**Politicizing the Condition of Diabetes Online: Counter Narratives
and the Pursuit of Normalcy**

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DISSERTATION

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This dissertation is dedicated to Kimberly Hislop, a fierce diabetes advocate who shared her story to create change for all people with diabetes. Kim's beautifully radical spirit informs the work I've done throughout this dissertation. I hope that wherever she is, she knows what a difference she has made.

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LIST OF ABBRIVIATIONS

ADA   Americans with Disabilities Act

CAP   Critical Appreciative Process

DCCT   The Diabetes Control and Complications Trial

DM   Direct Messaging

DOC   Diabetes Online Community

GAI   Generative Appreciative Inquiry

HRW   Heather Rose Walker

IRB   Institutional Review Board

PAR   Participatory Action Research

PWD   Person with Diabetes

SUMMARY

We live in a social environment that understands diabetes as a consequence of gluttony and inactivity – an individual problem rooted in personal knowledge, choice, and will. This broadly accepted narrative effectively acts to depoliticize the condition of diabetes en masse. My dual-study dissertation calls this depoliticization into question by inquiring into the culture of diabetes online communities (DOCs) across three social media platforms, and facilitating a generative appreciative inquiry action workgroup with eight DOC leaders. Using a combination of netnographic methods, I explore *how* the condition of diabetes is being politicized online. By gazing deeply into narratives, I found that *diabetes is politicized* largely through the sharing of personal stories online. Online, people are connectively rebranding diabetes as an unrelenting, difficult, though manageable condition. They share vulnerability with humility, working to challenge and ultimately change the minds of those who subscribe to the broadly accepted narrative. Online, people appeal to a diabetes identity that serves as a powerful instrument of social change. To complicate this, however, they concurrently attempt to self-protect by advocating only with kindness and gentility.

Throughout this dissertation, I contend with issues of within-group conflict, empowered consciousness, and a connective proclivity toward advocacy strategies that have not been shown to be effective in other historical contexts. I conclude by putting forth a provocative preposition iteratively developed parallel to the action workgroup compelling people with diabetes, researchers, and clinicians to further inquire into alternative, perhaps more direct, modes of politicization in the context of diabetes.

1. INTRODUCTION

It was the kind of uncomfortable silence that is difficult to breathe through. It was November 2013 in Palo Alto California at the Diabetes Mine Tech Innovation Summit, and a panel of high-level payers (health insurance representatives) had just spoken about their beliefs as to why technological innovation in the diabetes sector was slow. They described feeling obligated to avoid covering new technology because they needed to focus on balancing their books. Diabetes advocate, Corinna Cornejo, stood up in this room filled with pharmaceutical and payer representatives and said, "*I don't give a shit about your spreadsheets*." I could hear the nearly inaudible gulp of the person sitting three tables away from me. Time stood still in this act of protest and resistance – the rest of us in the audience in waiting while the palpable discomfort in the room stagnated. It has only been six years since then, and I cannot say I remember how resolve occurred in that room. But I do remember the feeling of movement, and change, and power. I had been living with diabetes for nearly thirteen years at that point in my life, but I had never witnessed such a courageous and outright response to an injustice that impacted me directly. Corinna continued, bluntly calling attention to the problem of prioritizing the bottom line overdoing social good. Other advocates in the room followed suit, sharing their stories of injustice through denials, appeals, and disempowerments. Since that moment, I have found it impossible to turn away from the light Corinna's courageous comment lit in my belly.

This dissertation begins with my story – my story of beginning a journey to understand how change unfolds in the context of diabetes. A hint, this story has no resolution. It does, however, turn in ways unexpected. I invite you to join me and allow yourself to be challenged by the cultural elements of social change I attempt to unpack. I invite you to experiment with the radical shifts in perspective I believe this work offers.

As an emerging scholar in disability studies, my aim is to add to the field by applying disability studies concepts and ideals to diabetes and similarly draw the story of diabetes into the field. If dear reader, you think what I just proposed is a stretch, then this dissertation is for you.

