggling with a disease no one sees, I stared at my phone, the only number I could think to call that was glowing back at me: The Suicide Hotline. I have never pressed call, but I have stared at that number for hours, waiting for the wave of desperation to pass. I did not want to scare my parents with my emotion, I knew my friends, as sweet hearted as they are, could not empathize, and I did not want them to look at me differently when I smiled. So, there I lay, time after time. Always, eventually, pulling myself up off the ground. I’ve gone to therapists, I’ve laid my soul out to my significant other, but I’ve found nothing as grounding as connecting with someone who has experienced similar moments of both struggle and joy.

Diabetes Mellitus

Approximately 1.25 million American children and adults have type 1 diabetes (ADA, 2018) (See Appendix B).

“Type 1 diabetes (T1D) is an autoimmune disease in which insulin-producing beta cells in the pancreas are mistakenly destroyed by the body’s immune system. Its causes are not fully known, and there is currently no cure. People with T1D are dependent on injected or pumped insulin to survive. Most people with T1D spend the majority of their time with blood-glucose levels outside the recommended healthy range, which can lead to potentially deadly episodes of hyperglycemia (high blood sugar) and hypoglycemia (low blood sugar). Chronic high blood sugar often causes devastating health complications
later in life, including blindness, kidney failure, heart disease and nerve damage that can lead to amputations.” (JDRF.org)

An Invisible Disease

There is a misconception that people with T1D are able to perfectly control levels by taking the correct amount of insulin for the food we eat. The hard truth is that the disease is much more complex. Here are just a few internal and external elements that affect sugar levels:

- Illness
- Hormones
- Food/ Nutrition
- Periods
- Sleep
- Muscle density
- Body fat
- Location of insulin injection
- Health of insulin injection spot
- Exercise
- Electrolyte balance
- Water consumption
- Body temperature
- Environmental temperature

Not only is T1D a very physically intense disease, living with T1D can be a very lonely and isolating disease (See Appendix C) This is the driving agent in this project. Here are a few ways T1D affects people psychologically:

- Food - If a person with T1D miscalculates insulin doses we could die and the margin for error is very small.
- Sleep - 1 in 20 people with T1D will die from hypoglycemia in their sleep.
- Exercise - This can both help and harm a T1D depending on glucose levels.
- Travel - The added layers of stress on a T1Ds body can be very hard to balance.
- Body Image - Insulin makes T1Ds gain weight when a person with T1Ds treatment is not balanced.
- Mood Swings - Blood sugar swings can cause rapid changes in a person's mood, such as making them sad and irritable. This is especially true during hypoglycemic episodes (medicalnewstoday.com).

Why a Network

My aspiration for this project was to co-create a safe space for people in the intersectional space of both identifying as female and having T1D to be in relationship. This matters because on average people with T1D spend only 1 hour per year with a physician getting professional
support a year (see Appendix C). With a disease that is so all consuming, this just is not enough support.

A support group provides an opportunity for people to share personal experiences and feelings, coping strategies, or firsthand information about diseases or treatments. For many people, a health-related support group may fill a gap between medical treatment and the need for emotional support. A person's relationship with a doctor or other medical personnel may not provide adequate emotional support, and a person's family and friends may not understand the impact of a disease or treatment. A support group among people with shared experiences may function as a bridge between medical and emotional needs. (Mayo Clinic, 2018)

My goals for this project included having in person gatherings where generative and valuable conversation may occur. Centered around generating deep relationships, my goal is for women to gain personal sovereignty, self-efficacy, and sense of empowerment (see Appendix D). In addition, I sought to generate an online platform where members and non members could access past, present, and future event information.

There are support groups for persons with T1D out there, but nothing here in Reno/Tahoe serving the T1D community in this way. I was inspired by Ilan Illich’s To Hell with Good Intentions and a conversation I had with professor Daniel Baker in 2009. Both of these made me realize I did not want to replicate the history of white people acting like saviors and operationalizing oppression. I had to be accountable and lean into my learning edges by naming it, recognizing it, and taking steps towards inclusivity.

When I embody the leadership practices the MLS program emphasizes, I feel the creation of this safe space has the potential to generate sustained and positive effects.
Power and Privilege within Healthcare

Reno is a diverse city. The racial makeup of the city was 74.2% White, 2.9% African American, 1.3% American Indian, 6.3% Asian, 0.7% Pacific Islander, 24.3% hispanic or latino. Additionally, there are 4 tribal Nations consist of 27 tribes/bands located on both reservations and colonies located throughout Nevada (NDE, 2012). For every 100 females age 18 and over, there were 102.7 males. (Census, 2010)

The Northern Nevada T1D Women’s Community is nested within systems all steeped in systematic gender and racial oppression. There are many ways the U.S. healthcare system has failed and generated barriers for people of color and women. Regulations are made by people with political and social power, who are often disproportionately white men. These barriers are often generated, or exacerbated by those currently in power who wish to remain in power. Currently 13 white men at the highest level of government, in the U.S. Senate generate health care law for the country (Graves, 2017). In fear of being replaced, many of the decisions are politically motivated, not motivated by facts (Levin, 2017). In a white supremacy system, white privilege and racial oppression are two sides of the same coin (Anzaldúa, 1990). This is why it is so important to me to participate in the generation of a group, within this flawed system, that could potentially challenge the expectations impressed upon us, as women, and as people with chronic illness.

Health and well-being are inextricably linked to the social and economic conditions in which people live. Research has shown that only 20 percent of health can be attributed to medical care, while social and economic factors—like access to healthy food, housing status, educational attainment and access to transportation—account for 40 percent. Currently, 3.6 million individuals do not access medical care because they experience transportation barriers,
and 4 percent of all children miss a medical appointment because of transportation issues. Transportation barriers are the third leading cause of missing a medical appointment for seniors across the country (Heath, 2017). By far the most consistent predictors of the decision to seek preventive care are having a regular doctor and having a high school education. Women who had a regular doctor were at least twice as likely as those who did not have a regular doctor to have received preventive care (Smith 2002). Even the challenges faced in order to receive a high school diploma are systemic and ingrained.

