

Examining Peer Support as Defined by Adults with Diabetes

BY

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THESIS

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This thesis is dedicated to members of the diabetes online community (DOC), whom I have come to cherish and celebrate. The DOC has become a home for me over the years, and it is to those who keep it active that I owe my health. Thank you for taking me in and allowing me the space to morph and grow as a human. The unwavering virtual and in-real-life support you provide are what brought me to consider graduate school, and what pushed me to keep writing through the challenges. I did this for and with all of you, and I hope it is only the beginning of a long journey in partnership.

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LIST OF ABBREVIATIONS

ADA	American Diabetes Association
CDC	Center for Disease Control and Prevention
CDE	Certified Diabetes Educator
CGMS	Continuous Glucose Monitoring System
CGM	Continuous Glucose Monitor
CMS	Centers for Medicare and Medicaid Services
DAWN	Diabetes Attitudes, Wishes, and Needs Study
DSME	Diabetes Self-Management Education
DOC	Diabetes Online Community
FDA	Food and Drug Administration
GSD	Guided Self-Determination
JDRF	Formerly Juvenile Diabetes Research Foundation
NIDDK	Nation Institute of Diabetes and Digestive and Kidney Diseases
PAR	Participatory Action Research

I. ETHNOGRAPHIC PROLOGUE

Wishing I didn't have a chronic illness is a common occurrence in my life. Despite the gifts, skills, determination, and community I've gained along the way, all the work and hardship does not feel worth it from time to time. The sense of worthwhile-ness falling away is indicative of *burnout* in the diabetes world. It signals a process of relinquishing and eventually regaining one's sense of choice and control. It is a process I, myself, have cycled through too many times to count. Burnout has led me down some of the darkest paths I have encountered. Burnout has led me to question my entire life's purpose and the purpose of *challenge* as a mechanism of the human experience. Until the Diabetes UnConference in 2016, my lived-experience had led me to believe that diabetes and chronic illness were two things no one chose. I believed that the way one managed their condition was the only source of choice involved in living with chronic illness. However, at the UnConference in a sweaty hotel in Atlantic City, my understanding of this shifted.

I sat, a silent but present witness in the exchange of peer support. I watched as a woman, roughly fifty years old, said through sheets of tears "I feel so guilty that he has to be with someone who has as many health problems as me." The woman was speaking to a peer, a married woman with diabetes who was about the same age. The peer looked to her, waited calmly for the sobbing to cool, and said, "Julie, listen to me. Your husband chose you, knowing full well you had all this going on. Your husband chose diabetes." I watched as Julie's cry changed from one of pain and sorrow to one of release and gratitude. Then I, third-party to this interaction and exchange, began to weep the warmest cry about diabetes I had had in years. I went home from the UnConference and had a remarkably healing conversation with my partner that ended the cycle of burnout I had

been in for months. I was able to jump back on the self-management train, simply because I witnessed two people take part in the exchange of peer support. I said nothing to Julie, nor to our peer. I just watched.

Stories like this one are not uncommon in the diabetes community. Online, in-person, and blended forms of social interaction between people living with diabetes result in the activation of peer support. In the Diabetes Online Community (DOC), my role in the interaction detailed above would be identified as *lurking*. Lurking has been defined as a process of concealment in online community spaces involving prolonged periods of consuming and receiving communication without directly contributing one's personal thoughts and experiences (Nonnecke & Preece, 1999). Though this paper did not start as an examination into lurking in the context of peer support, it is what it became. So fundamental to peer support working well is this process, that lurking herein takes center stage.

A. **The Story of Us**



Figure 1. Diabetes UnConference 2016 Atlantic City

The tables are round and covered with notebooks and pens, a small bowl of candies at the center: typical of any conference. The room is a theater ballroom; the golden curtains and patterned carpet appear to have been around for decades and the stage is ornate with twenty-foot tall wooden columns. Adults, mostly Caucasian, between 21-70 years old fill the red fabric seats. Scattered around the room are standing pairs and trios engaging in friendly conversation. Hugs abound. The atmosphere is vibrant, warm, and welcoming. There is no one sitting alone, though roughly 100 individuals are present. There is laughter in bouts every three minutes or so. As the conference start-time descends, attendees are asked to find a seat near someone unfamiliar. As this happens, few handshakes occur; hugging is the primary form of introduction. One particularly boisterous attendee says, "I'm a hugger, get used to it" with a laugh before hugging a new peer. The conference begins as it has in previous years. Attendees are asked to each share the number of years spent with diabetes with those at their table and then write a guess estimate for how many total years of diabetes are in the room. While each attendee forms their estimate, the facilitators, also adults with diabetes, walk the room gathering tabulated totals from each table. One attendee comes within 20 years of the actual total and wins a hug from the speaker. The atmosphere has transitioned into playful, lighthearted, and hopeful. Few are not smiling.

I recognize many in the room from online forums and conversations. The attendees of the Diabetes UnConference are members of the DOC. They are thought-leaders, non-profit founders, and peer-group directors. They are the engaged and activated patients healthcare providers simultaneously wish for and fear. They are advocates. The attendees here took time off from work and paid to fly or drive to Atlantic City to be here.

This is their vacation. The Diabetes UnConference is a conference that brings together advocates with diabetes who freely and openly dedicate their time to self-care and self-management to the point that they use their vacation for it. The conference is formed and governed by adults with diabetes. Only one facilitator of the seven there has a special degree and training in managing psychosocial aspects of diabetes, though none have those qualifications for work in group settings.

There are two rules at the UnConference: 1) the law of two-feet, and 2) that a social media blackout rule. The former is a policy enforcing self-care. If an attendee is not benefitting from a topic of conversation, they are permitted without judgment to get up to find another or to take a break. The latter is a policy enforcing confidentiality. Internet connected phones and electronic devices are not to be used during sessions on sensitive topics, such as burnout, sexuality, and relationship with food.

B. Bearing Witness, Sharing Space

As the weekend-long conference progresses, the atmosphere changes from lighthearted and hopeful, to deep and insightful. In full-room round-robin-style dialogue, attendees share secrets about diabetes they have kept hidden from spouses, parents, friends, and even from themselves. During whole-group sessions, the microphone is used –passed from sharer to sharer. The space changes into one of collective self-discovery. It feels safe, welcoming, present, and supportive. Sharing in this way is similar to a confession, a request for space to open honestly rather than to get feedback, validation, or advice. I learn as others share. I learn as they share not with me specifically, but with the room, with the conference. I share when I have something to contribute or something to confess, but otherwise I sit and watch, bearing witness to the exchange of peer support

while remaining a receptacle of support myself. It is this space of bearing witness that I project the concept and practice of *lurking* onto. Though the term has historically been used in the pejorative, I take this opportunity to give lurking a new face. Rather than equate lurking to creeping, sulking, or concealing, this paper equates it to bearing witness and giving presence to, without the expectation of feedback, validation, or advice.

C. **The Merits of Being an Insider-Researcher**

I selected the Diabetes UnConference as a location of community participation and data collection because I had attended previous UnConferences as a community member and observed its value. At the Diabetes UnConference, persons living with diabetes serve as experts. The collective creates the conference agenda upon arrival. It is the only fully peer-designed and peer-led conference for adults with diabetes, and welcomes adults with any type of diabetes (Marchand-Aprigliano, 2015). Stephen Shaul, a dedicated diabetes advocate attended the first Diabetes UnConference in March 2015, and served as a facilitator for every UnConference since. His testimonial speaks to the opportunity peer support programs like the Diabetes UnConference offer. He writes, “People shared some of their most closely held fears and secrets. People emerged stronger. People emerged not feeling so alone. People were empowered to take another look at diabetes and their friends who live with diabetes, making a collective investment in a better future for all of us. We are all in” (Shaul, 2015, p.10). The resulting collective investment Shaul mentions emanates from attendees throughout the weekend-long conference. Empowerment is generated and amplified within the community itself. It can neither be described as top-down, nor bottom-up, because it expands from the center. Community members lift each other up, using community resources, investing in the growth of both

the network and the individuals that make it up. As a member of the community at events like the Diabetes UnConference, I've played the roles of supporter, supported, and lurker. I have experienced the power and influence peer support has over my willingness and ability to put the needed effort forth to self-manage.

I was diagnosed with diabetes when I was eleven years old. I wore an insulin pump for ten of my fifteen years living with diabetes, and used multiple daily injections the other five. I have checked my blood glucose over 33,000 times and have been wearing a continuous glucose monitor (CGM) for the last three years. I have seen an endocrinologist every 2-3 months since diagnosis. Managing diabetes doesn't end after the finger stick and the injection. My experience leads me to argue that it doesn't even start there. Diabetes management is about more than the medical procedures; it is about balancing the psychological and social nature of living with a disease that requires eight-thousand hours of self-management per year (Hilliard, Sparling, Hitchcock, Oser, & Hood, 2015). Diabetes is about navigating relationships jeopardized by the irritability that comes with elevated blood glucose. It is about accepting a forever you did not ask for. Diabetes is about preparing for every meal, every walk around the block, every trip to the grocery store, every day at work with precise tools and backup plans. I know that that our health care system largely fails to recognize psychosocial elements of diabetes because I have lived through the consequences of not having my health care needs met. I know that diabetes is a complex disease treated with only with simple solutions because I have tried every provider-formulated recommendation to no avail. I have the lived-experience to know that there is something to peer support as a psychosocial element of diabetes care and treatment that is worth further and closer investigation.

I research in the diabetes space primarily because I have the insight to know where to look, and because I have built rapport and established trust with fellow community members. Having shared experience in the subject matter allows the discussion to flow. As an insider, my research in the area aims to meet three goals: 1) to produce research findings which are useful to the community; 2) to disrupt academic norms; and 3) to set forth steps toward positive change for the diabetes community.

i. **Highlighting insight over bias**

As an insider-researcher, subject to scrutiny over bias, I present a defense of my position as a member of the participant community. Historically, science has been touted as an objective truth-uncovering process. When a researcher is deemed too close to the subject-matter, they are pejoratively identified as bias-laden. Such paternalistic research standards in the name of objectivity have, however, stifled knowledge production by discounting the work of researchers belonging to any minority group, be it women, people of color, gender non-binary folks, or the disabled (Roberts, 1981). Rather than highlighting insight, the academy has relegated it to an indication of un-truth, of bias, of faulty research methodologies. The requirement of objectivity is challenged here on the basis that it perpetuates the exclusion of minority research and researchers, because it loses and devalues the richness of subjective data, and because it assumes there is only one true reality to know.

As a researcher, I openly state my positionality as a group member because it highlights and places value in insight over bias. I choose to actively step away from the screen of “rational,” “objective,” and “bias-free” science into a more self-aware methodology (Fausto-Sterling, 2008). I position myself as a diabetic, disabled women and

defend my insider-status against paternalistic research standards and requirements of objectivity (Rock, 1998).

ii. **Disrupting academic norms**

My status as an insider researcher not only challenges the value structure of traditional research by highlighting insight over bias, but it also bridges boundaries between research and activism and political goals (Goodley & Moore, 2000). In many academic fields, the norm is for research and activism to remain separate entities. The separation is in part due to efforts toward objectivity, but also an effort to leave dissemination and action to the people who it potentially impacts. Even disability studies, my field of study, has been criticized for the tendency to fashion and or enforce dichotomies of “us” and “them”, by attempting to understand an imagined universal disability-experience (Davis, 2000). The academy produces knowledge about populations by attempting to identify commonalities and principles that apply to all affected. However, I argue that because I am an insider, I am already keen to differences within the community of study. That is, I am better equipped to welcome variations in perspective, experience, and sharing modalities in order to not reproduce the hegemonic forces that disability studies itself tries to dismantle (Davis, 2000).

II. INTRODUCTION

Nearly 30 million people in the United States live with diabetes (Fast Facts, 2014). Diabetes is a self-managed disease, meaning that the individuals living with it must self-administer medication and perform daily activities required for survival outside of the doctor's office. In fact, persons with diabetes spend over "8,000 hours per year self-managing their diabetes outside of the medical setting" (Hilliard et al., 2015, p. 262). Surviving with diabetes is not accomplished by administering the right amount of insulin/oral medication, dieting, and exercise alone. Rather, it requires a healthy mindset, a will to keep working hard, and psychosocial support necessary for healthy coping (Herzer & Hood, 2010). Diabetes is a complex disease, requiring the act of *transformative* learning, a process of learning and relearning as circumstances and the environment change (Cooper & Geyer, 2009). However, most physicians do not treat to the degree of complexity through which diabetes is experienced.

In the groundbreaking study funded by Novo Nordisk called the Diabetes Attitudes, Wishes, and Needs II study (DAWN2), researchers found that "better support was associated with better outcomes for well-being and quality of life, suggesting that reductions in disease burden and increases in support may lead to better psychosocial outcomes in people with diabetes" (Holt & Karla, 2015, p. 13). Several research teams have used the DAWN2 findings as a rationale for studies which train clinicians to provide support to diabetic patients. For example, one study assumes the reduction in burden can be addressed by healthcare providers *if* providers are trained in a grounded-theory based technique called guided self-determination (GSD). Participants offered the opportunity to discuss burdens and taboo topics of diabetes throughout life with health care providers

showed improvement in self-management and self-efficacy (Zoffman et al., 2012). Nevertheless, it may be that outcomes were improved because intensive training and extra time during visits to follow the research procedures were allotted. Contrary to this, further DAWN2 results suggest a majority of healthcare providers who treat diabetic patients do not feel they have time in a regular visit to discuss psychosocial aspects of diabetes in-depth (Nicolucci et al., 2013). Thus, though research backs the delivery of psychosocial support to patients with diabetes, but a best mode of transmission has yet to be validated. Finding ways to approach these issues may work best outside of a traditional care delivery setting.

Adults with diabetes, along with patients in other diagnosis-groups, have observed this gap in treatment and created their own solution: peer support. Kim Vlasnik, diabetes advocate and blogger, and founder of the You Can Do This Project, explains in her Stanford Medicine X ePatient Ignite! talk, that it is common for people without diabetes to think the hardest parts of living with diabetes are the “things you can see;” the injections and blood tests (Vlasnik, 2014, p. 9). She goes on to share that, for her, the burden of diabetes is not physical, but rather “the psychosocial impact.” After detailing the psychological and social complexities involved in living with diabetes, Vlasnik credits peer support as her most valuable resource in confronting that burden. In her words, “Peer to peer support fosters resilience and confidence, it turns our shared vulnerability into empowerment and we can gain strength from the places we normally feel weak.” (Vlasnik, 2014, min. 1:51). A fellow diabetes advocate, Kerri Sparling, affirms Vlasnik’s claim, “...online patient communities of all kinds are supporting patients and empowering them to take control of their health” (Sparling, 2013, p. 1). Research has shown that Vlasnik,

Sparling, and other diabetes advocates' experiences with the power of peer support is generalizable for a multicultural and diverse diabetes community (Baig et al., 2012; Brownson & Heisler, 2009; Fisher et al., 2015; Kowitt et al., 2015).

The present qualitative study examines peer support in the context of diabetes using a participatory community research framework. The prologue introduced you to insider-researcher dynamics, insights, and goal. Following from the present introduction, Chapter III: Diabetes Explained illuminates the meaning of the diabetes experience physically, socially, and environmentally. Specifically, the theory of Compulsory Able-Bodiness by McRuer is discussed. Moreover, Chapter III explores theoretical and practical approaches to the stigma and ableism that maintain and result from the conception of diabetes as a "*lifestyle*" disease. The paper progresses to Chapter IV: The Current Landscape of Diabetes Care and Research. The funding structure for research and knowledge production is discussed at three social levels: macro, mezzo, and micro. Chapter IV concludes by introducing peer support as the missing link in the effort to improve diabetes care and outcomes.

III. DIABETES EXPLAINED

According to the National Committee for Quality Assurance (NCQA), of the nearly 30 million adults ages 18-75 who have been diagnosed with diabetes, between 30-48% are considered to be *in poor control* (NCQA, 2007). These patients, often labeled non-compliant, have elevated glucose levels as measured by a blood test measuring glycated hemoglobin. The test, called an HbA1c, is checked every three months in diabetic patients. Doctors have reported feeling frustrated with patients with diagnosed diabetes who have repeatedly high blood values (Wens, Vermeire, Van Royan, Sabbe, & Denekens, 2003). They site lifestyle factors as the cause, arguing that their patients have been given all the tools to manage their diabetes well, yet choose not to (Wens et al., 2003). On the other side, adults with diabetes have reported feeling dissatisfied with their care when they sense they judgment for an inability or unwillingness to meet health outcomes (Funnel & Anderson, 2007). Taken together, there has been a fundamental miscommunication between patients and doctors about diabetes self-management and outcomes goals. I argue that that miscommunication stems from the conception of diabetes as a *lifestyle disease*.

A. The Stigma of “LifeStyle”

According to disability studies scholar, Robert McRuer, we live in a cultural climate which favors able bodies and posits disabled bodies as defective and imperfect. He argues that normalcy is both favored and striven for to that point that the endeavor to meet its standards are compulsory (McRuer, 2006). In McRuer’s formulation, being able-bodied is the primary standard of normalcy. This preference for an able body has been termed *ableism* in the disability community and academic sector. Other scholars argue

that “embedded deeply and subliminally within culture, ableism therefore reproduces a widespread collective belief that ‘impairment is inherently negative and should the opportunity present itself, be ameliorated, cured or eliminated.’” (Jammaers, Zaroni, & Hardonk, 2016,p. 1367). In the diabetes context, then, I argue that there is a compulsion to self-manage the condition through diet, exercise, and medication. Further, I’d argue that this compulsion is rooted in diabetes conceived of as a condition which, when well managed, allows the patient to lead a completely normal life (Cramer, 2004).

Diabetes stigma is wrapped around the notion that one has control over their outcomes. If they only changed their habits, said no to that cheeseburger, went for walks, then they would never have been diagnosed to begin with. If they only *cared more about their health*, they would not be struggling now. These themes have been recorded as producers of stigma as experienced by adults with diabetes (Bock, 2012). Diabetes is seen as a deserved disease; one that is preventable and curable. When a person internalizes that stigma, self-blame can impede their ability and willingness to self-manage their condition. And diabetes is an extremely difficult disease to live with. I know from personal experience, though the research also points to this. Diabetes management can be so tedious and consuming, that it can and does impact sense of self and identity (Jammaers, Zaroni, & Hardonk, 2016).

IV. EFFORTS IN DIABETES (THE CURRENT LANDSCAPE)

The big question in diabetes research today is: why isn't it working? What are we missing? Diabetes care and treatment has supported the same three management strategies for decades: exercise, medication adherence, and good nutrition. Doctors, care teams, and researchers have tried flipping around the approach to education, tried implementing various adherence techniques, and poured millions into curative and preventative research.

A. Funding for Diabetes Research in the United States

Of the national spending on diabetes research in the United States in 2016, roughly 748 million came from three research organizations. The three most prolific funders of diabetes research are the American Diabetes Association (ADA), the National Institute on Diabetes and Digestive and Kidney Diseases (NIDDK), and the JRDF (formerly known as the Juvenile Diabetes Research Foundation [JDRF]). A summary of the funding levels and research priorities of each organization (Figure 1) is provided.

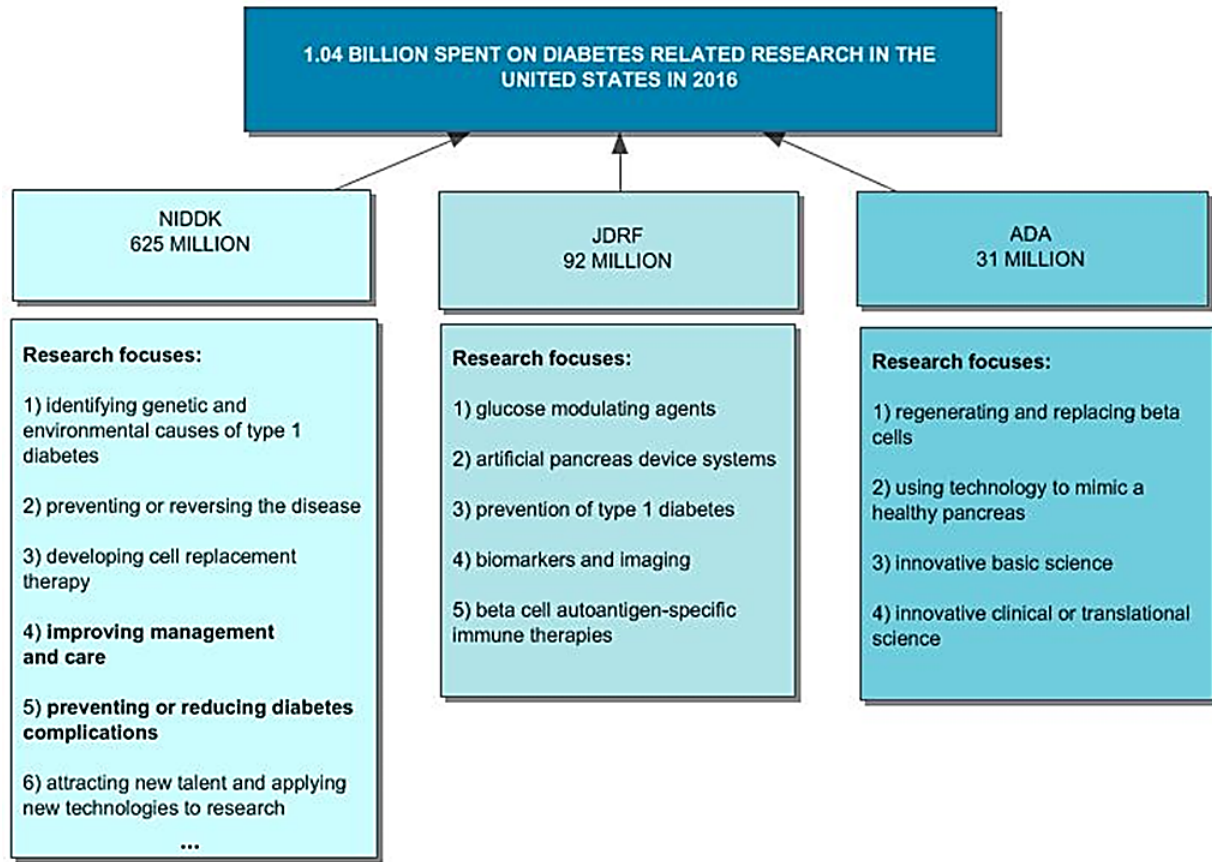


Figure 2: Summary of research funding for diabetes in the United States

Although NIDDK, JDRF, and ADA all place value in researching ways to “reduce the burden of diabetes” on individuals living with it, very few research dollars go toward doing so in an immediate capacity. Most funding focuses on curative or preventative research. The ADA does have one priority of notable exception: innovative clinical or translational science. However, projects funded under this priority have historically focused on improving clinical visits and capacity (e.g., doctor-patient relationship, and diabetes education).

Diabetes has been called an epidemic in the United States. The media, the public, and doctors alike see diabetes as a killer; a killer of the economy, a killer of people, a killer of life as it once was. Diabetes is the thing your family member doesn't take care of. It's the little voice in your head telling you not to eat an unhealthy meal. Diabetes is the joke no one laughs at anymore. Diabetes is linked with obesity, kidney disease, and many other secondary complications. Because diagnosis rates are still rising and the costs associated with its maintenance and care continue to skyrocket, hundreds of billions of dollars have been thrown at curative research and the development of technologies and therapies to reduce those costly complications of poorly-managed diabetes. What is even more striking, is that despite all of the funding, which is estimated at about 1 billion dollars in 2016 alone, 15 million of the 30 million diagnosed do not meet even the basic health outcome goals set forth by the American Diabetes Association (NCQA, 2007).

On November 22, 2016, the American Diabetes Association released a position statement to address the staggering rate of sub-optimal health outcomes in the diabetic population. They argue that diabetes "management cannot be successful unless lifestyle and emotional status of the individual is taken into consideration" (Young-Hyman et al., 2016, p. 2137). The position statement, geared toward providers, pushes for a more complex plan for diabetes care and treatment. It urges practitioners to focus on the psychosocial elements of diabetes in their practice. I'm thankful to the American Diabetes Association for releasing this pivotal position statement. They are the first major diabetes organization in the United States to do so. With that said, addressing solely providers does not go far enough. Because research on the psychosocial elements of diabetes has only gone so far as to demonstrate that there is a substantial unmet need within the

diabetic population, solution-based treatment plans have yet to be developed. The American Diabetes Association is going to begin training providers to identify diabetes-related psychosocial problems in their patients, but because there are no evidence-based treatments specific to diabetes, their training will stop there. If providers are able to identify but not treat a psychosocial problem, the problem persists. People with diabetes will continue to not get the things they need to be healthy. There has been a palpable scarcity of funding for psychosocial research in the context of diabetes, and even less specifically dedicated to research on peer support.

Recognizing the overwhelming financial burden of chronic illnesses like diabetes, the House and Senate passed historic legislation: The Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (Hastert, 2003). Section 721 of the MMA established the Chronic Care Improvement Program, which sets forth coverage parameters for evidence-based services that aim to improve health outcomes for beneficiaries with diabetes, cardiovascular issues, and pulmonary disease (Hastert, 2003). Under this section, services like the UnConference could qualify. However, because their reach does not meet the required impact goal of 10,000 people, it is excluded. Requiring services to cater to such a large number of people using the same programmatic features, is using a one-size-fits-all model, which directly counters the overall goal of section 721. If we can move this policy slightly to begin reimbursing for smaller impact services, we might make headway in reducing the national expenditure of diabetes.

The Illinois Diabetes State Plan 2013-2018 put forth an action plan which includes collaborating with communities to “nurture and support collaborative partnerships to

leverage the reach of diabetes programs” and to “Identify and implement environmental change policies to promote healthy lifestyle behaviors and self-management of diabetes” (IDPH, 2014, p. 27). The problem with these suggestions is they are too broad; so broad, in fact, that they will likely lead to no action at all. The plan also aims to “increase community educational opportunities to support self-management skills” (IDPH, 2014,30). While peer support services could tackle this, it has yet to be an examined strategy despite academic research demonstrating its effectiveness (Heisler, Vijan, Makki, & Piette, 2010).

Lastly, a strategy the Illinois Diabetes State Plan puts forth is to “Enhance the ability of state and local providers to establish a reimbursement mechanism for implementation of evidence-based interventions” (IDPH, 2014, p. 31). Two of the action items which follow from that are: 1) “Support new and/or enhanced models of diabetes self-management education (DSME) reimbursement to facilitate health care coordination and reduce disparities in cost and quality of care for individuals with third party providers”; and 2) collaborate with ADA and The American Association of Diabetes Educators to research funding opportunities to fund future DSME locations within diabetes high prevalence areas” (IDPH, 2014, p. 31).

B. Rationale for the Present Study

Work in diabetes care and treatment has a long way to go, and deserves examination beyond HbA1c values and outcomes. This is why it is so important to begin shifting the focus of diabetes research toward psychosocial interventions, therapies, programs, and services. Given the complex nature of diabetes, and evidence demonstrating the development of psychosocial problems resulting from it (such as

diabetes distress, anxiety, disordered eating), we need this shift to lean toward solution-based research. We need to look for and test a multitude of programs and supports with the potential to reduce the psychosocial burden of diabetes. If we can identify solutions to the psychosocial problems, we will be able to live in a country where a higher percentage of people with diabetes meet basic health outcome goals (Young-Hyman et al., 2016). Perhaps we can even live in a country where people with diabetes are able to thrive just as any other American would.

We have to start creating a system of care that provides what is needed, and pays providers of that care adequately. Through this, albeit unfunded research, I am a part of the turn I suggest. However, I also believe we can do this by pivoting the research priorities at organizations like the National Institute for Diabetes and Digestive and Kidney Disease toward solution-based psychosocial therapies. There are several community organizations like the Diabetes Collective Inc., DiabetesSisters, Diabetes Hands Foundation, and College Diabetes Network, who have generated and continue to provide psychosocial services to people with diabetes in the U.S. Their collective service-base is in the millions. Leaders of these organizations, namely, Christel Marchand-Aprigliano, Anna Norton, Gene Kuntz, and Christina Roth respectively, are eager to partner with researchers examining psychosocial problems. The capacity is there. The community is willing and able.

We must make this shift because diabetes is not the thing your family member doesn't take care of. It is the thing they need help with. Diabetes is only a killer when we fail to discover alternative therapies and supports for those impacted by it. Diabetes is not a disease easily managed. It is a complicated, messy chronic illness that interferes in

every life experience. We have a responsibility to discover innovative interventions and therapies for the 15 million people living with diabetes in the United States, myself included, whom are being failed by the current medical system despite everyone's best efforts. We have a responsibility to extend our research beyond the bounds of finger sticks, injections, and the like. We have a responsibility to generate the evidence-based research needed to adequately train providers to move beyond identification of a problem and toward the delivery of a solution. The National Institute of Diabetes and Digestive and Kidney Disease, as a generator of knowledge, has a responsibility to field diabetes-specific psychosocial research. The present research study will only go so far, much more is needed.

C. **Peer Support: The Missing Link**

Today, the largest source of peer support for people with diabetes exists online (Hilliard et al., 2015). To illustrate, a google search of "Diabetes Online Support" yields approximately 144 million results. Advocates and bloggers who create and sustain a space for support online call it, the Diabetes Online Community (DOC). Major social media sites such as FaceBook, Twitter, and Tumblr house many DOC dialogues. However, entire user-generated community networks dedicated to people with diabetes remain buzzing with peer support, such as TuDiabetes (and for Spanish speakers, EsTuDiabetes), Glu, DiabetesSisters, Diabetic Connect, Children with Diabetes, Diabetes Daily, College Diabetes Network, etc. (Collins & Lewis, 2013). Searchable online, the DOC and its members can be found using #dsma, #doc, #diabeticprobs, #dblogweek, #OurD, #IWishPeopleKnewThatDiabetes, #WalkWithD, and #T1D among others. Despite the DOC being the largest source of peer support, its proponents have no government

service funding. This means that peer support is so vital to persons with diabetes that they create and maintain the DOC in their spare time.

Even though the DOC is a means of accessing peer support at any time, anywhere in the world, some advocates, such as Karen Graffeo, have expressed a need for in-person peer support. She explains, “I love the DOC and am so grateful to be able to connect online any time day or night. But there is something crazy special about being in the same room, talking face to face, and hugging it out” (Graffeo, 2014, p. 3). Graffeo is not alone in this sentiment. After many other diabetes advocates who contribute to the DOC mimicked Graffeo’s thought, an entire conference was designed to address the critical unmet need of peer support for people with diabetes. Spearheaded by advocate and blogger, Christel Marchand Aprigliano, the Diabetes UnConference, thus, was born.

However, services generated within and provided solely by members of the diabetes community have not been studied for efficacy and effectiveness. Peer support has been linked with improvements in several health outcomes, however, most studies have measured the impact of peer-support interventions designed and run by clinicians and providers. Peers are extensively trained and monitored, often creating a hierarchy between peers. If these services and the people at them continue to go unstudied, their value will never be recognized by providers and funders.

V. PEER SUPPORT IN DIABETES LITERATURE

Studies have shown that peer support programming, regardless of method of delivery (e.g., in-person, online, over the phone), can reduce HbA1c (Lorig et al., 2010), reduce frequencies of both hypoglycemia and hyperglycemia (Lorig, Ritter, Villa & Piette, 2008), increase levels of physical activity (Klug, 2008), significantly increase frequency of glucose monitoring (Keyserling et al., 2002), increase diabetes-related knowledge (Baksi et al., 2008), increase perceived social support (Heisler et al., 2010), reduce diabetes-related distress and depression (de Vries et al., 2014; Glasgow et al., 2003), and improve diabetes-related self-efficacy (Lorig et al., 2010).

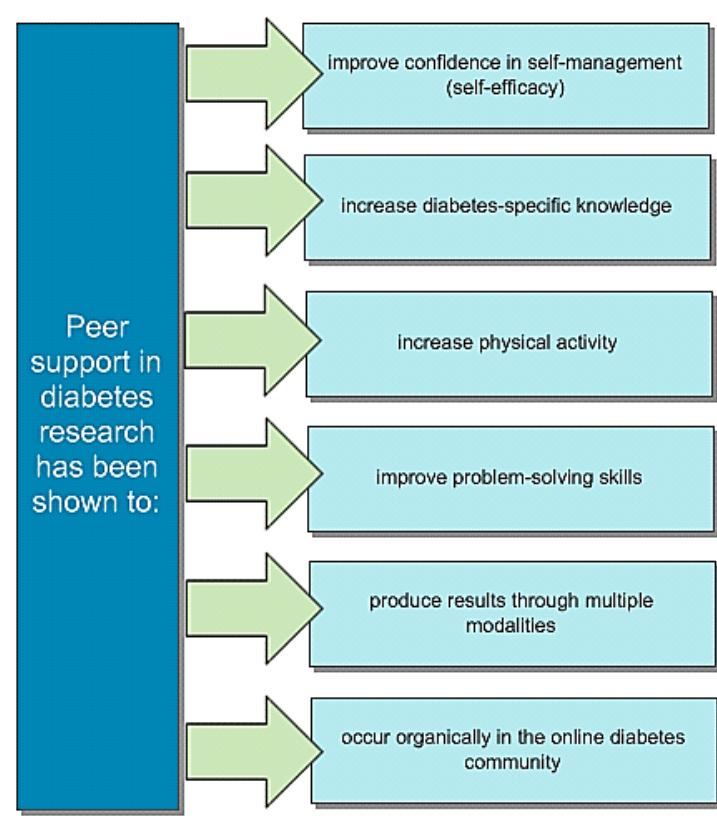


Figure 3. Summary of peer support impacts

Peer support, used synonymously in the literature with social support, has been theorized to produce improved outcomes based on the theory of social capital and network building (Joensen, Filges, & Willaing, 2016). According to this theory, a person's social capital is fluid and changes based on connections, actual or virtual, with other individuals and groups (Putnam, 1995). Social capital refers to the benefits one receives from membership in and shared values with others in groups. When a person's social capital is high, they rate themselves as healthier overall (Goodall & Halford, 1991). Thus, the literature suggests that the primary value of peer support is the potential for increases in a person's social capital. Alternative theories are present in the literature, though none as dominant (van Dam, Van der Horst, Van den Borne, Ryckman, & Crebolder, 2003). Some alternative theories include: the development of coping strategies, reinforcing help-seeking behaviors, promoting social comparisons, and aiding in the boosting of self-esteem (Dennis, 2003).