Language is often written about as a barrier. But speaking a language other than English is not a barrier in itself, it is an asset to be celebrated. However, the health care systems are failing those who do not speak English. Although Spanish was the primary language of an estimated 11% of adults in the year 2000, the U.S. healthcare system is largely geared toward serving English speakers. Six (86%) of the seven studies evaluating quality of care found a significant detrimental effect of language. (Timmins, 2002). A system set up by white English speaking politicians, doctors and teachers will mirror the needs of those in power. Language is the basic tie between human beings and the world that surrounds them. Without the tool of language — and that doesn’t always mean spoken language — people have little control over how they’re treated by their environment and the people in it. (xoài phảm, 2016) A large population in Reno primarily speaks Spanish. I do not want to enter into their spaces and act like a “white savior”. A white savior is defined as a white person “saving” a person of color from their oppression. This racializes morality and frames people of color as not able to solve their problems (Edell, 2016). It is not only appropriate, it adds to systematic oppression by victimizing people of color in the process.
Before understanding the complexities and ways white supremacy is intertwined in our culture, I was unknowingly perpetuating it. I used deficit thinking and ways of speaking when communicating about race and culture. I read many papers written by scholars whom perpetuated this as the norm, and I did not stop to question the affect their writing was having on me and society. As hard as I thought I was trying to understand, I was not really getting it. I had no concept of how things that were “normal” in my life were perpetuating white supremacy. Things such as: perfectionism, sense of urgency, defensiveness, individualism, right to comfort. As I now start to slowly peel back the layers of my own understanding, I am deeply shaken knowing the ways I have perpetuated white supremacy. It motivates me to continue to learn more and to work daily to steer the conversation away from deficit thinking towards an asset-based paradigm. In recent conversation with a friend, who is a nurse and has been with me on this journey, we talked about the importance of transitioning away from using deficit language such as “barriers”. My hope is this conversation will catalyze a paradigm shift that will hopefully ripple out from her to others she works closely with. I would like to have a future T1D gathering be focused on these exact topics, to help bright light to blind spots and have generative conversation within the group.

CHAPTER 2: METHODS

Theory of Change

The theory of change driving this project is an understanding that with development of interpersonal connection grows self determination, personal sovereignty, and better T1D health management. When people with disabilities come to the conclusion that they have the right to be in the community, to have a say in how that community treats them, they are beginning to
develop a consciousness about taking control over their lives and resisting all attempts to give others that control. (Roberts, Charlton, 1998)

The underlying assumptions that inform my decisions are that people need human interaction, we connect with others with similar lived experiences, diabetes is a tough disease to handle on your own, and health care providers do not always have patients best interests in mind.

I was inspired to focus on information flow structure in Donella Meadows Model of Leverage Points of places to intervene in a system. Missing feedback is one of the most common causes of system malfunction. Adding or restoring information can be a powerful intervention (Meadows, 1999). When a person’s physical glucose information monitors malfunction, the condition worsens. In a broader sense, I began to notice I was taking advice from other people with T1D via social media posts, and it was working. We were changing the information flows within the system from a strictly traditional physician-T1Dpatient flow into a physician-T1DHuman and then an interT1DHuman conversation.

When the dynamics of information flow changes, I feel I regain a little humanity in the process. I am able to step out from behind the identity of being T1D and can be seen as an intelligent, strong woman. There is a difference in hearing management methods from others with the same lived experiences, than hearing it from a doctor who, try as they might, will never understand the layers of complexities people with T1D engage with daily. Paternalism is defined as the policy or practice of restricting a person or group’s freedom or autonomy in their supposed best interest. (Culter, 2018). But, the lived oppression that people with disabilities have experienced and continue to experience is a human rights tragedy of epic proportions… for the first time, a movement of people with disabilities has emerged in every region of the world
which is demanding recognition of their human rights and their central role in determining those rights. (Charlton, 1998)

Female Identifying

Identifying as a female and having the T1D autoimmune disease was the point of intersectionality I sought to explore (see Appendix D). There are moments that we as women with T1D will experience that men will not, and people without T1D will not. For instance, for people who experience periods, childbirth, or menopause, we sit with what sometimes feels like an almost impossible task of keeping blood sugar stable regardless of the hormone fluctuations.

The intersectionality of being both female and having this autoimmune disease can be a tough place to exist alone, and the research suggests, having a safe space is not only beneficial, but critical.

There are still breakthroughs in skills acquisition, learning and leadership that happen most easily in women-only settings...Similar boosts to female leadership and self-esteem have long been documented in graduates of all-female US colleges such as Smith and Wellesley, and from the until recently single-sex St Hilda's and St Hugh's. And I have seen the vast leaps in confidence and skill set acquisition that comes from all-female training settings. (Wolf, 2013)

It’s unfortunate that it often takes being in women-only spaces to hear the truth about women go through, because this means men don’t hear our stories as much as they otherwise might… We have sought each other out for support and championing, and we’ve created alliances and networks and sisterhoods because there are no wide-open roads for women as there are for men. (Warner, 2017)

Connecting Globally

My strategy to form a well thought out, dynamic group that could be of service to all, was to seek out advice from other T1Ds around the world. I recognize the danger of a single story, and if I based this group solely on my own needs, it would not serve a greater community. I
reached out via social media to diabetic influencers that have had an impact on my care management. I set up phone appointments and listened to their stories and advice. In total I spoke with 6 people with T1Ds: 1 male and 5 females, all with T1D for varying amounts of time, all in different locations, and all with different lived experiences. They each shared feelings of being alone, against the oppressive machine like medical system. The each desired human connection with others that have felt previously unheard by their doctors and families. And, they shared a likeness in feeling as though their current and future health management was not currently in their own hands, but in the political systems.

Table 1
T1D Information Form

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<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
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<tr>
<td>Would being part of a T1D community group be of interest to you?</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>Are you currently, or have you been part of a T1D community?</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>What value do you see in T1D communities?</td>
<td>“feeling of not being alone, solidarity, shared experience, Humanizing Finding unifying bottom line factor”</td>
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The conversations showed a desire for connectivity amongst people with T1D. It is common within the experience of having this disease to feel isolated, disconnected, and alone and having a community of support would be helpful. Because T1D can be so challenging emotionally, in these conversations we often flowed through emotions from, mutual fruteration...
of the medical industry, to laughing at moments only other people with T1D would empathize with, and excitement and hope for technology developments on the horizon.

When meeting with new NN T1D members, I commonly ask if they are plugged into social media and following diabetes hashtags and other members of the diabetic community. If they are not, I recommend it. I have had several members come back to me weeks later talking about the diabetes memes and posts they have been engaging with. For me, this simple process of leaning in virtually has been a game changer in feeling connected. It has offered the community a platform that we previous did not have. The women in the group have expressed several times the importance and gratitude of having a place to just share their story and be with their diabetes in a community of others who understand. It is important for the community to be heard and to have a safe space to share our experiences.

One danger in connecting through social media posts is being virtually bombarded with witnessing only good experiences and good numbers. When only seeing people having good numbers all the time a few things run through my mind; What am I doing wrong? Why are my numbers not like theirs? What does this mean about me? There is a push to be more “real”. It is a movement to show different sides of the disease which allows the virtual community to stay positive, but also show the struggles we face daily.

Strategy

I did not know anyone in the area with T1D. So my initial strategy for initial contact with women with T1D in Reno/Tahoe was to create and hand delivery flyers to local clinics, hospitals, and specialists (See Image 1). I wanted the flyer to symbolize empowerment, and not pity. People with T1D get enough of those looks walking through life with needles and insulin pumps.
I believed this would be a simple task of doing an internet search of these facilities in the area, hoping in my car, and dropping them off. As many things in life go, it proved to be much more difficult than anticipated. The internet contact and addresses were often outdated or incorrect. I had to come back to the drawing board and cross check all of the locations and doctors with their websites before attempting to dropping off the flyers again.