Health communities beyond diabetes have seen success in the training and positioning of community health workers to support fellow patients (Balcazar et al., 2011). Similarly, Kate Lorig's work in self-management programs for diabetes showed that programs delivered by peers were show statistically significant improvements in health status indicators and health behaviors – self-efficacy among them (Lorig et al., 2010).

Research in diabetes and peer support has also sought to differentiate between various types of support. The three most common types found in diabetes peer support, according to one systematic review, are 1) emotional support – expressions of care and reassurance without criticism; 2) informational support – problem solving with through

knowledge sharing; and 3) appraisal support – process-oriented self-evaluation tools for motivation and encouragement (Dale, Williams, & Bowyer, 2012).

Though diabetes peer support research has been limited overall in terms of sample size and frequency, several models of peer support delivery have been analyzed. It is important to note that only provider/clinician generated programs and services have been examined. In other words, research has yet to be published that analyzes the effectiveness of community-generated programs and services. Community-generated programs and services that exist to address the unmet psychosocial needs of people with diabetes –like those by non-profit organizations such as The Diabetes Collective, The Diabetes Hands Foundation, DiabetesSisters, College Diabetes Network, and We Are Diabetes – have been involved in research projects before. Figure 4 is a summary of one of the gaps in research on peer support. The need for research measuring the impact of community generated programs and services is highlighted.

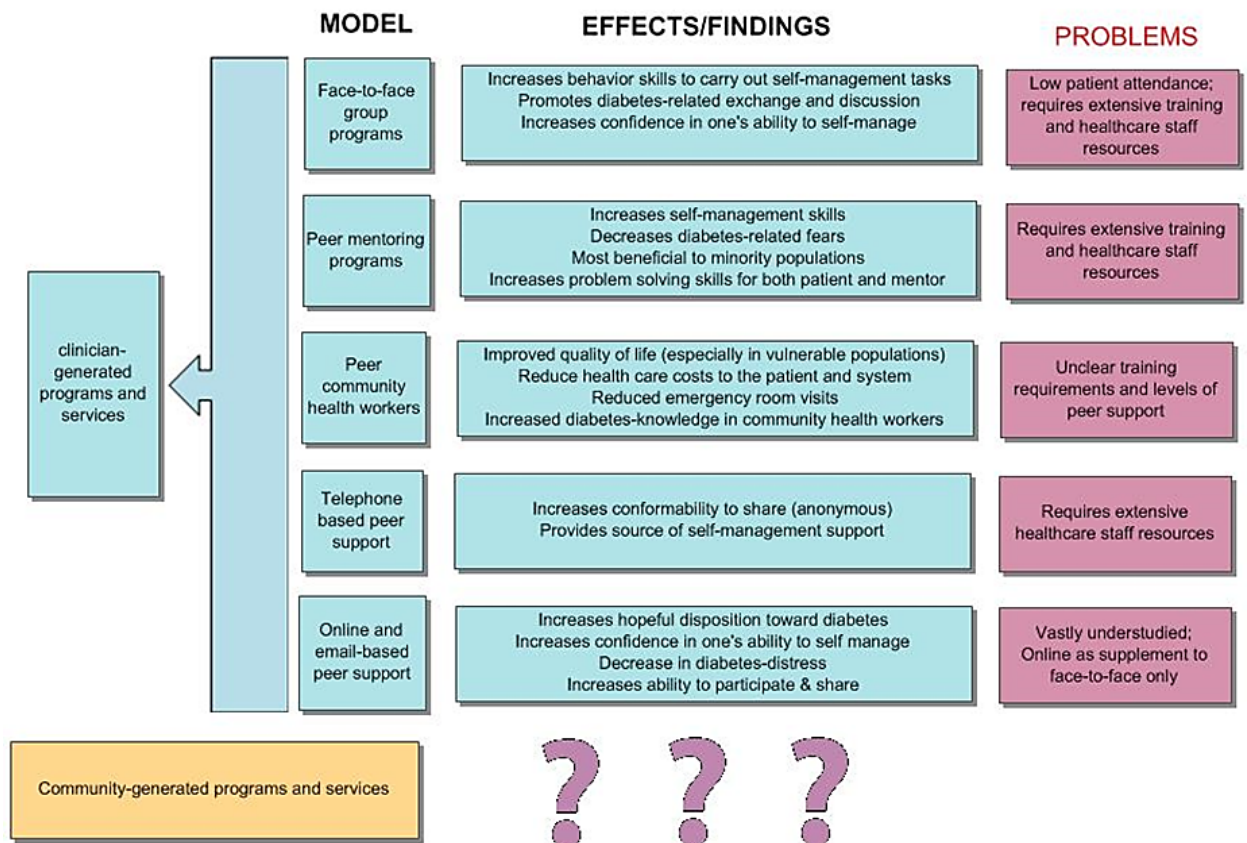


Figure 4: Summary of peer support models, effects, and problems

With that said, some of the aforementioned diabetes non-profit groups do partner with research teams. Notably, DiabetesSisters is currently involved in a research project funded by the Patient-Centered Research Institute to assess the effectiveness of an online forum replica of their online peer support platform. However, aside from the DiabetesSisters study currently being conducted, no other research project has examined the services provided by the organization itself. This is particularly important when considering the fact that the majority of problems associated with the peer support modalities researched thus far revolve around the need for extensive staff resources. If

research on peer support were to start with an organization with the capacity to continue providing a service, less staff and facility resources would be needed. This is but one possible avenue for research on peer support.

Another issue concerning the modalities of peer support covered in the literature is a lack of accessibility to patients. Face to face groups, while most beneficial in terms of outcomes, had the highest rates of attrition (Dale et al., 2012). Patients stop attending meetings when they conflict with other life activities. Cost barriers to participate have also been a recorded problem (Rabi et al., 2006).

Compounding the importance of this issue is the influence of income on access to medical care and support. The graph below demonstrates the impact of income on whom parents go to when their child with diabetes encounters a diabetes-related problem. Lower income parents tend toward family members or personal knowledge to help their children (Walker, Schatz, Johnson, Silverstein, & Rohrs, 2015). Higher income parents overwhelmingly seek medical services. This could be occurring because of a lack of insurance, lack of time to schedule and attend appointments, etc.

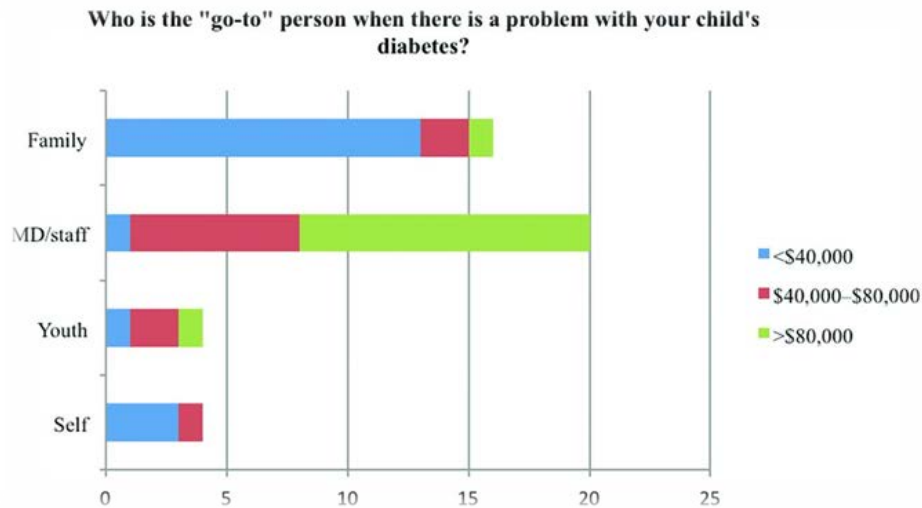


Figure 5: Impact of income on support seeking, source: Walker et al., 2015

If the only peer support interventions being examined are housed in clinical settings and facilitated by healthcare providers and thus only reach diabetics who have the time and income to seek medical help in the face of a diabetes-related problems, a greater disparity between high and low income families is produced.

The Center for Disease Control (CDC) sets forth coverage parameters for major insurance providers, such as Medicaid. Today, the strategies for successful diabetes management sanctioned by the CDC revolve around exercise, nutrition, and healthcare visits. While these things are important for successful diabetes management, they fail to address any kind of non-medical need experienced people living with diabetes. The psychosocial burdens are given no weight by the CDC, and thus are not addressed by payers. All peer support endeavors are self-funded.

Peer support should be accessible to underprivileged populations. Only those financially able to attend peer- support events like the UnConference, or those who can give enough time before or after work get access to resources like the DOC, currently have access. In other words, only those with higher socioeconomic status are granted access.

This is a huge problem because diabetes is most prevalent among low income populations (Rabi et al., 2006). So, the great majority of people with diabetes are without access to the peer support so many advocates have found to be vital for successful self-care and diabetes management. This lack of access creates a disparity between people with diabetes of privilege and people with diabetes without.

Gaps in the literature revolve around two themes. First, peer support has not yet been defined by persons with diabetes. What does peer support mean to them and how does it differ from the support they may receive from loved ones who do not live with diabetes? Do patients define peer support similarly to health care providers? Second, what does peer support look like when generated from within the community with no health care provider intervention? Are self-generated and community-governed peer support services as effective as those facilitated by providers?

VI. METHODOLOGY

This qualitative research study used a naturalistic inquiry design strategy paired with methodology borrowed from the participatory action research (PAR) canon. By combining focus groups, brief open-ended interviewing, and member checking, this study captured rich qualitative data (Krefting, 1991). Participants and non-participating community members were integrated into the question formulation, data collection, and data analysis phases of research. In addition, ethnographic methods were used throughout this study. At each diabetes event I attended which provided opportunities for peer support, I recorded field notes through participant observation (Emerson, Fretz, & Shaw, 2011).

The present study design most closely echoes the PAR framework and approach. PAR was developed in response to and as a departure from conventional research (Cornwall & Jewkes, 1995). Conventional research, which is principally contractual, is often contested by PAR researchers on the basis that it reproduces the power structure between researcher and subject, fails to encourage mutual learning, and is conducted by, for, and in the interest of the institutions and researchers who initiate it (Cornwall & Jewkes, 1995). By countering the aforementioned, PAR emerged as a framework capable of disrupting the post-positivist approach health research had thus been dominated by (Wallerstein & Duran, 2008). PAR bridges the gap between theory and practice and rejects the post positivist belief that “researchers study an objective world separate from the meanings understood by participants as they act in their world” (Wallerstein & Duran, 2008,p. 27). When using PAR methods, researchers acts a co-equals with participants to uncover and contextualize the complexities of lived-experience. Through this process,

researcher and participant roles overlap for the sake of action, and for the sake of emancipating oppressed populations through the production of knowledge (Oliver, 1992).

While there is an overarching set of PAR principles: fostering collaboration between communities and research teams, changing and studying discourse and practice, illuminating and encouraging the complexification of social problems, and taking action in local and systems settings, the prioritization of said principles varies depending upon the context in which PAR is engaged (McTaggart, 1991). When collaborating with disabled populations, for example, researchers have argued that the *primary* aim must be to understand the problem disabled people themselves articulate and define (Balcazar, 1998). Doing so recognizes community members as valued change agents and empowers them to continue expanding their involvement in community action, which is particularly central for this historically marginalized group (Buettgens, Dubay, & Kenney, 2016). Further, by working with community members during the question formulation phase of the research, the study can move toward addressing a reality more authentic to community members' experience (Balcazar, 1998). The prioritization of PAR principles in the present study most closely aligns with those focusing on other disabled populations and communities.

The diabetes community, as previously detailed, is saturated by stigma and life-style-based discrimination (Hopper, 1981). Adults with diabetes have been spoken over and spoken for at the research, policy, and systems levels. As a member of the diabetes community, I am awake to the challenges the community faces particularly in the production of knowledge. Elements of PAR were used to present a more authentic voicing

of the problems in diabetes care, to build capacity within the community, and to bridge the gap between theory and practice that pervades the diabetes space.

A. **Research Questions**

There are three research questions prompting this study. These questions attempt to bridge the gap in the current literature on diabetes and peer support.

1. How do diabetes advocates *describe* peer support?
2. What factors and qualities are *built into* a good peer support experience?
3. What would diabetes-specific peer support look like best delivered?

B. **Study Goals**

The goal of this research is three-fold. First, to develop a functional definition of peer support as described by people with diabetes. Second, to build a conceptual model of peer support as it would be best delivered to people with diabetes. And third, to situate findings and the built model within the current context and landscape of diabetes care in the United States.

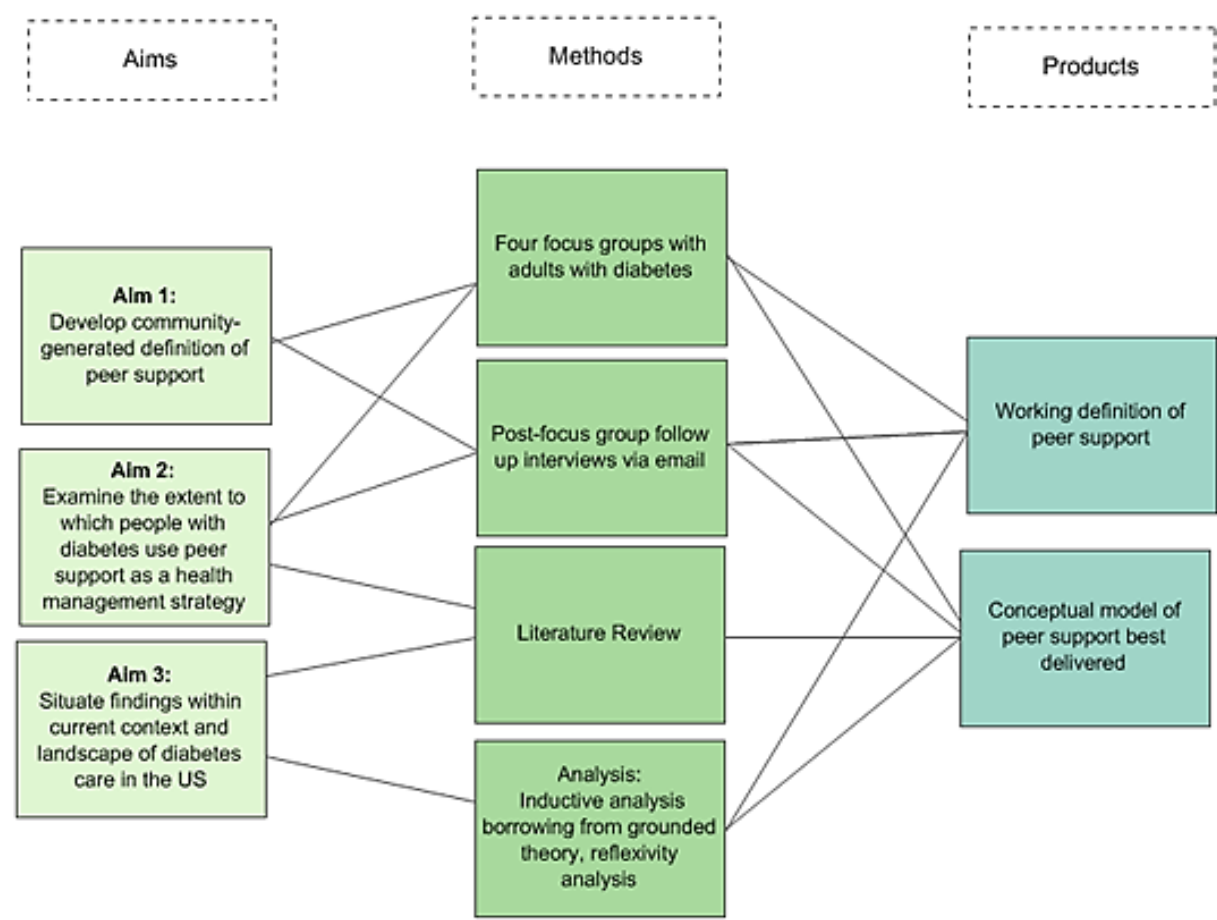


Figure 6: Summary of research process

The endpoints of this research are as follows.

Primary Endpoints:

1. To develop a working definition of peer support as defined by people living with diabetes;
2. To identify some key elements of peer support as prioritized by people with diabetes;
3. To examine the extent to which people with diabetes are using social supports or peer support as a health management strategy; and

4. To conceptualize what type of peer/social learning would be most beneficial to people with diabetes over time.

Secondary Endpoints:

1. To examine existing models, frameworks or promising practice demonstration projects that use peer mentoring as a health maintenance strategy;
2. To analyze how peer support could be integrated into existing community-based services to serve people with diabetes; and
3. To analyze what systems changes are needed to evaluate the long-term impact of community-governed peer support services for people with diabetes.

C. Participants and Recruitment

In total, 36 participants were enrolled in this study. Eight community members contributed research questions before the official data collection began. Because their voices are present in this study, they are counted as participants. Of the 8 who contributed research questions, three also participated in the focus groups. Thus, 41 total community members took part in this research. Four focus groups were held: two at the Diabetes UnConference in Las Vegas, March 13-14, 2016; and one at the Diabetes UnConference in Atlantic City, September 10, 2016, and one at the DiabetesSisters Leadership Institute October 2, 2016. An electronic flyer was distributed to registered attendees of the Diabetes UnConferences in Las Vegas and Atlantic City one week prior to the events via newsletter by conference organizer, Christel Marchand-Aprigliano. An electronic flyer was distributed to registered attendees of the DiabetesSisters Leadership Institute three weeks prior to the event via newsletter by CEO, Anna Norton. A copy of the flyer can be found in Appendix A. After the flyers were distributed, I was contacted via telephone by

five potential participants for the first UnConference, zero for the second UnConference, and two for the DiabetesSisters event. All seven were taken through the 15-minute phone screening, were deemed eligible, and were enrolled in the study. Because of the low enrollment before all events, I was offered a spot at the registration desk to continue recruitment. I recruited twelve participants (making 17 total) for focus group participation at the first UnConference, thirteen at the second UnConference (making 13 total), and four at the DiabetesSisters event (making six total). One participant was not accepted for the study because they had not had diabetes for five or more years.

Every participant attended the diabetes event in which the research took place on their own volition. They paid money out of pocket to be there. The adults who attend these events are not run of the mill patients with diabetes. They are advocates who actively participated in peer support on a regular basis. They were selected as a participant base because they are knowledgeable and have extensive experience with such services.

During the consent process, each participant was invited to opt-in for continued participation in the study. The purpose for follow-up was a two-fold. First, it was a precautionary measure in case anything said during the focus group/workshop needed elaboration or clarification. Second, to maintain a participatory research approach, participants were offered to have the option of taking part in the data analysis process. While 35 of the 36 enrolled participants opted-in for continued participation, only ten were contacted post focus group. Of the ten, two did not respond, five agreed to a mini follow-up interview, and three agreed to provide feedback on developing themes from the focus group. A summary of all participation activities with the number of participants and community members involved is presented.

Participation Activities (Formal and Informal)

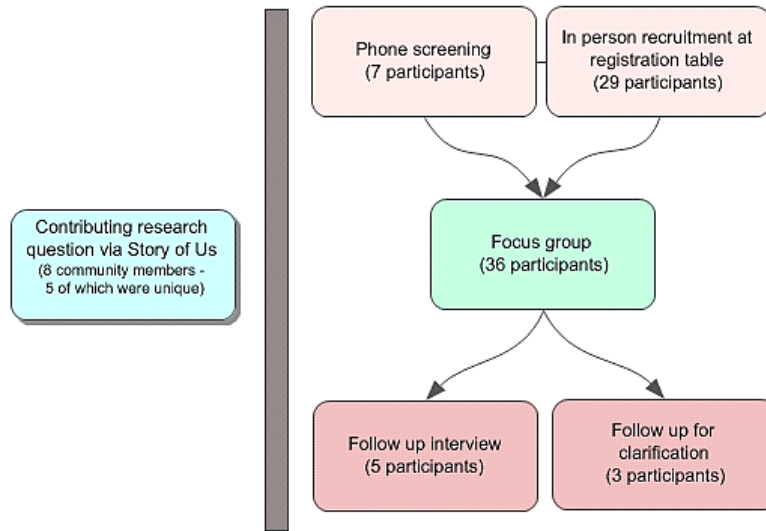


Figure 7: Participation activity visual

D. Procedures Using Participatory Action Research Principles

The first procedure involved in this study was an unofficial one. It was conducted before my studies as a doctoral student began. When I learned I was accepted to graduate school, I created a website called “The Story of Us,” which solicited community feedback for the development of the research question. Though informal, this process initiated contact between community members and my scholarship (Torre, Fine, Stoudt, & Fox, 2012). A call for input was broadcasted via Twitter, Facebook, and my own community blog and corresponding website. Appendix A and Appendix B show screenshots of the website through which community members submitted their initial suggestions for inquiry. All identifiable information has been distorted, and the website has been archived for the sake of privacy. Further, community members who had both contributed a question and who were in attendance at the first Diabetes Unconference

assisted with question revisions and prioritization before the focus groups took place. This process utilized reflexivity and empowerment principles to encourage community members to take ownership over issues that matter to them (Fawcett et al., 1995). Thus, the research question posed above was crafted to meet the suggestions of and feedback from the community. This initial participatory process was echoed throughout this study using varying levels of participation in order to meet each person where they are at (Conder, Milner, & Mirfin-Vietch, 2011).

i. **Focus groups**

The use of focus groups was chosen as a method to elicit group ideas and interaction around the topic of peer support (Morgan, 1996). The focus group process used throughout this study was modeled after Krueger and Casey's (2009) formulation. Before each focus group started, ground rules for equitable participation were established and interaction between participants was noted throughout (Krueger & Casey, 2009). The focus group questions were developed in coordination with one senior faculty member and two PhD student peers and changed from focus group to focus group. The following focus group questions were used in the first two focus groups:

- Question 1: What does peer support mean to you?
- Question 2: When you seek peer support, what are you looking for? What does it look like? What form does it take?
- Question 3: Will you tell me about a time when you had all the support you needed?
- Question 4: Dream with me, imagine every person with diabetes who wanted peer it had access to peer support, what would that look like?

- Question 5: What can you do to bring peer support resources available in the diabetes community to more people living with diabetes?

Focus group questions were modified after the first two groups to account for feedback from participants. Participants made the following suggestions: 1) make question two less suggestive leaving it open for when people *find* peer support but aren't looking for it; 2) find a place to describe different roles in peer support; 3) put a dollar amount on question four to make it more digestible; and 4) take out question five. By including participants in the reformulation of focus group questions, ownership of every aspect of the research process becomes shared, a principle of PAR (Jason, Keys, & Suarez-Balcazar, 2004). The following set of focus group questions were used in the third and fourth focus groups:

- Question 1: When you hear the words "peer-support" what comes to mind?
- Question 2: Describe the role you play in peer-support.
- Question 3: How would you describe the type of support you get from peers living with diabetes?
- Question 4: Tell me about a time when you felt completely supported in your diabetes management?
- Question 5: Imagine a generous donor decided to put 10 billion dollars toward peer-support for people with diabetes. What would that look like? What could we do?
- BONUS Question: What else would you like to tell me about your experience with peer-support?

ii. **Follow-up mini interviews**

After the first round of data analysis was done, ten participants were contacted for feedback and member checking. Sharing data that has been partially translated into thematic categories ensures that participant's viewpoints have been accurately recorded and interpreted (Krefting, 1991). The ten participants whom were selected for continued participation were chosen intentionally based on their insights shared during the focus group and on stark differences from other group members – participants with perspectives that depart from the group offer opportunities to capture the multiple realities of lived-experience. This process also increases rigor to the study (Krefting, 1991).

After lurking emerged as a theme throughout the data, six participants who opted in were emailed the following set of four questions:

- Question 1: What is involved in lurking?
- Question 2: Who is a lurker and who is not? Do these roles change (i.e., are they fixed or fluid)?
- Question 3: In what ways does lurking matter in peer-support, if at all? What is its value?
- Question 4: Do you think lurking happens in person at events like the Diabetes UnConference? Or is lurking unique to the online context? Explain.

Five of the six participants responded to the questions via email. Member checking was also done in a less formal capacity. When attending another diabetes conference, MasterLab hosted by the Diabetes Hands Foundation, two participants were approached separately and asked for feedback on the potential payment of peer support work, another

emerging theme. Lastly, two participants were contacted via text message about the negative connotation attached to the term “support group.” One of the two contacted via text responded. By reaching out to members using multiple platforms and contexts, the likelihood of response increased and varied (Morse, Barrett, Mayan, Olsen, & Spiers, 2002). Doing so also allowed the design to remain aligned with the PAR principle of not disrupting the community by meeting them where and as they are (Conder et al., 2011).

E. **Data Analysis**

The focus group data was analyzed using a combination of inductive analysis, framework analysis, and grounded theory techniques. Data analysis began before the first focus group and continued throughout data collection (Butler, 2000). Key terms and practices specific to the diabetes population were inventoried and defined, and then used to develop a coding system for analysis (Patton, 2015). Using indigenous concept analysis, a working definition of peer support was generated and from that definition a conceptual model of a high-impact peer support service for people with diabetes was developed. The process of heuristic inquiry in which the researcher applies phenomenological analysis to one's own experience was used throughout (Patton, 2015).

As mentioned prior, the data-analysis process was participatory. Three of the focus group participants who opted-in to continue their participation provided feedback and more insight into primary analysis findings. The results that follow incorporate member checking and mini-interview feedback from participants who continued participation past the focus group.

VII. RESULTS

This study examined the lived experiences of diabetes advocates who engage in peer support services and events. This chapter contains a description of the themes and categories that emerged from all four focus groups and the eight continued participation follow-ups conducted as a part of this study. Each focus group recording was transcribed, reviewed, and analyzed multiple times before grouping the data into thematic categories (Patton, 2015). I went through this process with each transcript one by one. This allowed the categories from previously analyzed transcripts guide the thematic category formation of the following.

Because the purpose of this study was to understand the lived-experience with and using peer support in the diabetes space, data analysis focused on finding themes and patterns that would build a picture of and highlight the experiences of diabetes advocates who both use and create peer support resources. This chapter presents data from the study to answer the three research questions guiding this investigation:

1. How do diabetes advocates *describe* peer support?
2. What factors and qualities are *built into* a good peer support experience?
3. What would diabetes-specific peer support look like best delivered?

Advocates explicitly described peer support as associated with *shared experience*, *trust*, *empathy*, *problem solving and solution generation*, and *okayness with disease state*. To some, peer support (centered on knowledge acquisition) was functionally more results-oriented, while for others, peer support (centered on emotional acknowledgement exchange) was functionally more process-oriented. Thus, peer support seemed to be

located at the intersection of results and process related experiences based on shared lived-experience.

Advocates identified three roles as vital to the peer support process: supporter, supported, and observer (referred to henceforth as lurker). In every group, these three roles were described as fluid. A person's status or role in the exchange of peer support changes depending on the context and modality of the exchange. It is to be noted, that 'exchange' is used here to denote the process of peer support taking place, rather than as a transaction as the term implies. Advocates did not identify the peer support process as *transactional*, but rather as *relational*.

Though not identified as a theme which would answer the research questions, one thread did follow through every focus group. It focused on setting. Though the modality (the way one engages with peer support) did not seem to influence the nature of peer support, the setting (the location within which one engages in peer support) did. Out of the 36 participants who participated in a focus group, 35 discussed peer support located in medical or clinical settings as being ineffective. Some argued that clinic-based peer support groups tend to focus on education rather than support, and is usually led by a healthcare professional who is not a 'peer'. The following quotes demonstrate these standpoints:

I see peer support as being functionally different than anything I get from the doctor's or the educator's office insofar as there's something to be gained from getting something from a person who's gone through the actual experience themselves that you can't learn in the textbook. (Ivan, Group 3)

Similarly, another advocate from the same group discussed clinical settings as judgement-laden. She shared that a provider working from textbooks and guidelines lacks the complex approach she gets through peer interaction:

Peer support to me means non-judgment from my peers relative to the judgment I get from traditional medical, uh, situations and, uh, um, brainstorming, problem-solving and challenges with others that also have it. Telling what works for you is different than the doctor telling me what the [American Diabetes Association] says I'm supposed to be doing. (Micki, Group 3)

When probed to explain further, Micki described the peer support experiences she had been through in clinical settings. She discussed the difference between clinic-based experiences and community-based ones. She said:

I'd initially gone to several hospital-based support groups and, uh, where one, we were lectured ... well, in most of them we were lectured at by the nurse or the CDE and it was sort of more about their position of authority in disseminating what they wanted to tell us versus, um, getting any feedback, um, from the participants who were there with diabetes. Uh, and that is a ... almost the antithesis to what I get out of peer-run groups, um, even if the ... the [Certified Diabetes Educator] has diabetes, I call that peer, but when somebody thinks they know what they're supposed to tell you, it's very judgmental, and I get very non-judgmental feedback from peer groups, and I think of them as much more positive and uplifting, um, and a greater sense of reward and almost happiness or mastery, um, that we've done something together that we ... we didn't ask for the diabetes, but we are

accomplishing something and it's not top-down telling us about compliance and what you should do. It's about what we can do. (Micki, Group 3)

Consistent with Micki's observation of a power differential between patient and provider, another advocate defined peer support as only occurring between non-medical persons. She said:

I'll start, peer-support is when the person that you are discussing or asking for help with or they are asking for help or sharing experiences you guys have the same condition, the other person is not a doctor or a nurse, or not a medical professional.

Two equals. (Beth, Group 1)

Fundamentally, peer support to Beth is devoid of a power differential. Though not discussions directly identified it as Micki and Beth did, all did connect it with a form of unwanted education. An advocate from group 2 shares:

I think it's really important um, to me, and moving forward, to acknowledge, or clarify for anyone else, um, peer support to me is not education, and there's [crosstalk 00:31:55] far too many experiences showing up, and often, but not always, by a healthcare professional doing the support group for people with diabetes, and it ends up being, "Lets teach you about card counting. (Ruby, Group 2)

To reiterate, though not identified as a theme which could answer the research questions, noting this thread was important. To the advocates participating, support groups not only do not work in clinical settings, but are actively avoided on the basis that they do not provide what they claim to offer.

The remainder of this chapter outlines thematic categories which do get at answering the research questions of investigation. Themes are divided between process-oriented and results-oriented responses. There was significant overlap between and within the two, however. These categories were selected based on previous literature in diabetes peer support. They are neither fixed nor rigid.

A. **Process-Oriented Components of Peer Support**

This category of themes refers to the components of peer support which describe and modify the *process* through which one goes, rather than the destination in which one will end up. When the generation and temporal nature of motivation to act was theorized and examined through a process-oriented perspective, it was found that actors are often solely motivated by “the journey” (Dörnyei, 2000). The following themes highlight the process of experiencing peer support and the benefits advocates have gained from it: shared experience, trust, and empathy; okayness with disease state; and belonging and not alone. Each theme is described below.

i. **Shared experience, empathy, and trust**

Advocates acknowledged the interrelation of three interpersonal dynamics as vital to peer support functioning well: having shared experience, approaching one other with empathy, and establishing trust. Several advocates defined peer support through shared experience and similarity. When prompted with the question, “When you hear peer support what comes to mind?” the following short responses were shared:

Just having a common understanding, having a peer, whether it is related to a medical condition or anything in life, it is having that, kind of, equal, I guess. (August, Group 1)

Um, a group of people who all uh, have a commonality of some sort that are helping each other make it through life. Wade through the shit.

(Ginger, Group 2)

...people in similar circumstances. (George, Group 3)

...a group of two or more with similar concerns of similar background.

(Amberly, Group 4)

Others like me. (Sebrina, Group 4)

Friendship, comradery, motivation, similar concerns, safety net. (Carla, Group 4)

Taken together, these comments demonstrate that the connection through shared experience is important to peer support within the diabetes space.

Only advocates in Group 2 explicitly discussed *trust* as a mechanism of peer support, though advocates in other groups explained trust as one result of connection through shared experience. Nannete is one advocate who came to trust peers with diabetes after feeling isolated for most of her life. She explains:

I spent most of my first 30-some odd years as a diabetic alone because I didn't know anyone else who was a diabetic and it was always very, very difficult for me to reach out to anybody, even my closest friends, because they just really didn't get it and the last three years, I found enormous support and friends that I can trust with so many things that I haven't been able to trust people I've known for 40 years with because they get it. They understand what I'm living with. (Nannete, Group 3)

Similar to Nannete, Theresa suggested trust as necessary precursor to sharing. She also explained that 'hearing' others depends on developed trust. She said:

And also evokes a trust that, that makes me able to share with them, and also take in what they may share with me. (Theresa, Group 2)

Gary, also in Theresa's group defined peer support being heavily reliant on the formation of trust, "trust is a big part of, of peer support" (Gary, Group 2). Despite mention of trust several times throughout the discussion in group two, many aspects remain unclear. For example, the directionality of trust to shared experience and empathy was not explored in the group discussions. Further research into this may be revealing.

Empathy was discussed in each of the four focus groups as a result of shared live-experiences which are challenging and difficult. Advocates have lived the ups and downs of diabetes and deeply feel the discomforts and inconveniences of life lived this way. One advocate described it as pain. She explained:

Peer is a support system and it is on an intellectual and on an empathetic basis, not sympathy, so much, but empathy. I learned a long time ago as far as a definition that not specifically about sympathy, cause sympathy is sympathy, but empathy is your pain in my heart. (Irene, Group 1)

For an advocate in a different group, empathy is the key to peer support. She described it as a requirement and as a way to differentiate peer support from other types of support. She said:

For me, the, the most important aspect of peer support is empathy. It's, it's understanding, it's truly being able to be in your shoes, as compared to sympathy where there's, you can feel for someone, but you don't really understand. And so that's a component that's different than other types of support. (Holly, Group 2)

The combination of trust, empathy, and shared experience seems to underlie peer support overall. Advocates describe the connection through illness as a powerful one which can bond people quickly.

ii. **Okayness with disease state**

Okayness with disease state was explained by many advocates as a washing sense of relief. Being okay with the fact that one is not 'normal' and that one requires medicine, shots, and finger sticks to survive is described as a difficult state to maintain. Like burnout, okayness or acceptability of living with diabetes seemed cyclical for advocates. Peer support was mentioned as one thing that helped them cycle back into disease acceptance. In Group 2, one advocate's explanation of this brought the group together in full nods. Ruby said:

And it is this relief, like I just feel my body going, Okay. It's okay. Here we are.