There was a lot of emotion wrapped up in the flyer drop offs. I was never sure if it was a waste of time, and if my business cards and flyers were even making it into the hands of the doctors and patients. At only one office was I able to even speak directly to the doctor directly. He was excited about the project and saw a lot of value in what I was trying to do. (See voice memo from January 4). At most offices I was only able to drop the flyers off at the front desk and give a quick pitch to the receptionist.

Much of the anxiety I felt in this process came from knowing that many people with T1D may not be able to afford T1D specialists. Having T1D is expensive. It can cost up to and even over $1000 a month between supplies and medications, not including doctors appointments (Ramsey, 2016). There is a challenging balance of staying healthy enough to work just to cover medical costs, that many of the women in the group face daily. And many people with T1D rely on assistance from family members. I sat with this a lot, as I have experienced the privilege of having my family support and seeing specialists since diagnosis, and I am aware this has set me in the trajectory I am on today. It almost brings me to tears to think about how many times I have had to choose between paying for health care and the other things in life I’d prefer or need to spend money on, some days even groceries and gas for my car. It is heartbreaking to linger on. Without the advantages myself and many of the group members have had in life, the care we received might look completely different.
There are many reasons why people with T1D may not see a specialist. The social determinants of health are the conditions in which people are born into, grow from, live in, and work including a wide range of other forces and governmental and social systems that shape daily life (Gomez, 2017). The manifestations of people in power exercising their control include the following: perpetuating low socioeconomic status, which is associated with educational attainment, occupation, and income; and immigration status (Gomez, 2017).

From everything I have learned about white privilege and colonization, it was important to me to reach a broader audience than just the white, middle-upper class women I typically see in the specialists offices. I researched local private and government clinics in the area. I visited with my flyers and gave quick pitches to the receptionists.

The group began to blossom, but we were primarily attracting middle class, white women between the ages of 25-50. Based on statistics from the diabetes association I knew T1D effects more than people from this specific demographic. And, I wondered why only these women were reaching out and showing up. I knew systematic oppression played a roll in access, education, transportation, and many more factors.

I want to make a real effort to connect with and be able to provide a service for everyone, where needed and wanted. This summer I took a Spanish class. I feel very strongly that if the community is going to be welcoming to everyone, I should have some experience communicating in the second most widely used language in Reno. Two members of the community are integrally connected within the hispanic communities in town. Both have parents who came to Reno via Mexico, and both have voiced their excitement to be involved and build a path between the two communities.
Not all challenges are imposed by the healthcare system directly, some are generated within a community. One national survey from The Steve Fund, shows stigma, reluctance to seek help for mental health needs, and cultural mistrust of mental health professionals among people of color are barriers that often lead them to suffer in silence (Primm, 2018). Stigmas associated with mental health issues come from misguided views that these individuals are “different,” from everyone else. Early beliefs about what causes mental health issues included demonic or spiritual possession, which led to caution, fear, and discrimination. Society has stereotyped views about mental illness and how it affects people. The role of media in mental health stigmas also cannot be denied. News reports often link mental illness with violence or portray those with mental health issues as dangerous, criminal, evil, or disabled – often in television shows and movies (Destination hope, 2017). Stigmas are changed through paradigm shifts. While this can happen by campaigns through public service announcements and education, it can also happen through information sharing person to person, little by little. For the group, I wanted to make sure people could see and read about the benefits through at least the website. It was important to me to show that T1Ds can be as strong, independent, and creative as anyone else.

All in all, I only received one phone call because of the flyers I handed out. The best method has really been wearing my insulin pump in a visible location everywhere I go, everyday. This has generated important conversations with people about T1D. Some of the people I have spoken with have joined the group, some have not, and that’s okay. They have my contact information for when and if the time is right and the need is there.
Co-Creation

In my mind, the goal was to co-create the group so that it would grow to be something larger than just my own needs and vision. This is important to me, because the group is not just a space for me, it is a space for all those who want and need it.

With the first member to reach out, I drove to meet her in Truckee, California. Together conceptualized a group that would meet up to participate in outdoor activities and coffee shop conversations. She and I were like minded in terms of what we needed and wanted. We then designed and built our website together. But, I realized something right away - it was going to be challenging to co-create a community with someone who had no training or learning experiences with power and privilege dynamics and inclusivity. I was unsure if it was my responsibility to bring her up to speed with what I had been learning in MLS over the past year.

A moment of realization came as we filtered through stock photos online for a suitable image that would be eye catching for our website landing page. She was eager to use a photo of women skiing in the backcountry. As much as I loved the idea of going skiing together, I knew this photo might immediately exclude potential members, while still exciting and intriguing others. I decided to slowly drip some of the learnings from MLS to her. We talked about this for a while and settled on using a neutral background color instead of an image. We decided we would take photos at our meetings and use real images once we had them. We did not want to accidentally exclude people.

Having participated in the MLS program my expectations for the group and trying to reach a diverse group was different than her expectations that everyone who would be in the group would have access to time off, transportation, backcountry ski and hiking equipment, and many other tangible and intangible things that both she and I take for granted. We met up a few
more times with the intention to do more planning, but we always got side tracked and lost in
conversation about diabetes and our experiences and things we were excited for. So, I eventually
decided to reach out to the slowly growing member community for their opinions on group
direction.

What I found through conversation and the survey is that the current members are
interested in showing up and participating in events, but are not currently interested in taking on
the responsibility of planning. My hope is as the group continues to grow and develop, other
members may join who are interested in taking a leadership role so I am not alone in the
planning and implementation of group activities and direction.

Community Events

The focus of the group is creating events that are not directly related to T1D, but are the
platform for gathering and discussing what naturally bubbles up. The strategy when planning
community events was to check in with a few members to see which day worked best with their
schedule. We then created invitations and emailed them out to the Diabetes Sisters and N.N. T1D
community. We have had a total of four gatherings so far, with a fifth scheduled (see Appendix
for details) and below blog posts.

Table 2
Blog Posts

<table>
<thead>
<tr>
<th>Title</th>
<th>Author</th>
<th>Published Date</th>
<th>Link</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dusty Boots and Diabetes</td>
<td>Celia Johnson</td>
<td>Jan 18 2018</td>
<td><a href="https://www.nevadat1d.org/blog/stay-tuned">https://www.nevadat1d.org/blog/stay-tuned</a></td>
</tr>
<tr>
<td>Internal Dialog of a Traveler with</td>
<td>Celia Johnson</td>
<td>March 27 2018</td>
<td><a href="https://www.nevadat1d.org/blog/a-b-q-g-x-l-w-your-glucoses-">https://www.nevadat1d.org/blog/a-b-q-g-x-l-w-your-glucoses-</a></td>
</tr>
<tr>
<td>Diabetes</td>
<td></td>
<td></td>
<td>reaction-to-life</td>
</tr>
</tbody>
</table>
CHAPTER 3: RESULTS

“It’s the little things that make a world of difference”

It is hard quantify the impact a group like this can have on a person’s sovereignty, self-efficacy, and sense of empowerment. But, to see the way members engage at the events, leave smiling and laughing, and tell stories about how their diabetes care is changing, it is clear to see how the community has become a positive addition to member’s lives.