(Ruby, Group 2)

A fellow group member reached out for and held Ruby's hand and responded:

It's like you're immediately wrapped in care. (Amy, Group 2)

The image of being wrapped in care presented in other groups as well. Some shared stories of internal conflict and struggle over and facing the diabetes diagnosis. Some described getting burnout and giving up as a result of that internal conflict. And some shared how their outcomes had changed as a result of coming into contact with peer support. One advocates story demonstrates all of these interactions. Howard explained:

...So, I've had diabetes for 19 years and I spent 15 of those years in pretty constant burn-out, just done with it, um, like to a point that I didn't test my blood sugar for an entire year. I just didn't care. I didn't give a shit. I was done, you know? And so,

here's the lose my shit part: I feel the peer support thing saved my life. Um, 4 years ago, I ... I got engaged with peer support, finally met people who I could relate to. They weren't local people. They were new people. They were new people. Um, it ... it changed me, and then looking beyond just, you know, my experience, the ... this ... this is everything like, this is the most important thing in me. You know? Um, it's not just about ... it's not just ... I don't know. It's not just about like ... and I ... I've learned about technology that I didn't know about. Last year, at the ... at the same conference, I saw my first CGM. I talked to people. They talked about how amazing it was. I got one and three months later, my A1C went from 8.5 to 6.8. (Howard, Group 3)

iii. **Belonging, and not alone**

Advocates in Groups 2, 3, and 4 discussed decreased feelings of isolation as one result of peer support done well. Notes of relief outline this theme as it did with the previous theme addressed. Some advocates tied connection through peer support as a mental health solution. Paulette from Group 4 described her own transition from isolation to connection:

I feel like there's something to be said of mental health and feeling alone can hurt and peer support is a way to understand that you're not alone. Many of us have lived several years with diabetes and not even realized that there are people out there to connect with, and then, when you get ... when you get that peer support, you ... it's kind of a ... it's a solution to some mental health concerns. (Paulette, Group 4)

Similarly, other advocates, like Theresa from Group 2, claimed that connecting with others allowed them to destress knowing that if they had diabetes-related problems and concerns, they would know to whom they would turn. Theresa explained:

It was that sense of, "Oh. Okay. I, I found other people who get it." And it was um, very relieving when I didn't know I was stressed out about it. It was like, this sense of calmness came from now I know where to go if I have issues with this. (Theresa, Group 2)

The power in finding connection for Paulette and Theresa seemed to be described as mostly internal. However, for one advocates in Group 3, this process was unknown but visible to her friends and family. She said:

And I cannot believe that I lived for 40 ... oh, for 35 years without [peer support] and, now that I have it, I mean, people who have known me for years just cannot believe my level of happiness because I have this support. It's ... it ... it ... they just say to me, like, "What happened when you moved up north?" I said, "I don't know. The people. It's the people and the support I get from them and that's huge. (Nannete, Group 3)

Finding a sense of belonging and moving from a state of isolation to community have been noted in several research studies as beneficial to overall health (Putnam, 1995). Advocates here are described their own transitions from isolation to community as powerful and visible both internally and externally.

B. Results-Oriented Components of Peer Support

Results-oriented components refer to those which describe tangible outcomes and a take-aways as a result of peer support exchange and interaction. For some advocates,

peer support resulted in trying new technologies, therapies, tips and tricks. For some, it resulted in a decision to request a different, more supportive, doctor. Collectively, results-oriented components of peer support revolve around problem solving and solution generation, and the acquisition of actionable knowledge.

i. **Problem solving, solution generation**

According to Lexie from Group 3, peer support is all about problem solving.

When asked to define peer support she said:

I think it's, um, like a bunch of minds solving like problems. (Lexie, Group 3)

Lexie's formulation was a departure from most of her group members which described peer support as more process-oriented, relating it more to emotional support. Lexie identified herself as "*new* to the peer support scene," however, which may explain her divergence from the rest of the group. With that said, Lexie's formulation did come up in other groups.

For Groups 1 and 2, peer support interaction was described as the motivation behind taking actionable steps toward self-management improvement and therapy changes. Consider the following:

I've made more decisions about changes to my therapy based on the, a feeling of support, and feeling of knowing someone else who has made that choice, than I do actually from receiving the clinician's suggestions about what might be a, a therapy choice for me. (Amy, Group 2)

Peer-to-peer support made a big difference in my outcomes, in my ability to manage my diabetes and my ability to manage my conditions and my happiness and sort of accepting having diabetes and dealing with it. (Jack, Group 1)

Together, these two threads illuminate the difference between changes made based on the suggestions, stories, and support from peers and that from providers. Peer support, then, not only provides emotional stability and a sense of belonging to those with diabetes, but also serves as an opportunity to internalize actionable steps to improve one's health outcomes.

ii. **Knowledge acquisition**

One advocate's reflection of his experiences with peer support help to explain the difference between problem solving and solution generation and knowledge acquisition. It is inferred that the difference lies primarily in action taken or not taken as a result of acquiring the knowledge. Thomas from Group 2 described his knowledge acquisition through peer support as akin to increase awareness. He said:

There's been a lot of filling in knowledge gaps. There are things that I know, but there are many things that I was unaware of until I found it through peer support. So that's been very, very helpful, and a lot of that is something that I don't get, as good as my medical team is, I don't get from my medical team. (Thomas, Group 2)

When probed to provide an example of something he learned, Thomas said:

Uh, just simple understandings of insulin on board, combo boluses. Um, uh, the nature of some of the type 2 medications that are out there today because I'm type 1, and I don't quite understand that. Uh, the role that the FDA plays in getting things

approved or, or sending them back to uh, companies to uh, rework so that they can get approved. Those kind of things. (Thomas, Group 2)

While problem solving involves the completion or follow through on some kind of task, knowledge acquisition seems to be more centered on awareness and coming to know something. However, the difference between these two categories is less apparent than the commonalities shared, as is demonstrated in Thomas's explanation.

C. **Engagement with Peer Support: Roles**

In all four focus groups, advocates discussed the roles they play in the process and unfolding of peer support. Most explained that they are both receivers and givers of peer support. Every single advocates described the roles as flexible and fluid.

i. **Fluidity between roles**

Advocates described their state of being within peer support as neither mutually exclusive nor definite. Not only can a single person move between roles, but they can also play multiple roles simultaneously. One participant explained:

...you do play multiple roles and that's rewarding, I think, because you feel like you're contributing something, um, that you were able to get from someone else, number one. And, number two, I think we play all of these different roles, um, with our different reac ... um, interactions with people, so in some cases you're playing one role and in other cases you're on the receiving end where you're ... you're receiving help, um, and that's a pretty valuable experience for me, um, because this disease requires so much of us and being able to have the sense that you can help somebody else out with an experience that you've dealt with, uh, is rewarding. (Ivan, Group 3)

Ivan's description here plays into the complexity of living with diabetes and the sense of reward an advocate might get from serving a helper role.

I kind of see two roles, which are the supported and the supportive, and I feel like, for me and for many here, the length of time dealing with living with diabetes has prepared me to be a support ... the supportive and hopefully, through that, helping others go from supported to supportive, but that doesn't excuse my need for support, so I'm also the supported. (Howard, Group 3)

Both Howard and Ivan described two roles they have experienced directly as providers and consumers of peer support. Also, both speak to the non-linearity of peer support roles. As Howard attempts to explain his process of moving from a person in need of support to one giving support, he retracts back to needing while providing. Though each role does have distinct elements, the roles appear to follow in and out of one another.

ii. **The supported**

When discussing their experiences with being *supported* in peer interactions, advocates highlighted the lack of hierarchy involved. To be exact, they noted that there was no power differential experienced in times of need. This contrasts with literature on peer support which use mentorship and peer support interchangeably (Heisler, 2007). In mentorship interactions, there is an identifiable trained peer who is meant to guide the untrained peer. This lack of a power differential is one thing advocates explained was unique to peer support. In Group 3, advocates discussed showing up as the most necessary component of playing the role of the supported, and Group 2 discussed a similar thread. George in Group 3 described the lack of power differential in the following way:

I think it's quite fine to be a recipient of peer support as your role in peer support and that you should not feel any ... any, like ... like there's no hierarchy in peer support. It's ... you know what I mean? So, just be ... ha ... be here! (George, Group 3)

Another advocate in Group 3 immediately affirmed George's comment, and said warmly, "be here, be you" (Micki, Group 3).

In contrast, to group 2, playing the role of the supported was described as more passive, though powerful. Amy and Ruby described it as a process of allowing oneself to be swooped up mentally and emotionally. Amy explained:

I refer to it as the mother ship picks you up and you like, you know, you're like ... It, it's like all those movies where like, the alien finds out, like who their actual people are supposed to be, and there's this like, you know, like, Superman meeting his parents. And you're like, "So there are more of us?" (Amy, Group 2)

In response to Amy's explication, Ruby clarified:

And it's not just like, someone's got glucose tabs if you need them. I mean that's a, very definitely, all the technical, physical things, but, but it's also just the feeling. Like, we all know it is okay. It's all right. (Ruby, Group 2)

Again, these categories are fluid and not mutually exclusive. Though one person might be discovering they are not alone through being supported, they may also be providing support elsewhere.

iii. **The supporter**

The counterpart to 'the supported' seems to be 'the supporter'. In theory the nature of peer support is bi-directional and transactional (Embaldemiya et al., 2013).

Some advocates did explain their role in peer support this way, though the majority did not. Three advocates' whose descriptions of the supporter role as more transactional in nature are highlighted below, each of which demonstrate an aspect of the supporter role identified as needed by other members of the group. First is Maryam from Group 4. She explained to her group that her role as a supporter is akin to being a connector. She described giving support by creating bonds between others. She explained:

I host a DiabetesSisters PODS group and lead the sessions. I am, I'm a support person, giving, um, the support. I connect others to each other and I inspire them to stay connected past when we meet. (Maryam, Group 4)

While Maryam provides support through connecting people to one another, Mysty from Group 2 said she is a supporter by being there and being willing to listen. She explained that being the supporter was rewarding and worth the struggle of living with diabetes herself. She said:

You know I hated that time, it was a very rough time in my life, but being able to even help just one person deal with and be able to vent and have someone else listen made it worth it. If having diabetes, if it is shit and you don't want to deal with it, but by me having it can help one person with their diagnosis, then it has been worth it. (Mysty, Group 1)

For one advocate, being a supporter is about showing up and serving as a guide, but also about dissolving power differentials between supporters and the supported. Alice described herself as a guide through communicating with others, but ultimately brought it back to being equal to the peers she guides. Alice explained:

It is showing up at an event. It is communicating with people. It is guiding people and directing people that may want or need a direction or a direction that you see they need, so as a general, to just share when you can and how it is best for you because each of us at this table had a different experience. The year we were diagnosed, the age we were diagnosed, the type we have, and it is all about pancreases that don't work right. I mean that's, that's what it is. (Alice, Group 1)

Nannete's description of her role as a supporter was closer linked to the fluid model of peer support described by most other advocates. Nannete provided a personal take on serving as the supporter. She said that she plays that role, but not without prompting. She described:

They understand what I'm living with, and I don't even have to say to them, you know, like, "I'm low." They can just look at me and know that I'm not there. So, to me, it's ... it's huge, but I always found, as far as me being supportive, I usually wait until someone asks for it and then I can like give 250% of me, but I don't usually volunteer it. (Nannete, Group 3)

iv. **The lurker**

Unique to this study, is the explicit mention of the *observer* or *lurker* as a necessary role in the functioning of peer support. Advocates from three groups described their observation of others exchanging peer support as an active form of engagement. Only one group plainly identified it as lurking, though three referred to it as a part of the process. Some advocates questioned lurker's participation and the messages they may or may not be getting. Others described their primary role as a holder of space. Some explained that their job was to absorb and be a body in the room (virtual and in-person).

There were various thoughts about whether or not an observer could be said to be contributing agent. Many described lurking as a shy person's role, seen as a form of hiding. Many variations are explored below. The first is an interaction between several members in Group 1. Eric brought up lurkers in the context of online peer support which began a dialogue. Because they cannot be easily tracked, Eric questioned lurkers' contributions and take aways. The conversation occurred as follows.

One other thing about the peer-support network is there is you know how do we measure their value lurkers, because there are tons of lurkers. These two ladies I work with both LOVE the local group message board, but they don't ever post anything. You know, one of them is going to do the tour de cure so she is going to do that but you know she doesn't ask questions, so... (Eric, Group 1)

But so aren't lurkers the silent majority? And don't we like disregard their participation?" (Jack, Group 1)

Well they must be getting something, what are they getting? Are they getting the right message or the wrong message? Are they getting a totally different message? (Eric, Group 1)

You have to dip your toe in the water first. (August, group 1)

As a type 2, I lurk a lot. Which is good when it comes to question about technology about type 1s use because I have no experience so I should not be the one commenting on that. So that's the area that I lurk in. (Beth, Group 1)

Here, when lurking is brought up in the pejorative by Eric, a fellow advocate responds by attempting to re-credit the practice. Jack gives power to lurkers through majority rule, allowing for August and Beth to step forward offering their understanding of and experience with serving an observational role. Advocates in other groups also described their role as observational. For example, Rachel from Group 3 said she lurks because she is not up to date and is not yet in a place to give back to the community. Rachel said:

I was kind of playing both sides of the peer support role that, at this point in my life, I'm kind of soaking up the information and so I'm not really sure what I have to give to the support groups yet, other than just meeting people and getting information and ... 'cause I feel like I'm a little out of the loop on all this technology, and, yeah, so ... I'm in a very soak up all the information that I want to be able to give back to the diabetes community, I just haven't figured out what my niche is yet. (Rachel, Group 3)

Rachel's formulation of the observer role involves non-contribution. To her, being an observer is a role one plays before choosing to interact. Rachel suggested that she is in a state of uptake or consumption rather than providing. Similar to Rachel's formulation was Holly's. Holly explained her role as sponge-like, and predicted that overtime she will change to a more involved one. She said:

So right now the role I'm playing is just trying to be a sponge and soak up as much as I can and, I'm sure like, my roles will change like over time like the more I get into it. (Holly, Group 2)

Contrary to Rachel and Holly's ideas, Rita, Nannete, Murple, and Jo described their role as observers as fundamentally contributory. The following conversation occurred in Group 3 when advocates were asked to explain their role. Rita's comment appeared to have come in response to Rachel's comment above. Rita shared:

Um, I don't look at it as having to have a lot of knowledge to be a peer support person. It's ... it's reaching over and holding someone's hand, uh, when they're having a bad time. Um, so there's all kinds of things you can do, even if you think you're too new. (Rita, Group 3)

Here, Rita provides an opportunity for other group members to find value in their role within peer support, even when being an observer. Rita's comment encouraged the next three advocates to explicitly place value in that role. First, was Nannete, who said:

I'm not quite sure what role I really play or what I contributed or can contribute, um, although I do try, I think, like Rita said, a lot of it is just being another person there and being somebody else, um, you know, to ... to share things with. (Nannete, Group 3)

Nannete, slightly unsure in her delivery, was followed by Murple. Murple expounded upon Rita's comment. Murple declaratively clarified:

I just want to say that even ... even just being there and soaking it up. Saying, "me, too" is a form of peer support to the people that you're talking to, even if you're just saying, "Oh, my god. That happens to me, too. That's amazing," you're not only

acknowledging that you just got peer support, you're giving peer support back in the same statement. (Murple, Group 3)

Toward the end of her declaration, she was looking directly at Nannete, who responded with an elaboration of her experience. Nannete explained, now with confidence, that she benefited greatly by serving the observer role. She described:

It started with online and looking, um, looking at different things online, and then I went to an event for adults with diabetes, um, like, I don't know 4 or 5 months ago. People talk about technology being like a game changer, but like, the peer support was the game changer for me. (Nannete, Group 3)

Last to answer the question in the group was Jo. Jo enthusiastically described her role as a listener eager to learn and absorb. Her response was similar to Rachel's, but did not include a negative slant. Jo explained:

When I was in that room, you know, listening, I took about three pages of notes. Try this and try this and try ... and I ... I would never have thought about that, you know, but someone popped out with then a, "Oh, I'm gonna try that," "Oh, okay, try this," or "Try" ... you know, and I just ... it's very good. It's broadening to me. It helps my mind continue to grow. (Jo, Group 3)

After lurking emerged so prominently in the data, and after two groups' mention involved a re-crediting of the practice, a list of questions was formed to clarify aspects of lurking in the diabetes space. I was curious why the interactions unfolded as they did. Why did some advocates defend the practice during the groups? The list of questions was sent to ten advocates who had participated in the focus groups. Six responded.

When asked about what lurking is and who does it, advocates argued that lurking was about observing and looking in. They did, however, relegate its practice to those who were shy. Irene and Eric suggested the following:

Although the connotation might be perceived as negative, I think that we as humans are naturally curious to learn what others do in similar situations, and diabetes is no different. We lurk – or look in on to read – what others do to see if we’re “normal” or if others do the same things we do – or do better things - and if what we do is normal or not. (Irene, Continued Participation)

Irene here seems to be pulling away from what she identifies as a negative connotation. She described lurking as a process of *looking in* for both validation and new ideas. Eric, who offered a pragmatic definition of lurking suggested that the practice was reserved for those who were shy. He said, “I’m sure that there were wallflower types” (Eric, Continued Participation).

When asked where lurking took place and whether or not it took place in face-to-face contexts Mysty and Howard both suggested that it does. Mysty took a protectionist approach, and provided an explanation and justification for the practice. Mysty said:

Lurking is most notable in the online world, but it happens in person as well. At some point in our lives we’ve been standing around in a group talking and one person (or more) is actively listening and very into the conversation, but isn’t talking themselves. They truly want to hear what is being said and are very interested, but don’t have anything they feel is valuable to contribute at that time. This should not be discouraged as doing so would alienate and push away people who need

the community more than we can possibly imagine. (Mysty, Continued Participation)

Like Mysty, Amy sees lurking as taking place in both online and in person contexts. Amy suggested that lurking allows for some to join a community, even if uncomfortable sharing. Her commentary is suggestive of the open and welcoming nature of community-generate events like the Diabetes UnConference. Amy explained:

Lurking allows one to know that he is not alone without making himself vulnerable. And yes, it happens in person. Not everyone is comfortable engaging or sharing with relative strangers, but they may experience feelings of community and acceptance simply by being present. (Amy, Continued Participation)

Howard also ends up defending the practice of lurking, though sees it as both the beginning of a process toward participation and for those who are shy. It seems as though at the end of his statement Howard himself identifies as a person who was once shy and did not offer insights. He acknowledged that there is value in the process, though supported becoming a sharer as a slightly superior status or position. Howard explained:

It is harder to hide yourself at a live event, but I suppose the same principles can be applied. Some people lurk due to cognitive roadblocks (some introverts, shy people, those with social anxiety, new people, etc) that hold them back while others are very vocal and confident. We know both are there because we can see them, but if the right opportunity doesn't come up it may be difficult to get them involved. They may be learning and absorbing value without offering a single insight of their own. I think it is an important place to draw people out and help them overcome roadblocks. Feeling welcome helps people engage to a deeper level, and

increases their chances of lasting benefit. Regardless of whether an individual becomes an influencer, it is okay and useful to lurk... I have lurked on many conversations that have opened new flood gates of new knowledge without revealing my presence. (Howard, Continued Participation)

In sum, the role of the lurker is debated within the community in terms of participation and engagement. Though, regardless of this debate, amongst these advocates observers being integral to the functioning of peer support is not contested.

D. **Peer Support Best Delivered**

To answer the last research question, commentary about the way in which peer support is provided, and used was analyzed. Between all four groups, there was consensus that peer support in diabetes would be best if it were *everywhere at all times*. In two of the four groups, the model of support developed in Alcoholics Anonymous was favored and wished for. Though, within each group there was hesitation around this idea as well. Fellow advocates in both groups where Alcoholic Anonymous responded with hesitation. It was alluded to that the model would not work for the diabetes population because it was all volunteer based. Following from this hesitation, both groups imagined a world in which peer support work was paid. Paid peer support work was mentioned in every group, whether the Alcoholics Anonymous was mentioned or not. What follows is a break-down of the two themes which get at the answer the third research question.

i. **Everywhere, all times**

When questioned about what peer support would look like if it were accessible to all people with diabetes, Group 2 turned their conversation toward

Alcoholics Anonymous as a model. Advocates felt that this model worked because it was everywhere all the time, because it connects each person with a one-on-one sponsor,

It'd look like [Alcoholics Anonymous]. And there'd be thousands of people with that shared experience. And not that I'm wishing you know, millions of people had diabetes, um, but if there was something that was, you just know it's there. My husband doesn't ever have to wonder if he goes somewhere, is there gonna be support? It, it'll be there. You know, there's millions of people worldwide. It would look something like that. No matter where I went... and the sponsor situation.

(Holly, Group 2)

It appeared all group members were in agreement, some looked as though they were surprised to hear such a suggestion. Ginger followed with a comment about a sponsor-like experience she had with a national diabetes organization. She explained:

It's because of that one person that you can trust. You know, my favorite thing about DiabeteSisters is the one person that I met that became my best friend that I got to take with me. And like, I think you know, the closeness that, that these conferences foster would not necessarily happen at, at just group meetings. I think there's something to be said about like a conference setting. (Ginger, Group 2)

In response to Ginger, Amy shared a personal story. Amy began by sharing that peer support works outside of a conference setting. She went on to tell a powerful story about a vulnerable time in her adult life. She shared:

But um, but I found it online too. Often in the middle of the night. Like, I remember a night where I had just had it. I believe I was, during one of my pregnancies so my, my level of management was at like, the, the highest level of, of trying to do

everything right, and I had a pump site fail so my blood sugar was insanely high. So it's scary during pregnancy, and I just sort of broke down into fetal position. Like, "This is so fucking hard," and I did everything right this time and I'm dealing with this. And I just put out a little call on, I think on Twitter. And the amount of support at like, one in the morning that I got back instantaneously from people who were like, "No, it's fucked up and I get it. I've been there and you, you know, you don't deserve this." I went to sleep cradling my phone that night. (Amy, Group 2)

Amy's story brought one group member to tears. There was a pause in chatter in the group. After this short pause, Gary re-centered the conversation on access. He said:

We the diabetes community, have not figured out, we have not invented the wheel. Okay? We have not invented [Alcoholics Anonymous], or whatever that looks like. Um, and you know, the other, the other thing is, is that it, it's gotta be about access, the ability for access for all, um, and not the same people that keep coming. (Gary, Group 2)

What started out as an answer to what peer support for all people with diabetes would look like, morphed into a discussion about extending the peer support services that exist to those who do not have access. Gary's attention to access reverberated throughout the focus group session. Though this thread ended here. Group 4 also carried conversation about the alcoholic anonymous peer support model. However, it arose more through the frustration of using a model that has been experienced by Carla as not working.

At my meetings, sometimes only one other person shows up and I think it is, it's because people don't know where, uh, to look, or to look at anything at all. We

have been meeting every month for years. We tell the clinics and but nobody shows. If PWD [people with diabetes] all knew they needed support, like people in [Alcoholics Anonymous] do, they might, they might, I think, show up, because [Alcoholics Anonymous] is everywhere and every single alcoholic person knows about it. (Sebrina, Group 4)

There was verbal agreement from every group member, each one a leader of a local support group. Carla expanded upon Sebrina's suggestion, calling for dedicated locations where peer support could take place. She suggested:

...and what we need are actual, though, like, centers which insurance would pay for, I know it is a rather, well, a really very long shot, but who knows. (Carla, Group 4)

One advocate to the right of Carla, exclaimed enthusiastically:

Diabetes centers in each city, county, state! (Audra, Group 4)

ii. **Discoverable**

At least one member in each group made mention of stumbling upon or discovering peer support as a pathway to it. In Group 2 Amy mentioned it when asked about why she seeks peer support. She corrected the question by stating:

I didn't actually seek peer support. I discovered it. And it was such a, a, a life-changing experience for me to like, accidentally find peer support when I was not, I, I didn't feel its absence until I understood its presence. (Amy, Group 2)

Lexie from group three made a similar comment. However, hers addressed people with diabetes who have not yet found support, and her experience having to find it without the help of her doctor. She said:

I wish there was a way to let people know about peer support that are not aware it exists. Cause I would say, maybe I'm wrong, confirm if I'm wrong, most doctors don't mention peer support so unless they know someone that is involved, how do they even know about it? (Lexie, Group 3)

Similarly, after a fellow advocate suggested needing to make peer support services more financially accessible, Alice argued that it may not make a difference if discoverability is not addressed. Alice explained:

I think there is a step even before this because, a lot of people don't either 1) know that they need peer-support, or 2) know that there is peer-support out there. So they have to know what it is that they are missing. (Alice, Group 1)

In one summative comment from Group 4, Carla explains that getting people in the door for peer support is difficult because people do not know they might benefit from it. She summed up comments from fellow advocates:

But we've also, many of us have said that we didn't know it was missing. (Carla, Group 4)

All groups, then, mentioned peer support in diabetes as a resource a person does not know they need until they experience it.

iii. **As needed**

In addition to the mention of Alcoholics Anonymous as a model of peer support which is available everywhere at all times, advocates described the importance of the diabetes online community (DOC) as a form of community-governed support which is alive and active 24/7. After Ivan from Group 3 explained the sense of invisibility experienced through diabetes, he shared that the DOC is itself a connector. He said:

We do sort of feel invisible with diabetes and you wouldn't know somebody has diabetes by looking at them, and what are you going to do? Ask them? Whereas the online, um, experience has enabled us to find one another, which didn't exist when I was a kid. (Ivan, Group 3)

For Ivan, the DOC is a source of connection to peers who would not be recognizable in public.

In Group 1, a thread discussion was initiated by Mysty who argued that peer support needed to come in different forms. Mysty explained:

...like with the different tables in this room, there would be the support that we need but each table would be a different type of support, there would be the “this is what worked for me” support, there is the “I hear you, it’s okay to just rant support”, there is the “I know it is frustrating here let’s break something or hit something so you can get that frustration out” support. (Mysty, Group 1)

As a follow up, another group member suggested this already happens in the online space. Eric said:

But that is sort of what you can get on a message board because you can define a topic and then talk about it you know and there is whole range of topics, TuDiabetes has probably what, 30 thousand topics? (Eric, Group 1)

In agreeance with Eric’s comment, Irene shared:

Whereas now through the peer support online and out, it is more refined. I have a group that is for [identifiable information removed]. It is very precise. (Irene, Group 1)

While Group 1 discussed the multifaceted and targeted nature of peer support as it is delivered online, Group 2 discussed the way online support removes the stigma of attending a support group. When asked about what getting peer support to all who wanted it, Victoria shared her preference for getting peer support online, which initiated the conversation. Victoria shared:

A lot of the time I like my peer support to be online. It can be easier to tell your story if you don't have to you know, do it face-to-face sometimes. That can be a really easy way to get in there. (Victoria, Group 2)

Amy followed up on Victoria's comment by addressing the feeling of vulnerability that can come from needing support. Amy described her own rejection of peer support earlier in life when she conceived of support groups as where people go when they need help. Amy explained:

And the concept of going to a support group was so distasteful to me. And that I felt like I was admitting that vulnerability, I was admitting weakness. I didn't support, a support group. Oh my God. Like, I was fine. I was doing things with my life. Um, so this idea that for those who wanted it, I think the problem is further back than that. How do we make people um, feel the yearning for peer support, and feel okay with the vulnerability that that, that potentially brings, to draw them into a support situation? (Amy, Group 2)

At the end of Amy's comment, all group members were nodding. Ginger jumped in with a comment clarifying the problem with perceiving support groups as a space for those who need help. Ginger said:

And I, I think it's, I think it's the wording. I mean it's 'cause you hear support group, you hear, "I have a problem and I need help, which means there's something wrong with me." And you hear, "Let's sit around for an hour and talk about you know ...No... We go get lunch. Because you don't say to, I mean, especially to like I, e-, anyone I know in their 20s, like, "Hey, do you want to go sit down and talk about your emotions around diabetes?" Like, "No. I don't want to do that. That sounds awful." Like, I, there's nothing in me that wants to do that. But like, "Do you want to go get a beer, and like, you know, chat?" "Yeah, that sounds like a lot of fun," and it, especially when you're talking about like, peer support. Like going to get a drink, going to get a bite to eat. (Ginger, Group 2)

Ginger's response here expresses her own preference for lower-risk peer support activities. When the setting for peer support mimics a meeting between friends who do not share a common diagnosis, Ginger seems to be more drawn to attend. After Ginger finished explaining her position and experience with this, all group members nodded. One group member responded,

That's exactly why we are here [at the Diabetes UnConference]. (Theresa, Group 2)

The next comment altered the direction of the conversation. Victoria started a thread about affordability, commenting on the UnConference being an expense many cannot afford. She said:

I think it's important though that we address people who are not here. We all obviously could afford to come here. We have family that was able to let us be. I think this should apply to the people who can't afford it. To the people who are too

disabled to make a flight here. We need to get that access to people that aren't us 'cause we already have it. (Victoria, Group 2)

Group members all nodded, and some appeared to have taken pause. The conversation began focusing on funding for events like the UnConference and on paying for peer support work, which is described in the next section.

In sum, it seems these advocates want peer support that is available when they need it, discoverable for those who have not yet found it, constructed to meet non-diabetes-related precise life-criteria, and at a cost everyone can afford.

iv. **Peer support work as paid work**

In every group, the idea of paid peer support work was mentioned. To some, being paid to provide peer support services was described as a dream life, as something that would allow their passion to drive their careers. For one of the five advocates who expanded upon the idea in their respective groups, one specified payment for peer support provided in the online context, though others were less specific. June from Group 1, had a non-specific explanation involving feeding her passion. For June, diabetes work is happening at a self-management level anyway and naturally feed into her desire to do the work. June explained:

Well, diabetes is part of me. It's who ... it is who I am, so, why wouldn't that be my passion in trying to help others and have that ... to be paid to have employment to be able to do something like that would make me very happy. (June, Group 1)

Similar to June's passion was Maryam's from Group 4. Maryam, however, described the things that currently hold her back from being able to spend more time dedicated to providing and accessing peer support services. She shared:

I do this, you know, for free already. It deserves more of my, uh, of of my time, but I just, you know I have to work, I have to, pay rent, and it's, if I could get paid to do this, and you know, just this, all the time, I'd drop the job I love, like, I'd do that today, not even questionable. That would be the best thing that ever happened to me. (Maryam, Group 4)

George from Group 3 expressed similar doubts despite a strong desire to do peer support work full time. George argued that he has to prioritize his family over others, though it seems that the better scenario is being able to do both. George explained:

So, I think it's ... support the people ... support the peers doing peer support, right? Like, part of ... I can't blog as much as I used to anymore because I have to make a living. you're being pulled in multiple directions. Like, we all have to support our families and, if you can't support your families giving peer support, then you're ... then you can't do both. If you can't support ... like, your family first, self ... you have to care for self and family before you can for all ... for everyone else, right? So, if you can't pay your bills by doing peer support then that's just gonna kinda ... it either has to have a life cycle or a ... an evolution or something. There's gotta be some kind of success model built into it somewhere. As if being paid for peer support were a full-time job. What a dream life. (George, Group 3)

In the same group, Murple agreed that paying peers in every local area is a good idea. Though, Murple also highlighted the need for psychologists who specialize in diabetes or live with it themselves. Murple said:

Yeah, the idea of having paid people, paid peers to offer greater peer support in their areas, peer support for the Phoenix area where I live, or peer support for

another area where someone else lives, where you can give, not necessarily psychological assistance, but you can provide some ... some support for those people who can't ... who aren't getting ... I ... in my opinion, there should be, honestly, diabetic psychologists. There aren't. There's a couple of them that I've heard of. I think there should be a lot more of them. (Murple, Group 3)

In every group, comments were made about feasibility of a payment structure, which mostly contained doubt. In the Group 2 discussion, Gary made the following suggestion:

Now you really want a challenge? Go get health insurance to cover this. (Gary, Group 2)

E. **Constructing a New Definition of Peer Support**

When asked about the stuff of peer support, advocates identified several components. Some shared about the purpose of peer support. For example, Buddy from Group 2 said that to him, peer support is:

Help to live a healthier, productive, fulfilling life with my challenges. (Buddy, Group 2)

To Buddy, peer support is a kind of help. Though he did go on to elaborate a bit. During his elaboration, he identified a unified community as a factor in peer support. He explained that peer support is:

A group of connected people that empower each other and help work through the issues, and stay united. (Buddy, Group 2)

To others, peer support is about connection through shared language. Murple from Group 3, believes that peer support involves and exchange of perspectives. She said:

Peer support for me is the ability to both ask and give help from or to other people who speak the same language. Some of us may have spoken it for a few years. Some of us may have spoken it for a few decades, but it's always another way to get someone else's perspective on the issues that we are all living with at the same time. (Murple, Group 3)

Another advocate's thinking is in line with Murple's, however, she identifies it idea sources. To Maryam, peer support is about the ideas and hacks only those with lived-experience know about. Her conception reflects the minute details of life with a chronic complex illness like diabetes. She says:

Idea sourcing. Like, there's been so many, like, crazy ideas I've heard of, like, things people are doing that like, my doctor is like never going to like mention to me. So just being able to go out and like find out like what works for other people and like, what crazy thing they're trying this week. (Maryam, Group 4)

Ivan's thoughts about peer support echoed Maryam's idea. Ivan's description emphasized the peer aspect. He makes it clear that a doctor or healthcare provider is by definition not a peer. He said:

From my perspective, I think of peer support as something I cannot get from my endocrinologist, my general practitioner, or my certified diabetes educator. I can't get it from those guys. (Ivan, Group 3)

Two other notable descriptions which lend perspective to the generation of a new definition of peer support. The first is from Mysty from group one who described peer support as simply, "a ripple effect of sharing and care" (Mysty, Group 1).