Community

To be able to come into a space held for women and T1Ds, immediately forms an unspoken sense of community as evidenced by a shift from awkward silence to generative conversations. After only a few moments of awkward introductions, connections formed. At one meeting, a new member was sitting quietly until another mentioned she had completed her training to receive a T1D monitoring dog. The new member’s eyes lit up and she exclaimed “Wait, what?! You can have a dog to help you with your diabetes?” She immediately pulled out her phone and started taking notes as she and the other member dove deeply into conversation about the process to get a dog for her too.
Although people with T1D each lead different lives, the daily experiences have many commonalities that bond us. Being able to sit down and have a cup of tea, check blood sugar and not have to explain what the beeping coming from phones or monitors can be cathartic. When the group gets together there is an understanding that members will be looking at their cell phones, (or pricking their finger) to check their blood glucose levels, and the conversation does not pause, there is no need to ask or explain what is happening in the moment. A simple head nod or smile indicates after checking that the person’s glucose levels are okay and no words are needed.

Information sharing

What I have found to be one of the great benefits of this group is the vast information sharing that occurs. In the “Third Meeting NNT1D Homage Bakery” in the recordings table, are moments of realization, and people scribbling down notes of cell phone apps, doctors names, and medical information.

Because of the community members have felt more empowered to do more of the things they enjoy. For some members it is traveling, for another it is starting new jobs. For me, it meant seeking out a new doctor that I felt more comfortable with. We have others to bounce travel ideas off of, and to share backup equipment with. We have people to empathize with about how challenging it can be to go through flight security, and about how challenging blood sugar control is transitioning to new time zones, eating schedules, and with sleep deprivation.

Inspiration and Health Sovereignty

Hand in hand with information sharing is inspiration. Inspiration takes many forms including health sovereignty. From becoming excited about using new blood sugar trackers,
seeking out new medical advisors, to switching insulins, meal structure, and exercise habits. By taking back the power, the sickness transforms from a burden to a connecting point. I believe the conditions were created for members to feel comfortable sharing their stories and excitement by meeting in physical spaces where members could feel safe. This includes being in a female only space, and by offering the opportunity for people to volunteer to share, but not creating the expectation or pressure of sharing.

On a personal level I have made many changes in my life as a direct result of this group. I have switched insulin, changed kidney doctors, adjusted the way I take insulin when my blood sugar is high, started using several new glucose tracking apps, started writing about my experience, started voice recording about my experience, and joined a gym to exercise more consistently daily. While this looks like a long list of little changes, these have made a monumental shift in my diabetes care management. My attention to preventative care has increased, my insulin dosing has been updated, and my overall care has been elevated because of this group. As the group developed interpersonal connection, member’s self determination, personal sovereignty, and T1D health management began to evolve.

CHAPTER 4: EVALUATION

I evaluated this project by both a survey of group members and by tracking conversations with members. Along the journey I took voice recordings of all of the little moments that lead to the cultivation of the group (see Table 3). These recordings show the milestones of struggles, wins, and questions I faced in the process. It was a way to hold myself accountable for simultaneously sitting with uncertainty and not being paralyzed by fear into inactivity. The genesis of my fear was from wanting to create a space that was inviting and inclusive to everyone who wanted and or needed a space to be in relationship with others with T1D. At the
same time, I had never created anything similar, did not fully know where to start and what a
group like this would look like. After bringing these fears to the attention of peers and I realized
I could read all the books and articles in the world about community group creation and still
make mistakes, and that is okay. Mistakes are a critical part of every journey.

To access the impact of the group via survey I generated a survey on Nevadat1d.org (see Table 5). I kept it simple and short to see who has come to an event, if members found the event to be positive experience, and the direction they would like the group to take in the future. I took this feed back and used it to help plan the future events.

Group members commented regularly on how much they enjoyed the group and expressed gratitude consistently. There are several members who repeatedly, in person, have verbalized their gratitude for the groups existence. Knowing Nevada T1D has positively affected even a few peoples lives makes it all worth it.