Mysty's reflection here supports the idea that peer support as a process is a self-sustaining one. The ripple effect image implies that caring for others through peer support goes beyond the person you share with. Though a different thread, Lori's comment also speaks to the way in which that ripple effect continues. Lori expressed with humor the way in which peer support allows her to let everything show, and be vulnerable with her peers. Lori said:

What I love about peer support is you don't have to have your shit together when you come to peer support. But when you go to your endo or CDE, you got your 15 minutes, and you feel like you gotta have everything ... shit together, and, um ... In diabetes support ... in peer support, um, it's supporting those that don't have shit together or you can show your shit, and ... and they can help you put it together.

(Lori, Group 3)

In sum, according to the diabetes advocates who participated in this study, peer support is defined as *the coming together of people who have common and shared experiences who care for each other through contact and observation. The process of peer support elevates the community through the collective emotional 'lifting up' of individual members.*

For the sake of relating the data back to literature on peer support in the context of diabetes, an alternative academia-centric definition was also created. This secondary definition was formulated for two purposes: 1) to directly integrate concepts previously identified in the literature; and 2) to demonstrate the tendency in academic work to be jargon-heavy and thus inaccessible to community members. Using the terminology identified by scholars, this data indicates that peer support can be defined as *the*

concentric reproduction of care and encouragement delivered, received, and observed through the shared language and experience of equals culminating in the extension and augmentation of social capital and network within the community.

F. **Results Summary Table with Examples**

A table displaying a summary of the results is provided. With each theme, a summative description is provided.

TABLE I
RESULTS SUMMARY

Category	Theme	Description
Process-Oriented Components of Peer Support	Shared Experience	is the axis of connection, initial tool used to fuel the peer support process
	Empathy	is the internalization of another's pain based on similar lived-experience
	Trust	is the bond forged between peers which elicits mutual sharing
	Okayness with disease state	is the cyclical washing sense of relief and acceptance one feels toward their condition
	Belonging and Not Alone	is the transition from isolation to community
Results- Oriented Components of Peer Support	Problem Solving	is the collective process of troubleshooting self-management techniques
	Solution Generation	is the motivation to troubleshoot and work through self-management issues with peers
	Knowledge Acquisition	is the process of acquiring knowledge, usually without the objective to immediately follow-up or take action
Engagement with Peer Support: Roles	The Supporter	is the role in which a peer offers or gives support to another peer
	The Supported	is the is the non-hierarchical role in which a peer accepts support by showing up emotionally and physically (in-person or online)
	The Lurker	is the role in which a peer observes other peers engage in a peer interaction
	Fluidity Between Roles	is the non-mutually exclusive, non-fixed, and non-linearity nature of peer support role interaction
Peer Support Best Delivered	Everywhere	is the availability of peer support in every location
	All Times	is the availability of peer support at any time
	As Needed	is the accessibility and delivery of specific targeted peer support
	Discoverable	is the accessibility of information about peer support services anywhere
	Paid Peer Support Work	is the financial investment in peer support work as a formalized labor practice

VIII. DISCUSSION

A. Discussion I: Lurking Online and Off

The term “lurker” has been explored in the context of online peer support since individuals began using the internet to connect (Preece, Nonnecke, & Andrews, 2004). Computing research has found that nearly 90% of an online community’s traffic is generated through lurker engagement (Bishop, 2007). Findings suggest that those who visit peer support online forums and tools but do not contribute have many reasons for doing so (Preece et al., 2004), such as testing the waters or not needing to engage to receive support. One study found that engagement for some did not involve contributing, but that members for whom that was the case felt as essential to the community as those who did contribute (Nonnecke & Preece, 2000). While there is no literature on the concept of lurking within a diabetes context, we can assume a trend similar to general online community lurking studies would occur. What we do know, based on a website’s unique visitor counts and various studies, is that many more people are looking at content than creating or commenting on it (Katz, 1998).

Some research has set out to demonstrate online community participation as an evolutionary process. That is, a user may start out as a user, become familiar with the community, share a couple of times, become comfortable with other members, share more often, and eventually leave the role of lurker behind (Kim, 2000). In this formulation, there is a semi-linear pathway toward what is termed active participation in online communities (Kozinets, 1999). Movement from passive participation (lurking) to active participation has been attributed to phenotype and personality traits (Yoo & Gretzel, 2011), user satisfaction with the community (Mo & Coulson, 2010), and experience of

reception by the community after testing the waters of contribution (Bishop, 2007). Movement into active participation has also pointed to curiosity as a motivator of lurking behavior (Schneider et al., 2010). Curiosity, however, may not be the primary driver of lurking in the context of online health communities. Other research has suggested that lurkers do not move from passive to active participation when they are able to meet their information-seeking needs without posting, but rather do so when they achieve a certain level of intimacy with the community and the members within it regardless of knowledge acquisition (Rau, Gao, & Ding, 2008). When it comes to divulging personal health information, moving from passive to active participation may be most closely linked with the establishment of intimacy within the group.

However, I argue that the formulation of lurking as *passive* participation is faulty and misrepresents what is actually taking place. Based on the results of this study, lurking is a form of engagement which requires a process of internalization and reflection. If lurking behavior mimics in-person behavior in health communities like the diabetes community, we can shift our perspective. Though advocates who participated did conceive of lurking in ways that speak to the literature, they also brought complexity and subjective richness to the conversation.

A further examination of lurking is not within the scope of this thesis, however, the findings presented herein warrant further research exploring the possibility of lurking as a form of active rather than passive engagement and participation. Does the nature of lurking change depending on the type of community? Are there different qualities or circumstances of lurking in the context of online health communities?

B. **Discussion II: Building a Conceptual Model of Peer Support**

i. **The definition**

As described in the results section, two new definitions of peer support were established based on the thematic categories and coded data provided by diabetes advocates who participated. With that said, the conceptual model of peer support best delivered was constructed to reflect the new academic definition and needs described by advocates to propel peer support further. The academic definition generated is as follows: *Peer support in diabetes is defined as the concentric reproduction of care and encouragement delivered, received, and observed through the shared language and experience of equals culminating in the extension and augmentation of social capital and network within the community.*

This definition is complex and multifaceted to reflect the complex nature of diabetes itself. The definition begins by illustrating the motion of the peer support process, which was described by advocates as a cyclical self-sustaining production process. This was demonstrated in advocates' tendency to take on multiple roles at once and to build one another up through community services and engagements. In the model, the self-sustainability is exhibited by the long curved arrows moving from the final products back up to the investments.

There are four products described in the definition: care, encouragement, social capital of the network, and community capacity building. The word *care* was selected to underpin the conception of peer support as a form of payable work, described in more detail in a discussion to come. Though it could be argued that encouragement is a component of care, they are separated to denote encouragement as a distinct product in

the context of diabetes. Encouragement here refers to the diabetes advocates' mention of renewed capacity and willingness to self-manage their condition. Though encouragement may, for some, occur through a more passive interaction, it is none the less a notable product. Social capital for the network refers to the resources the community as a network has to expand service and program offerings. Community capacity building refers to increasing reach, membership, and impact. The latter two products are shown as such at the bottom of the model. Care and encouragement, however, are cross-listed as materials in the model. They are colored grey to represent the cross-listing. The model was constructed this way to show that the materials needed are also products being created/manufactured by the workers.

Next is the inclusion and breakdown of work roles described by advocates in the peer support process. There are three roles identified in the model, and each is linked with a term in the definition for clarity: 1) supporter/delivered; 2) supported/received; and 3) lurker/observed. As stated in the results section, a new role, which has not been forthright mentioned in peer support literature before was described by advocates who participated in this research. The observational role was of high importance to advocates. Based on the feedback from advocates, and though my own insights as an insider in the group, I attribute the inclusion of an observational role to dual-nature of participation in online and in-person peer support activities. Lurking has been studying as an internet community phenomenon, as previously discussed, for decades. It has not, however, been applied to an in-person context. Nor has the process of watching other exchange in peer support been explicitly identified. The model shows each role, with dual-head arrows to each of the other roles. These arrows indicate the way in which roles are neither mutually

exclusive nor linear. One person can play all multiple roles at once and shift between them at any time.

Shared language and shared experience in the definition and model denote the tools that workers use to create the products. Shared language and shared experience allow for the establishment of a connection and dialogue as equals.

Lastly, omitted from the definition, but included in the model is the delivery method through which peer support needs to take in order to qualify as best delivered. Figure 8 demonstrates the model, and shows everywhere, all times, as needed, discoverable, and as paid work as required aspects of delivery. As explained in results, advocates believed peer support needed to be accessible and findable to all. This meant that more services and programs needed to be available. However, in order for more services to be made available, more adults with diabetes would need the time and financial positioning to be able to volunteer time. Because of this identified problem, advocates argued the need for more formalized paid peer support work.

The following discussion section describes the current landscape of paid care work in the United States. I begin by problematizing the way in which care as informal labor has been incentivized through policy. Then, I explore peer support as a form of care, arguing that it ought to be honored as such because those with diabetes and other disability are uniquely qualified to do it. After presenting the counter arguments, which have kept peer support work from entering the formal labor market, I discuss steps advocates, and researchers (the two primary readers of this manuscript) can take in order to move toward the formalization of peer support work.

ii. **The model**

Figure 8 demonstrates the formulated model of peer support.

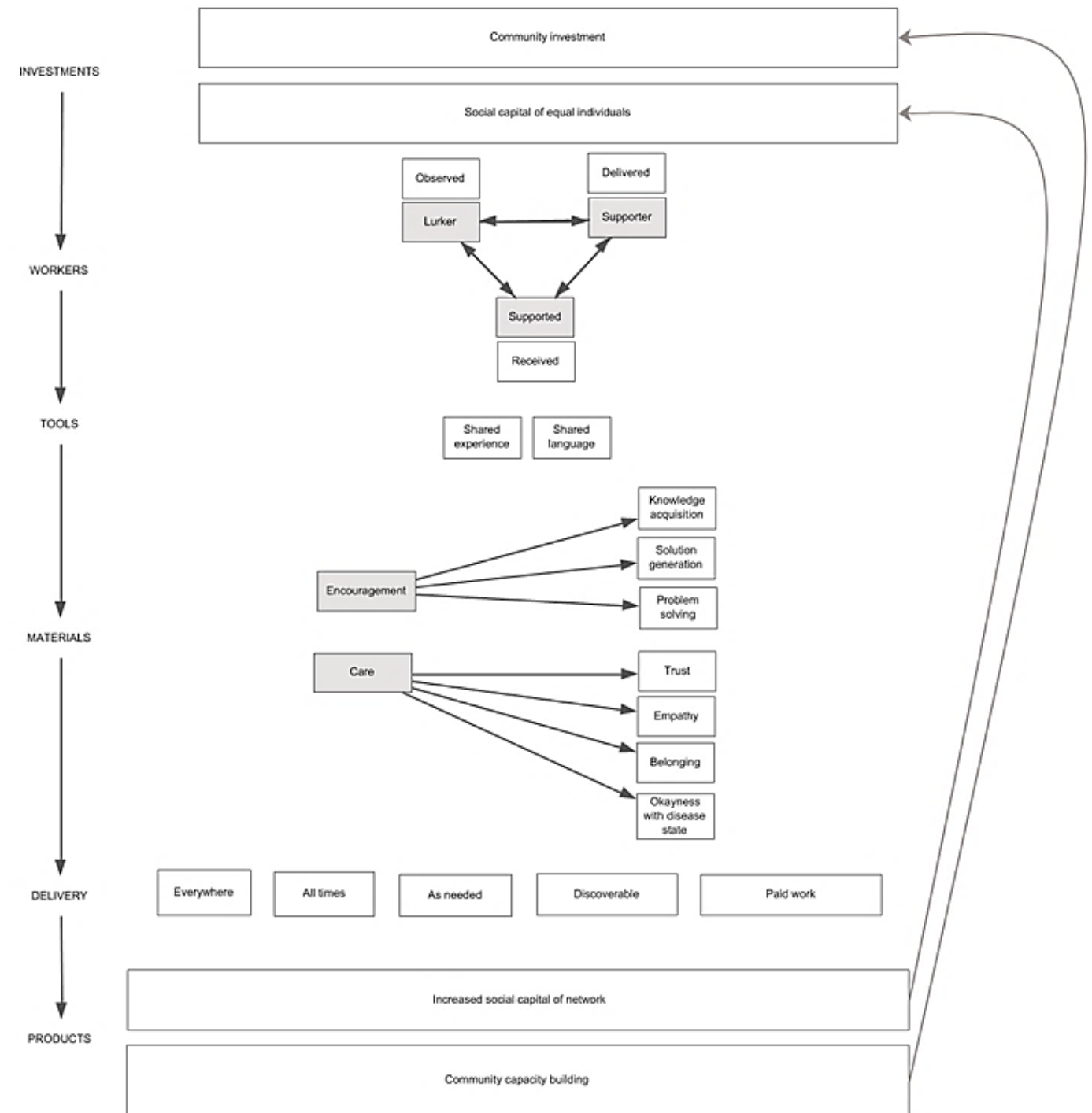


Figure 8: Conceptual model of peer support best delivered

C. **Discussion III: Formalizing Peer Support Work in Healthcare**

In the last 20 years, peer support services have been established, evaluated, and found to be effective as a mechanism of care and care delivery (Repper et al., 2013). When accompanied by routine and regular health care, peer support work has been found to be reimbursable by Medicaid in 27 states throughout the U.S. (CMMS, 2007). While some disabled persons are entering the formal labor market through service as a peer support specialist, the majority of peer support persons remain unpaid volunteers. Because peer support is bracketed as a form of care, it often takes place in the informal labor market. In this discussion, I argue that peer support work ought to more thoroughly transition to paid and thus formal employment within and beyond the healthcare context. Because this topic was an unexpected result of the research presented here, the discussion will take a wider, disability-wide perspective. As such, this discussion will first highlight some ideological problem points involved with care as informal labor. Then it will provide examples of how peer support is transitioning from informal to formal labor in some disability categories through Medicaid. After exploring the counterpoints arguing against formalizing peer support work, this discussion will provide action steps toward the formalization of peer support for all disability categories.

i. **Informal labor in care: Problematic themes**

Informal labor consists of unregulated, unprotected, and untaxed work like day labor, cleaning, baby-sitting, crafting, jewelry-making, etc. While informal labor can include care work, not all care work is such. Care labor, paid or unpaid, is a foundational aspect of a functioning human society. In a recent book, Duffy, Armenia, Stacey, and Nelson, 2015, argue that similar to the physical infrastructure built to sustain and order

civilization, there is a human infrastructure that maintains life. Duffy et al. argue that “a human infrastructure that adequately addresses the range of care needs of American families is equally important to supporting our economic, social, and civic lives” as is the physical one (2015, p. 7). What this analogy does not lend credence to, however, is the force of care-consumers upon which the care workforce depends.

While the disabled population, including people with diabetes, has been the crux of the development of a care workforce, consent of and control over care services is often determined not by the consumers of said services, but by those who provide and fund them. This is particularly problematic when disability is seen as a personal problem rather than a political one. When disability is conceptualized as deviance and abnormality, disabled people are categorically oppressed and marginalized as in need of fixing, as in need of care. However, the disadvantages of disability do not stem from an impairment, but rather from the sociocultural conditions and environment disabled people are in. In part this environmental state is maintained and reproduced by “the multi-million-dollar industry that houses and ‘cares’ for the disabled population that has developed as a consequence of this economic disenfranchisement” (Taylor, 2004, p. 40).

This multi-million-dollar industry, consisting of both paid and unpaid labor, lay and institutional settings, relies on a conception of disability as “tragically dependent” (Taylor, 2014). It relies on the idea that disabled people do not have the capacity to have a seat at the decision-making table in terms of their own care or the way that care in general is offered, allocated, and located (Duffy et al., 2015). According to a recent study, even when government waivers cover within-family caregiver support (which is rare), the disabled person is only given a choice over which family member will fill the caregiving

role one third of the time (Friedman & Rizzolo, 2016). Two thirds of the time, the choice of caregiver is made for them by providers or service agency administrators.

As if this was not problematic enough, there is a yet more looming ideological issue. The concept of 'care' constructs and drives a binary: carer and cared for. Care, as we use it today, involves choice and power. Care brings the assumption that those who need care "are unable to exert choice and control" (Morris, 1997, p. 54). There is disempowerment built into the care binary our healthcare system functions on (Morris, 1997). Disabled people, then, are neither recognized for their labor as consumers of care, nor are they afforded access to the carer side of the constructed care binary. There is one exception, however, disabled people are recognized as carers in the context of peer support.

Peer support "occurs when people share common concerns and draw on their own experiences to offer emotional and practical support to help each other move forwards" (Repper et al., 2013,4). In this way, disabled people are uniquely qualified to provide care in this way, through personal experience. Peer support has been valued as a mechanism of care amongst some, though not all, disabled populations for over two decades (Mead et al., 2001). Most literature exploring peer support as a mechanism of care can be found in health-related fields and center on mental health and substance categories. Some models of peer support have made it into policy and practice.

ii. **Peer support as care: Models in use**

While there are policies and practices in place which are helping more peer support services move into the formal labor market, there are many issues holding back its potential growth (Repper et al., 2013). Unpaid trainings, workplace flow, and getting

buy-in from clinic staff are three examples of some challenges still muddying the likelihood of peer support specialists entering the labor force as paid care providers. Specifically, unpaid training pervades even the most progressive attempts (Repper et al., 2013).