Table 3
Voice Memo Project Milestones

<table>
<thead>
<tr>
<th>Clip Name</th>
<th>Date</th>
<th>Link</th>
</tr>
</thead>
<tbody>
<tr>
<td>First Flyer Drop Off</td>
<td>Jan 1 2018</td>
<td><a href="https://drive.google.com/open?id=11ITLJ2AHHN6i9b6w2ncAivEY6v0lh2U0">https://drive.google.com/open?id=11ITLJ2AHHN6i9b6w2ncAivEY6v0lh2U0</a></td>
</tr>
<tr>
<td>Self Reflection - Struggle</td>
<td>Jan 2 2018</td>
<td><a href="https://drive.google.com/open?id=18YgOkUVlSPEyKcCw3rf67VTw_EuB9PYA">https://drive.google.com/open?id=18YgOkUVlSPEyKcCw3rf67VTw_EuB9PYA</a></td>
</tr>
<tr>
<td>Dr Caruso - Flyer Drop off</td>
<td>Jan 4 2018</td>
<td><a href="https://drive.google.com/open?id=182RP5cp9y0yIV3K-vi_3p1LAEFVySJJ">https://drive.google.com/open?id=182RP5cp9y0yIV3K-vi_3p1LAEFVySJJ</a></td>
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<tr>
<td>Tina - First meeting</td>
<td>Jan 11 2018</td>
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<tr>
<td>First NN T1D Meeting</td>
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<td><a href="https://drive.google.com/open?id=1y_3X_q0nR8xUG4XdV_x-WKxQrE3rFCPy">https://drive.google.com/open?id=1y_3X_q0nR8xUG4XdV_x-WKxQrE3rFCPy</a></td>
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<tr>
<td>Diabetes Sisters Meeting</td>
<td>Jan 16 2018</td>
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<tr>
<td>Event Description</td>
<td>Date</td>
<td>Link</td>
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<tr>
<td>-----------------------------------------</td>
<td>--------------</td>
<td>----------------------------------------------------------------------</td>
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<tr>
<td>First Day of Website build</td>
<td>Jan 17 2018</td>
<td><a href="https://drive.google.com/open?id=1vcP6vkRS18xZ4PAMgbUqHG5_oL7Zmf5O">https://drive.google.com/open?id=1vcP6vkRS18xZ4PAMgbUqHG5_oL7Zmf5O</a></td>
</tr>
<tr>
<td>Wells Ave clinic flyer drop off</td>
<td>March 5 2018</td>
<td><a href="https://drive.google.com/open?id=1tLjEZNcGck8mCmG7JqJuDABWeO1D-J-">https://drive.google.com/open?id=1tLjEZNcGck8mCmG7JqJuDABWeO1D-J-</a></td>
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<td>Trader Joe’s T1D man</td>
<td>March 23 2018</td>
<td><a href="https://drive.google.com/open?id=1GyulvGkVkii7vt_73FhgaZDDN_R4mJ">https://drive.google.com/open?id=1GyulvGkVkii7vt_73FhgaZDDN_R4mJ</a></td>
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<tr>
<td>Diabetes Thoughts</td>
<td>March 27 2018</td>
<td><a href="https://drive.google.com/open?id=1zq2s_JqXk4XCPUAD_W8fcMaIKkg4qriR">https://drive.google.com/open?id=1zq2s_JqXk4XCPUAD_W8fcMaIKkg4qriR</a></td>
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<tr>
<td>Beyond Diabetes App</td>
<td>April 4 2018</td>
<td><a href="https://drive.google.com/open?id=1i86Xqm-q-M6ATQCSj8dvPQPiFmagFS">https://drive.google.com/open?id=1i86Xqm-q-M6ATQCSj8dvPQPiFmagFS</a></td>
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<td>JDRF Gala</td>
<td>April 28 2018</td>
<td><a href="https://drive.google.com/open?id=12w56VNJLOQPi-bZT52b5NYHdcv310k4">https://drive.google.com/open?id=12w56VNJLOQPi-bZT52b5NYHdcv310k4</a></td>
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<tr>
<td>JDRF Gala 2</td>
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<td><a href="https://drive.google.com/open?id=1dgiMfOSy1l5du7np7OukGkGsThATiGcI">https://drive.google.com/open?id=1dgiMfOSy1l5du7np7OukGkGsThATiGcI</a></td>
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<tr>
<td>Rachael Iceland</td>
<td>April 30 2018</td>
<td><a href="https://drive.google.com/open?id=1xj3Gt4nNkgpNPQoCPresPmGDgh61LQm">https://drive.google.com/open?id=1xj3Gt4nNkgpNPQoCPresPmGDgh61LQm</a></td>
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<tr>
<td>Joshua Tree T1D Camping Trip</td>
<td>May 17 2018</td>
<td><a href="https://drive.google.com/open?id=17fSiLEpjaXMICYNILPBgzKhJ5-cpHhoL">https://drive.google.com/open?id=17fSiLEpjaXMICYNILPBgzKhJ5-cpHhoL</a></td>
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<tr>
<td>Third Meeting NNT1D Homage Bakery</td>
<td>May 21 2018</td>
<td><a href="https://drive.google.com/open?id=1eFaYWg_nPykpx1hrd6yXy1DxyxO-rOz">https://drive.google.com/open?id=1eFaYWg_nPykpx1hrd6yXy1DxyxO-rOz</a></td>
</tr>
<tr>
<td>Reflections on Meeting 3</td>
<td>May 21 2018</td>
<td><a href="https://drive.google.com/open?id=1a2GyjrzeiZDgOJ2_kZjO5v-KuHKwsDQ7">https://drive.google.com/open?id=1a2GyjrzeiZDgOJ2_kZjO5v-KuHKwsDQ7</a></td>
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<tr>
<td>Winco meeting Jenny</td>
<td>May 30 2018</td>
<td><a href="https://drive.google.com/open?id=1JDkiQqtqwGQk0saHBBMZ6_NxFp8GrCWG">https://drive.google.com/open?id=1JDkiQqtqwGQk0saHBBMZ6_NxFp8GrCWG</a></td>
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<tr>
<td>Hip hop class</td>
<td>June 11 2018</td>
<td></td>
</tr>
<tr>
<td>Cat Call turned T1D Convo</td>
<td>June 19 2018</td>
<td><a href="https://drive.google.com/open?id=1PCPK0dbe29ZHmWAWbvLzkXfBRGA0GtK">https://drive.google.com/open?id=1PCPK0dbe29ZHmWAWbvLzkXfBRGA0GtK</a></td>
</tr>
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</table>

Table 4
Video Updates
<table>
<thead>
<tr>
<th>Video Title</th>
<th>Date</th>
<th>Link</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sustain Seminar Takeaways</td>
<td></td>
<td><a href="https://youtu.be/MuBmpf-8CeY">https://youtu.be/MuBmpf-8CeY</a></td>
</tr>
<tr>
<td>Video Update #1</td>
<td>Jan 23 2018</td>
<td><a href="https://youtu.be/2SwZoTuyZig">https://youtu.be/2SwZoTuyZig</a></td>
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<tr>
<td>Video Update - JDRF Gala</td>
<td>April 28 2018</td>
<td><a href="https://youtu.be/fyWqrw0XQ-Y">https://youtu.be/fyWqrw0XQ-Y</a></td>
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</tbody>
</table>

Table 5
Member Survey

| Member survey | https://www.nevadat1d.org/survey.html |

Table 6
Survey Results

<table>
<thead>
<tr>
<th>Survey Question</th>
<th>Response</th>
<th>Quantity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you attended a N.N. T1D Community gathering?</td>
<td>Yes, I will attend more</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Yes, I will not attend more</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No, I plan to attend future events</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>No, I do not plan to attend events</td>
<td></td>
</tr>
<tr>
<td>If Yes, how did you feel about the overall experience?</td>
<td>“Lovely to meet other T1Ds in a relaxed, enjoyable experience.”</td>
<td></td>
</tr>
<tr>
<td></td>
<td>“Good!”</td>
<td></td>
</tr>
<tr>
<td></td>
<td>“It was fun.”</td>
<td></td>
</tr>
<tr>
<td>How has becoming part of the N.N. T1D Community impacted your relationship with your diabetes?</td>
<td>“I'm enjoying the enthusiasm and adventures of the younger participants.”</td>
<td></td>
</tr>
<tr>
<td></td>
<td>“Motivates me to ramp up my diabetes care.”</td>
<td></td>
</tr>
<tr>
<td></td>
<td>“I can always use the support. I do need to</td>
<td></td>
</tr>
</tbody>
</table>
“Nice to attend activities outside of just being T1D!!”

don’t talk about it with people who understand!”

Do you have suggestions for ways we can better support your journey?

<table>
<thead>
<tr>
<th>Activity</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hike</td>
<td>4</td>
</tr>
<tr>
<td>Paint</td>
<td>3</td>
</tr>
<tr>
<td>Coffee Meet up</td>
<td>3</td>
</tr>
<tr>
<td>Picnic</td>
<td>4</td>
</tr>
<tr>
<td>Speaker Series</td>
<td>4</td>
</tr>
<tr>
<td>JDRF Walks</td>
<td>3</td>
</tr>
<tr>
<td>Beach Day</td>
<td>1</td>
</tr>
<tr>
<td>Fundraiser</td>
<td></td>
</tr>
</tbody>
</table>

CHAPTER 5: RECOMMENDATIONS

It is clear from the data, and lived experiences, that change is needed. Not only does change need to occur at the national and local political levels, but also in our social structures. Studies and personal experience show that communities like this are beneficial. But, I realized while steeping in this project, that support communities on their own will not change the systematic oppression and structural issues that plague the US healthcare system. History has shown that those in power may not generate enough change to alter all of the barriers in place as these operate deeply within ingrained systems of oppression. Social change takes the efforts by
many. If we each take responsibility to learn into our strengths, and participate in whatever capacity we are able to, we can create a ripple of change.

On a personal level, I will work to develop a culture of appreciation where mistakes offer opportunities for learning. I plan to discuss with the group a plan for what it means to set goals of inclusivity and diversity, particularly in terms of time; I will continue to work on my defensiveness and understand the link between defensiveness and fear. I will work to recognize there are many forms of communication and recognize the contributions and skills that every person brings. I will work on noticing when people are simplifying complex issues and understanding that everybody has a world view and that everybody’s worldview affects the way they understand things. I will continue to develop relationships within the communities by attending open community events and having conversations where and when feels appropriate and invited.

The next steps for this project are to create conditions for more people who want to join the community, to access the events and information. The group will have a more set schedule for events so members will be able to plan their attendance and transportation accordingly. Thus far events have been on different days and different times, as few members have the same availability. I believe if we have a set day/time per month, it will help serve the community more effectively. At the moment, the current members have access to rides, and our meetings have been purposefully in close proximity to public transportation routes. I have gauged interest in participating in political action, but the response has been a resounding No. I believe one reason for this is, diabetes is already challenging daily. The idea of doing another “hard” thing associated directly with the disease can be overwhelming and emotional, even if it is towards a better future. Recently, I was asked by a friend at planned parenthood, to film a commercial
attacking a senator from Nevada who has threatened to dismantle the current healthcare system, without presenting a more positive alternative option. I was apprehensive, but I knew exercising political expression in this way might help vote into office someone who will uphold health care for people with pre existing conditions.

My goal for the next several gatherings is to bring community members and experts in to participate. For the next meeting we have a yoga instructor coming to teach an intro class. Movement can be very beneficial to T1D management, and based on conversations, I know many members have struggled with incorporating daily movement into their schedule, so my hope is this may open some opportunities for conversation.

A key learning is how leaning into something challenging can produce profound results. Owning T1D is a daily struggle for many, but engaging in a community that faces similar hurdles, can transform lived experiences. Recent conversations with three men with T1D have disclosed a need for a gathering space for men. While we did attempt one co-ed meet up, with these new connections, I plan to get another on the books soon. I am excited about the future of this group, the possibilities it holds, and how people’s lives may be enhanced by participating in the community.
diabetes can’t stop me from being a wonder woman

We are a community for women in Northern Nevada with T1D who are looking for a safe space to share their lived experiences. We gather over cups of coffee and by getting outside for an adventure. You are not alone in this.

Join us on Facebook at Northern Nevada's t1d Women's Community or at: Celia.Grace.Johnson@gmail.com 603-393-9988

Figure 1. Wonder Woman flyer
NORTHERN NEVADA’S T1D WOMEN’S COMMUNITY

watercolor, tea, & t1d

RANCHO SAN RAFAEL ARBORETUM
MARCH 22 AT 4PM
RSVP CELIA.GRACE.JOHNSON@GMAIL.COM

Figure 2. Meeting 1 flyer
NORTHER NEVADA’S T1D WOMEN’S COMMUNITY PRESENTS:

DUSTY SHOES & DIABETES

JOIN US FOR A MELLOW HIKE!
HIDDEN VALLEY TRAIL RENO, NV
FEBRUARY 1 AT 3PM
RSVP: CELIA.GRACE.JOHNSON@GMAIL.COM

Figure 3. Meeting 2 flyer
Figure 4. Meeting 3 flyer
NORTHERN NEVADA'S T1D WOMEN'S COMMUNITY PRESENTS:

PICNIC AT SPARKS MARINA

FOR MEN AND WOMEN WITH T1D
SATURDAY JUNE 30 AT 11AM

RSVP CELIA.GRACE.JOHNSON@GMAIL.COM OR 603-393-9988 FOR FULL DETAILS

Figure 5. Meeting 4 flyer
Annotated Bibliography
Celia Grace Johnson


Risk of developing depression is 50-100% higher among patients with diabetes compared to that among the general population. Diabetes and psychiatric disorders share a bidirectional association, both influencing each other in multiple ways. Up to 45% of the cases of mental disorder and severe psychological distress go undetected among patients being treated for diabetes.

Bao Nguyen, personal communication, October 19, 2017

Think about the name of the group- it carries a lot of weight and expectations - it gives a sense of what the group is about and what the goals are. Also pay close attention to the language used when generating and establishing the Description of the group.

Responsibility weighs heavy. Be okay with sitting with tension. Who do I want to co-create with? What are your hopes and dreams for this group?

Barbara Hunt, personal communication, October 27, 2017
Met with Barbara Hunt. Reviewed Diabetes Sisters guidelines and leader packet. Chatted about her experience within the group, how they operate, and what the group has offered her. After chatting I see continue to see the need for a group for younger women. Most of the members of her group are 60+ and originally diagnosed incorrectly with Type 2 before having their diagnosis updated to type


Beyond Type 1 is a new brand of philanthropy leveraging the power of social media and technology, changing what it means to live with Type 1 diabetes. By educating the global community about this chronic, autoimmune disease, as well as providing resources and support for those living with Type 1, Beyond Type 1 bridges the gap from diagnosis to cure, empowering people to both live well today and to fund a better tomorrow. Gathered information about new technology updates and group outings.

Butwicka, A. (n.d.). Are Children With Type 1 Diabetes at Increased Risk for Mental Illness?


The study included more than 17,000 children with type 1 diabetes and more than 18,800 of their healthy siblings, all of whom were born between 1973 and 2009 in Sweden. About 8 percent of the children with type 1 diabetes had a mental health
diagnosis. The risk of mental health problems, including suicide attempts and other common mental illnesses, was three times higher in children with type 1 diabetes during the 6 months after the onset of diabetes and two times higher throughout the 18-year study period.


The lived oppression that people with disabilities have experienced and continue to experience is a human rights tragedy of epic proportions… for the first time, a movement of people with disabilities has emerged in every region of the world which is demanding recognition of their human rights and their central role in determining those rights.


How do we define self efficacy and confidence? There is a simple formula to help sort it out.

Connect with others living with or caring for someone with type 1 diabetes. | Join the Glu community. Retrieved October 17, 2017, from https://myglu.org/

Glu is an online community of T1D Exchange, a unique nonprofit organization focused on driving faster, better research to improve outcomes in type 1 diabetes. I joined this website’s community to become part of the ongoing conversations and assist with their
daily information polls. I wanted to connect on a virtual social platform to see what was
already being offered.


Made In America. Retrieved August 27, 2018, from
Paternalism is defined as the policy or practice of restricting a person or group’s freedom or
autonomy in their supposed best interest.

https://diabetessisters.org/
DiabetesSisters offers a range of education and support services to help women of all
ages with all types of diabetes live healthier, fuller lives. They understand the fear and
isolation that often comes with living with diabetes because we are an organization that is
managed by women who are living with diabetes. I reached out to this organization to
make physical contacts here in Reno with the existing Pod group.

Erin Allgood, personal communication, September 13, 2017

Take what feedback i receive and formulate a group. Be dedicated to changing and evolving as it is necessary, desired, and be consistent. What is it that people want? Recognize how my energy changes a space. Am i welcome there?

Erin Allgood, personal communication, September 21, 2017

Host meetings to plan the group. Listen and do not jump in without a plan and intention. What are my needs? What am I good at? Generate leaders within the group.