In August 2007, The Center for Medicaid and State Operations (CMS) issued a guidance letter to State Medicaid Directors regarding peer support services and specialists in the context of mental health and substance abuse (CMMS, 2007). CMS agrees to provide coverage for peer support services under three authorities of the Social Security Act: Section 1905(a)(13), 1915(b) Waiver Authority, and 1915(c) Waiver Authority. This means that in three Medicaid funding authorities, peer support services are billable. CMS advises state directors to bill for peer support services only when the following three conditions are met: 1) the delivery of peer support services be supervised by a “competent mental health professional;” 2) the peer support service is one part of a comprehensive and individualized plan of care with set goals; and 3) peer support providers meet extensive training and certification requirements (CMMS, 2007). The letter from CMS defends coverage of peer support by recognizing “that the experiences of peer support providers, as consumers of mental health and substance use services, can be an important component in a State’s delivery of effective treatment” (CMMS, 2007,18).

Two years after the CMS letter was dispersed, the Pillars of Peer Support Summit took place which culminated in a research-informed guidance and scoping document for states to use when creating, establishing, defending, and evaluating Medicaid funded peer support services (Daniels et al., 2010). Members from 27 different states gathered at the Pillars of Peer Support Summit to identify strategies for implementing billable peer support services and assessing best practices currently in place. Of note, one best

practice strategy suggested regards the extent of training and certification needed. Summit members reported providing between 40-100 hours of training for their peer support specialists (Daniels et al., 2010). However, it is noted that training is not paid because it is not reimbursable. Because training for certification is not billable through Medicaid, in all 27 states represented, peer support specialist training is considered volunteer work. Forty hours of training equates to a full work week without pay. For many people with diabetes, the cost of medical supplies for that week alone is enough disincentive to pass on the opportunity. Further, the average pay for trained and certified peer support specialists is \$10.00 for a 15-minute unit of service. Peer support specialists on average earn around \$150 a month (Daniels et al., 2010). In sum, while there is a movement to transition peer support services into the formal labor market within the healthcare and reimbursement system, it fails to pay for training, fails to provide a reasonable living wage, and thus undervalues the care provided. There are many reasons why the Medicaid policy mechanism funding peer support has fallen short, some practical and some value-based.

iii. **The case against formalizing peer support work**

Many cases against the formalization of peer support work have been made over time. Of the most compelling, one stems from the power of volunteerism, and one from potential loss of disability benefits. In addition to formal arguments made against formalization, the process has mostly been slowed by phantom supporters. In a qualitative literature review, one collaborative found that although the healthcare system has acknowledged and supported the experience of living with a long term condition as a qualifier of providing peer support, evidence exists that it simultaneously reinforces the

medical paradigm (Embuldeniya et al., 2013). In other words, the healthcare system has said they value the non-clinical nature of peer support care, but still practice in a way that favors or prioritizes medical treatment. This in combination with the more compelling arguments against formalization have been enough to keep the process at bay since the Medicaid letter advancement in 2007.

Volunteerism is rooted in humanitarianism, in doing good for your fellow human, in altruism. It is argued that participating in volunteerism promotes social inclusion and well-being, and benefits both volunteer and intended benefactor (Kahana, Bhatta, Lovegren, Kahana, & Mildlarsky, 2013). Furthermore, studies show that when a volunteer's motivation is internal rather than external, it produces higher rates of dedication and attendance (Rushton, 2015). Volunteers show up more and do a better job when they are not paid. In this way, payment of volunteer-like work is said to be a disincentive to commit and follow through. On the basis that volunteerism is less effective when payment is involved, it is argued that peer support work should not be monetized. The weak spot of this argument is in its over-generalization. There has yet to be a phenotype common to all volunteers. Internal motivation to help does help some volunteers show up more, but for others a monetary incentive works better. To categorize all volunteers as intrinsically motivated is to miss the diversity and heterogeneity within the group (South et al., 2014).

The second argument against formalizing peer support is common to much disability-related employment policy. It revolves around the potential conflict over benefits. Some argue that peer support and community health workers should not be paid because it would be reportable income that might jeopardize benefits afforded the disabled individual at their current income level. The argument is made that unpaid peer support

is better for the disabled person because it gives them something to do without harming or changing their benefits (South et al., 2014). This argument is a strong one because it has an immediate impact on disabled people. However, a stronger argument is that our larger policy system restricts upward social and economic mobility for some, but not all, populations; disability being one of them. To claim that peer support work should not be paid because disabled people will lose their income is to reproduce the systemic restrictions already in place. It is to be stuck in fixed thinking.

iv. **Strategies toward formalization**

Because disabled people, and a part of them people with diabetes, are uniquely qualified to enter peer support work, it is essential that its formalization as a form of paid labor continue. In order to move peer support work away from the informal labor market, we need to politicize disability and care work. We need to transform our policy to recognize that care work in general is interdependent with the force of laboring care-consumers who have recognizable preferences and rights. While care work is a foundational aspect of our human infrastructure maintaining life, care-consuming is as well. Disabled people exist as both carers and cared for, within and beyond the peer support work context.

On the subject of unpaid and paid care labor as it pertains to disabled people (i.e., consumers of care services), it ought to be our priority to ask: who is at the table, whose opinions matter, who has voice and influence over decision-making? It is also imperative we ask who should be paid to provide care? What can we do to restructure employment policy, which currently is “shaped by medicalized misrepresentations of disabled people and the cultural stigma misunderstanding of disability as an inability to work” and self-

select into something that acknowledges consumers of care as valuable stakeholders and as providers of care (Abberley, 1987,8).

Below is a list of suggestions and recommendations for taking action toward formalizing peer support work directed at advocates and advocacy organizations, and researchers. While the recommendations are categorized based on role, collaboration and intermixing of responsibilities is suggested. This is a multi-stakeholder issue. Every role is vital to the process. The following recommendations were adapted from Leonard Jason's 2012 book, *The Principles of Social Change*.

Advocates and Advocacy Organizations

- Form a cross-diagnosis coalition. By bridging mental health, chronic illness, substance use, and physical and ID disabilities advocates, you create a stronger force. As a coalition, determine what type of change you'd like to make. Decide at what level(s) you will do your advocating.
- Take to social media – Develop and rally around a hashtag to spread your message. This will help you identify allies beyond your populations who share your goals. Be patient and persistent, and celebrate the little victories.
- Use Facebook Town Hall application to reach out to senators and members of your health care caucus to advocate for the formalization of peer support work for all diagnosis categories citing mental health as an example of why it work.

Researchers

- Build a budget that pays community leaders to collaborate with you. As a part of the research process, make their payment more than an honorarium, and in your funding mechanisms identify them as professionals vital to the space. By

recognizing disability advocates as valuable members of the research team, you further validate their capacity to work and earn equal pay.

- Collaborate with advocacy organizations and assist with measuring success of advocacy efforts. For social change, evaluation of accomplishment is paramount.
- Collaborate with policy makers to write a bill that builds a funding system which covers peer support work in all diagnosis categories. Do this by taking a page out of the mental health and substance use book, citing a need to expand to other applicable groups.

IX. CONCLUSION

The present work set out to answer research questions around the topic of peer support in the context of diabetes. By analyzing recorded experiences of advocates living with diabetes and interpreting the body of literature on this topic, a new definition of peer support was generated. The circumstances through which peer support may be best delivered was explored and put forth. A conceptual model of peer support best delivered was constructed based on the data and definition generated. The model and definition of peer support generated here add to the body of literature by explicitly identifying the lurker/observational role, and by conceiving of the process as self-sustaining.

Several arguments were made throughout this work: 1) there is a diabetes-specific stigma attached to the illness which has been linked to diabetes-distress; 2) the emotional and physical distress diabetes can lead to is not addressed in current treatment, therapies, and care; 3) the study of peer support is one way to begin addressing that distress; 4) funding for diabetes-related research needs to pivot toward more psychosocial studies; 5) in order to study peer support, researchers must look at organic community-generated peer support services and programs because they are more sustainable and reportedly work better than clinic-based services and programs; and 6) in order to study a robust peer support delivery service, resources must be allocated to their expansion, including but not limited to the payment of peer support workers.

Though providing peer support may come from a place of altruism, doing so ought to be recognized in the formal labor market because diabetic and disabled individuals are *uniquely qualified* to do the job. Furthermore, doing so would open up the social binary of care to disabled populations. We cannot continue “framing citizen involvement in health

only as time freely given [because it] does not account for the complexities of practice, nor intrinsic motivations” (South et al., 2014, p. 80). While Medicaid funding of peer support in the context of mental health and substance use is an excellent start, there is much more to be done. Peer support work should be formalized to improve the healthcare system and the social valuation of disabled persons.

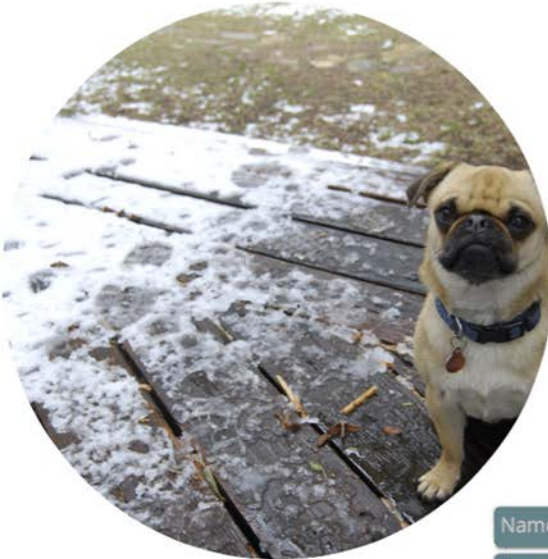
A. **Limitations**

This study had some limitations. First, only self-selecting diabetes advocates acted as participants. The argument has been made that the rigor of qualitative research decreases when only the most articulate high-status members of a group are chosen to participate (Sandelowski, 1986). Though I recognize this argument, selecting high-status members of the diabetes community was built into the design of the present study. The results may have been very different if adults with diabetes who had never accessed peer support or only done so on one or two occasions had participated. It would be worth studying the difference between groups of advocates and non-advocates around peer support. Second, though defended in the prologue, my status as an insider could be portrayed as a weakness in the study design. Though I made several methodological choices which would prevent investigator-guiding bias, my own assumptions could have negatively impacted the results.

APPENDICES

Appendix A

The Study of Us



CONSENT

By submitting a question, you are agreeing to participate in this study. If you wish to remain anonymous, use the email address anonymous@gmail.com. Your identity will be hidden if you request it to be so in the message box.

USAGE

Your questions will inform the principle investigator's (PI) research question formulation. If you wish to become more involved in the research process, indicate your interest after your question and the PI will contact you.

This is the submission page! Please fill out the form below asking your questions about the Diabetes Online Community.

If you need some help with directing or formatting your question, visit the [help page](#)!

REMEMBER! This website is research oriented. If you are simply looking for information about the diabetes online community, start with the DOC links at the bottom of this page.

Name	
Email	
Website	
Growth, Purpose, or Trait?	+
I agree to participate in this study. Y or N	
Message	

After you have submitted, [click here](#) to see what others in the community have asked!

Avoid getting hung up on the wording of your question by explaining what matters to you

Appendix B

[HOME](#)[CONTRIBUTE](#)[EXAMPLES](#)[CONTACT](#)[WHAT IS THIS?](#)

The Study of Us

EXAMPLE QUESTIONS

GROWTH

What does an expanding community do for those joining, and how does their joining effect veterans who have been around for a long time?

- Submitted by [REDACTED]

If fostering a tight-knit community without creating cliques and in-group/out-group dynamics is possible, would the diabetes online community be more conducive to growth?

- Submitted by [REDACTED]

What can a fast growing community do to sustain overall positive purpose and growth? Are there ways to "feed the system" to keep it moving forward in a positive way, or does trying too hard to force progress interfere with an already present natural positive evolution?

- Submitted by [REDACTED]

PURPOSE

How likely is a DOC participant to turn to advocacy beyond the virtual world?

- Submitted by [REDACTED]

Does the diabetes online community exemplify a supportive collective and if so, how? What does being a strong community look like to patients seeking support?

- Submitted by [REDACTED]

As a whole, the diabetes community remains largely segregated despite the appeal of union. If the diabetes community could transition to be more inclusive, how would the benefits recieved by participants change?

- Submitted by [REDACTED]

TRAITS

As social platforms become more integrated, incorporating similar methods of expression and cross-posting, what are the themes of diabetes-related conversation that are most common? Which themes are best suited for a single, specific platform?

- Submitted by [REDACTED]

How did the Diabetes Online Community come to be? If the history is tracable to a core group of individual advocates, what they have in common that propelled them to co-create the online space?

- Submitted by [REDACTED]



RESEARCH ORIENTED

When creating your questions, keep in mind they need to be oriented toward scientific testing.



Testability Checklist

1. **Compare Variables:** Does my question compare two or more distinct variables?
2. **Objectivity Test:** Is it possible to objectively test my question?
3. **Bias Free:** Is my question free of personal opinion?

Appendix C

UNIVERSITY OF ILLINOIS AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice Continuing Review

February 16, 2017

Heather Gabel, BA
Occupational Therapy
1919 W Taylor
M/C 811
Chicago, IL 60612
Phone: (530) 755-7673 / Fax: (312) 413-0256

RE: Protocol # 2016-0078
“Examining Peer-Support as Defined by Adults with Diabetes”

Dear Ms. Gabel:

Your Continuing Review was reviewed and approved by the Expedited review process on February 10, 2017. You may now continue your research.

Please note the following information about your approved research protocol:

<u>Protocol Approval Period:</u>	February 10, 2017 - February 10, 2018
<u>Approved Subject Enrollment #:</u>	160 (93 Subjects enrolled)
<u>Additional Determinations for Research Involving Minors:</u> These determinations have not been made for this study since it has not been approved for enrollment of minors.	
<u>Performance Sites:</u>	UIC
<u>Sponsor:</u>	None
<u>Research Protocol(s):</u>	
a) Examining Peer-Support as Defined by Adults with Diabetes, Version 3, 07/27/2016	
<u>Recruitment Material(s):</u>	
a) Peer-Support Diabetes Phone Script, Version 2, 02/19/2016	

Appendix C (Continued)

Informed Consent(s):

- a) Peer-support Diabetes: Focus Group - Consent Form, Version 3, 07/27/2016
- b) Alteration of informed consent as per 45 CFR 46.116 for the recruitment and screening via telephone
- c) Waiver of documentation of informed consent as per 45 CFR 46.1117 for the recruitment and screening via telephone

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific category(ies):

(6) Collection of data from voice, video, digital, or image recordings made for research purposes., (7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
01/19/2017	Continuing Review	Expedited	02/10/2017	Approved

Please remember to:

→ Use your **research protocol number** (2016-0078) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the guidance:

"UIC Investigator Responsibilities, Protection of Human Research Subjects"

(<http://research.uic.edu/irb/investigators-research-staff/investigator-responsibilities>)

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

Appendix C (Continued)

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 996-9299. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Allison A. Brown, PhD
IRB Coordinator, IRB # 2

Office for the Protection of Research Subjects

Please note that stamped and approved *.pdf files of all recruitment and consent documents will be forwarded as an attachment to a separate email. OPRS/IRB no longer issues paper letters and stamped/approved documents, so it will be necessary to retain these emailed documents for your files for auditing purposes.

Enclosure(s): None

1. Informed Consent Document(s):

a) Peer-support Diabetes: Focus Group - Consent Form, Version 3, 07/27/2016

2. Recruiting Material(s):

a) Peer-Support Diabetes Phone Script, Version 2, 02/19/2016

cc: Yolanda Suarez-Balcazar, Occupational Therapy, M/C 811
Joy Hammel, (Faculty Sponsor) Occupational Therapy, M/C 811

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CURRICULUM VITAE

HEATHER GABEL

HGABEL3@UIC.EDU

530.755.7673

EXPERIENCE

INSIDER RESEARCHER

2014 – PRESENT

Researcher wearing two hats: scientist and community member Research framework: participatory action research

RESEARCH & TEACHING ASSISTANT

JANUARY 2015 – PRESENT

Qualitative research specialist; Teaching assistant in “Disability, Health and Society,” and “Disability & World Cultures.”

ONLINE HEALTH ADVOCATE

2012 – PRESENT

Blogger at www.thechronicscholar.com, community representative and speaker at 27 conferences

EDUCATION

BA IN COMPARATIVE RELIGION / MAY, 2012

University of California at Berkeley – 3.85

MS IN DISABILITY AND HUMAN DEVELOPMENT / MAY, 2017

University of Illinois at Chicago – 4.0 Emphasis: Peer Support in the Context of Diabetes

PHD IN DISABILITY STUDIES / IN PROGRESS

University of Illinois at Chicago – 4.0

Emphasis: Online Health Communities, Impact and Meaning

SOCIAL MEDIA EXPERIENCE & ADVOCACY

Invited Speaker at HealtheVoices 2017 Conference for Online Health Advocates, Fellow at Diabetes Hands Foundation’s MasterLab 2017, Used FaceBook Live to stream MS thesis defense ~ 2,000 views.