Erin Allgood, personal communication, September 29, 2017

Be intentional, plan, co creating, listening before implementing. To contemplate: What serves growth the most? What am I good at? What is my intention with this group? Dynamic but stay true to the mission. What is my vested interest? Is this something I would do even if I wasn’t getting a degree? Am i inside my work? When do my personal goals + community needs align? Slow down.

Erin Allgood, personal communication, October 13, 2017

My goal - to have all women in northern nevada know they have a support network at their fingertips.

Erin Allgood, personal communication, October 20, 2017

Creating a friend zone & safe space within this region of intersectionality. Should I create the goals for the group? How does this work with co creation? This is a group for “this”
how can we accomplish this & serve needs? What does support look like? Where is the
growth in this for me? Generating & fostering connectivity between people. Time bound
for project purposes? Evaluation process? Milestones? (create social media platform, first
physical meeting, etc) Intangible milestones around connectivity.

(2017). Ventanillas de Salud: A Collaborative and Binational Health Access and

Graves, L. (2017, June 28). Why are 13 men in charge of healthcare for all American
healthcare-republican-senate-bill

Heath, S. (2017, November 20). Overcoming Transportation Barriers to Drive Patient
transportation-barriers-to-drive-patient-care-access

14, 2017, from https://www.huffingtonpost.com/danea-horn/living-with-
ilness_b_4570379.html

This article puts into words a feeling that I've struggled with for so long.
This article explains the intergral connection between insulin and weight management.


This Podcast was an interview between host Dr LO and guest Dr Jody Stanislaw. Dr Stanislaw has her degree in Naturopathic medicine and has been a type 1 diabetic for over 30 years. Her words spoke to me. Something clicked during the interview and
changed the course of my life. Listening to someone with diabetes talk about her wins and challenges was like having an immediate friend.


A support group provides an opportunity for people to share personal experiences and feelings, coping strategies, or firsthand information about diseases or treatments.


Being white in this country comes with advantages that I had previously never even considered. Reading this article made me realize just how everyday I walk through this world without taking notice of these situations. It made me relate better to my partner, who was not born into the same advantages.


How the World Health Organization defines patient empowerment.

Defining the complexities of personal sovereignty, this article helps put into context its importance.


From this article I learned more about the complexities of intersectionality, what it is, and what it isn't.


Curating questions that do not lead, but are in the correct order, specific enough, give all options to choose from, and staying unbiased, are all critical aspects to consider when writing a survey.


I wanted to should Yes! But, I was in a coffee shop and felt it might be inappropriate. Karen brought up the theme of powerlessness of disease. It was something I had never taken the time to acknowledge, but she recognized it in my writing right away.


Mindfulness practice - Sit for 5 mins at a time, 5 times a day, for 4 days. Finding ways to fit contemplative practices into my day to ground and center myself.


When trying to explain why women's only spaces are needed Warner does a great job of explaining what can be a tough concept to articulate.

What Is Diabetes? (n.d.). Retrieved June 18, 2018, from http://www.jdrf.org/about/what-is-t1d/&utm_source=googlegrant&utm_medium=cpc&utm_campaign=180410_General_Diabetes&utm_content=paid&s_src=googlegrant_cpc&s_subsrc=180410_General_Diabetes?gclid=EAIaIQobChMIjZuT0N_d2wIVg0BpCh0jCAk8EAAYASAAEgISb_D_BwE

A simple explanation for a very complicated disease. It gives good incite as to how the disease affects the body.


This articulated in an understandable way the concrete and important reasons behind having women's only spaces.

https://www.charitynavigator.org/index.cfm?bay=content.view&cpid=1559
Appendices

Appendix A

Letter to Doctors

To Whom it may concern,

I appreciate you taking the time to read my story, and see the value in the community I am creating.

My Journey:
Curled on the dirty carpet of my small midtown apartment, tears streaming from my eyes, shaking, and emotionally beaten down from ten years of struggling with a disease no one sees, I stared at my phone, the only number I could think to look up glowing back at me: The Suicide Hotline. I have never pressed call, but I have stared at that number for hours, waiting for the wave of desperation to pass. I did not want to scare my parents with my emotion, I knew my friends, as sweet hearted as they are, would not understand, and I did not want them to look at me differently when I smiled. So, there I lay, time after time. I’ve gone to therapists, I’ve laid my soul out to my significant other, but I’ve found nothing as grounding as connecting with someone who has experienced similar moments of joy and struggle.

Why:
Living with Type 1 Diabetes (T1D) can be a very lonely and isolating disease. Consider this: If a woman with diabetes visits her endocrinologist the recommended number of visits per year (four) and spends the average amount of time (15 minutes) with her doctor, she will spend a total of one hour per year working with her physician on her diabetes management. This leaves over 8,700 hours in the year for her to manage her diabetes on her own. It is during this “alone” time that questions often arise and support is needed. After all, no one can manage a chronic illness on her own. (DiabetesSisters, 2012). There are no networking resources accessible here in Northern
Nevada to members of the T1D community specifically geared towards helping the fem and fem-identifying community with T1D.

Sincerely,

Celia Grace Johnson
Community Coordinator
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Celia.Grace.Johnson@gmail.com
Appendix B

Statistically, You are Not Alone

T1D accounts for 5–10% of the total cases of diabetes worldwide. Data from large epidemiologic studies worldwide indicate that the incidence of T1D has been increasing by 2–5% worldwide and that the prevalence of T1D is approximately 1 in 300 in the US by 18 years of age. The Diamond project, initiated by the World Health Organization in 1990 set out with a main objective to describe the incidence of T1D in children. What they found is the incidence of T1D varied greatly around the world. A statistically significant male-to-female excess in incidence was reported in 3 centers, but no populations reported a female excess. In the SEARCH study for diabetes, the authors conclude that in the US, these rates of T1D among non-Hispanic white youth are among the highest in the world. These authors hypothesize that the explanation for the variation within ethnic groups may be due to differences in genetic admixture or environmental/behavioral factors. In the USA rates were highest in non-Hispanic white youth as compared to other race/ethnicities and were slightly higher in females as compared to males. Although the majority of T1D cases occur in individuals without a family history of the disease, T1D is strongly influenced by genetic factors. In the United States, individuals with a first-degree relative with T1D have a 1 in 20 lifetime risk of developing T1D, compared to a 1 in 300 lifetime risk for the general population (Maahs, 2011).
Appendix C

An Invisible Disease

Consider this: If a woman with diabetes visits her endocrinologist the recommended number of visits per year (four) and spends the average amount of time (15 minutes) with her doctor, she will spend a total of one hour per year working with her physician on her diabetes management. This leaves over 8,700 hours in the year for her to manage her diabetes on her own. It is during this “alone” time that questions often arise and support is needed. After all, no one can manage a chronic illness on her own (DiabetesSisters, 2012). There were no networking resources accessible here in Northern Nevada to members of the T1D community specifically geared towards helping the fem and fem-identifying community with T1D.

There are many elements of everyday living with T1D that are different that people might expect. Below are a few examples.

Food - Food is simultaneously our medicine and enemy. There are moments I am scared to eat because my blood sugar is level, and if I eat I know I may throw it back out of balance. If I mis calculate insulin to carbohydrate ratio I will be tired and lethargic, or even die. The difference between the two is a shockingly small amount of insulin. For a size comparison think, 1 drop of water to live, 1.5 drops of water to die.

Sleep - I often wake up in the middle of the night just to make sure I am alive. Statistics show that 1 in 20 people with T1D will die from hypoglycemia in their sleep (healthcentral.com). It is a constant fear of mine. I am lucky enough to have a continuous glucose monitor that, when it works, wakes me up if my glucose goes too low or too high. But, it is not foolproof and it weighs heavy on my mind as I fall to sleep.

Exercise - Finding the perfect time to exercise can be challenging. I often have to tailor my exercise to my diabetes. If my glucose is too high, I have to exercise slowly and without much exertion, like going for a walk. If my blood sugar is low, I cannot exercise unless I eat carbohydrates and wait for them to breakdown in my system. Many diabetics choose to exercise when we first wake up, before eating or drinking anything. This is the closest guarantee I can get that my blood sugar will remain stable.

Travel - Travel can be a beauty and a beast. Routine is often seen as our friend because T1D requires a lot of supplies. When traveling T1Ds have to bring supplies for normal daily activities, and backup supplies incase our pumps or monitors fail, or our travel plans are interrupted in any way. Please see my blog post about the complexities of travel.

Body Image - If being a human woman isn’t hard enough trying to keep up with the standards of beauty, and then to add the layers of diabetes seems a bit like a slap in the face. It can be challenging to maintain a stable body weight. Weight gain is a common side effect for people who take insulin (mayoclinic.org). I often work out much more
often and eat much healthier than my close friends, and I have put on over 35 lbs since being diagnosed that I am unable to lose.

Mood Swings - I often have to educate people who have friends with T1D that our personalities shift when our blood glucose levels are outside of the norm. Diabetes affects much more than blood sugar. It can impact nearly every body system and have an effect on a person's mood. Blood sugar swings can cause rapid changes in a person's mood, such as making them sad and irritable. This is especially true during hypoglycemic episodes (medicalnewstoday.com).
Appendix D

Defining Change

Personal Sovereignty

“Personal sovereignty is an issue which affects each of us as individuals and as a society, whether we realize it or not. Understanding it can help us to interpret what is going on within us and around us. Increasing it can radically transform our existence. Personal sovereignty, then, would imply the intrinsic authority and power of an individual to determine his or her own direction and destiny. If that sounds suspiciously like free will, it's because personal sovereignty and free will are the same thing… The way to increase your personal sovereignty is to increase your use of free will. The way to do that is to decide for yourself what actions to take and reactions to have in any situation, and to decide for yourself how to interpret your actions and reactions whether they are freely chosen or not… Beware, though. Personal sovereignty has a high price. It's called personal responsibility. As you increase your use of free will, you also increase your responsibility for your own actions and reactions.” (Kahili King, 1996)

Self-efficacy

“Self-efficacy is the term that psychologists use to describe the belief a person has that they can reach their goals. Unlike self-esteem which is more of a global judgement on the self and its worth, self-efficacy specifically isolates the way an individual assesses their competence in relation to achievements, goals and life events… We use the following formula for confidence: Confidence = self-efficacy + optimism. In other words, confidence is an individual’s belief that he/she can reach specific goals plus the general belief that the future is bright.” (Center for Confidence and Wellbeing, 2018). 

Patient Empowerment and Health Care

“WHO defines empowerment as “a process through which people gain greater control over decisions and actions affecting their health” and should be seen as both an individual and a community process. Four components have been reported as being fundamental to the process of patient empowerment: 1) understanding by the patient of his/her role; 2) acquisition by patients of sufficient knowledge to be able to engage with their healthcare provider; 3) patient skills; and 4) the presence of a facilitating environment. Based on these four components, empowerment can be defined as: A process in which patients understand their role, are given the knowledge and skills by their health-care provider to perform a task in an environment that recognizes community and cultural differences and encourages patient participation.” (World Health Organization, 2009)
Appendix E

Personal History with T1D

I have been diabetic for fifteen years. In this time I have had countless conversations in passing with people with T1D who share this similar sentiment, that in our doctor appointments there is an uneasy power dynamic that haunts us. We are spoken down to as if we are the condition, not people who have a condition. Partly as a social experiment, partly because I was frustrated and tired of this dynamic, I began speaking my truth to power. I started using my voice in doctor’s appointments to educate the physicians on life with T1D and podcasts where they could deepen their empathy and further their education. Because I came into the appointments with a different energy, there was a noticeable shift in the power dynamics and the respect I received. My doctors provided me with more information on my health, and were more engaged in communication. It felt like they were connecting with me, instead of just talking at me.
Appendix F

Intersectionality

What is intersectionality?

...intersectionality is an analysis related to identity, not an identity in itself. Everyone has multiple identities. Systems of hierarchy have been created around our identities, and the combinations (or intersections) of those systems affect how life goes for us. Some of these identities give us a leg up, while others push us a rung down the ladder. The combination of identities can compound (or diminish) advantage or compound (or relieve) harm, and there are perhaps endless variations. The point of intersectional practice is to look at all these possible combinations of privilege and vulnerability (Rinku, 2017).

There is no group like this for men in Reno. While Nevada T1D will continue, for now, to be a space for female identifying T1Ds only, I have started to recognize our positioning in providing a platform for a men’s branch. I am interested to know if men in Reno/Tahoe with T1D have similar sentiments to the women I have spoken with about wanting there to be a community for them to be a part of. Through my research on social media, it is clear there is some desire for this in both southern california and texas. It seems worthwhile to explore this in Reno too.
Appendix G

Community Events

We have had 4 events so far (see Images). The first was a hike out in the eastern hills of Reno where the wild horses roam. Only three of us were able to make it, but it was a perfect size group for our initial outing. (see Blog Posts). Although we were not doing anything directly related to diabetes itself, our actions reflected the way each of us choose to live with this disease. We checked our blood sugar in different ways, we checked at different times, brought different hypoglycemia snacks and drinks. But, because we are all diabetic, our conversations were generative and filled with true empathy and understanding. It felt cathartic.

At the second gathering, on the 22nd of March 2018, four of us gathered for watercolor painting at the arboretum at Rancho San Rafael. We had planned to only be there for about an hour, but as the hours passed and we packed up, we could not stop talking and connecting. In the parking lot as the sun was setting, we finally decided that our next gathering would focus on the topic we were so intrigued with: life with a semi closed loop pump and monitor system.

Our third gathering was around the topic of closed loop insulin pump systems. As it was raining outside, moved our event to a lovely little coffee shop in downtown reno. We featured two speakers who have two different pump systems, who both enthusiastically told their stories. Even now I get chills about how excited I am at the possibility of switching to one of these systems, when my insurance allows (in about a year from now). This meeting provided several of us with a lot of hope for the future. It is pretty easy to lose site of the good things to come, when we are staring down the barrel of diabetes complications.