1.1 <u>What to Expect</u>

In this dissertation, I use a three-manuscript format. Each manuscript stands alone as a publishable article. This introduction serves as Chapter 1. Here, I introduce the literature and concepts I grapple with throughout the wider work, in some cases providing definitions of specific contentious terms. In Chapter 2, I provide granular methodological details for both studies I conducted concurrently. The three manuscripts will not include the same level of detail regarding reporting methodology but will borrow material from it. Chapter 3 is the first of the three manuscripts, entitled, "*People need to feel like they're being heard*: A Generative Appreciative Inquiry in Diabetes Online Communities." This chapter covers the Peer Collaborator action group using generative appreciative inquiry with a participatory action research framework. In the methods chapter, it is referred to as *study 1*. Chapter 4 is the second of three manuscripts, entitled, "*Politicizing the Condition of Diabetes Online: A Netnography*." This chapter covers the larger netnographic study focusing on the social media platforms of Twitter, Instagram, and MyDiabetesSecret. In the methods chapter, it is referred to as *study 2*. Chapter 5 is the third of three manuscripts and is entitled, "*Diabetes Identity: A Mechanism of Social Change.*" This chapter focuses on diabetes identity. In the methods chapter, this will be included as a *part of study 2*. Chapter 6 is the discussion chapter, in which I weave together findings from both studies to answer the original research questions described at the end of this chapter as well. I discuss social, clinical, and academic implications. To conclude this chapter, I

describe limitations of the wider study and provide recommendations for future research. Finally, I close out this work with a concluding synopsis of the project.

1.2.   <u>The Social Landscape of Diabetes</u>

The story of diabetes is an ever-evolving one, spanning centuries and crossing cultures. Early texts referred to it as the *sugar disease* and attributed a person's diagnosis to wealth and access to gastro-delicacies (Feudtner, 2003). Diabetes, until the 1920s with the advent of synthetic insulin, was considered a terminal illness. Today, pop-cultural references to diabetes portray gluttony, laziness, and a profound lack of self-care (Chaufan, Constantino, & Davis, 2013). Diabetes is attributed not just to low-socioeconomic status and lack of access to healthy foods, but a lack of education about what foods are healthy to begin with (Rock, 2005). Today, the cost of insulin in the United States is so high that people are rationing the medication and using underground markets to acquire it at an affordable cost (Litchman et al., in press). What it means to have diabetes and the sociopolitical conditions impacting it have continued to shift throughout time[1]. Though there is ample research considering medical advances, technological advances, social determinants of health, disease self-management, and peer support surrounding the condition of diabetes, little to no research has been done to explore community perspectives of and efforts to make change. What issues light fires within the bellies of people with diabetes? What social injustices are they trying to address and dismantle? I argue throughout this dissertation, that what it means to live with diabetes today is as much about social justice as it is about self-management and self-efficacy. That is, the collective experience ought to be acknowledged to an equal extent as is the individual experience. In order to initiate the process

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[1] There are currently 13 different classifications of diabetes (types). The physiologies of those types do vary. However, identifying physiological differences is not within the scope of this research study. No heavily medicalized definition or exploration of the metabolic, auto-immune, and other physiological bases of the disease will be provided.

of the collective experience inquiry, I look to representation. In this project, I seek to address and unpack discourses of representation about diabetes as they occur across diabetes online groups and communities. What does it mean to have diabetes today? What are people with diabetes calling for as they publicly try to make meaning from their lives via their online diabetes community (DOC) experiences? Thus, here I consider the current social landscape of and the discourses around diabetes within the context of *social change*. My work serves to call out and disrupt hegemonic discourses of diabetes representation that attribute the disease to individual behaviors like gluttony, inactivity, and a profound lack of self-care. I argue that conversations occurring online with regard to changing this image are purposeful acts of politicization, worthy of study and recognition.

Diabetes has metabolic, autoimmune, and socio-economic roots – impacting roughly 30.3 million people in the United States (Centers for Disease Control and Prevention, 2017). Though diabetes has been recognized as an inequitable disease that disproportionately impacts people of color and those with lower social-economic statuses in the United States, reports of diabetes incidence rely more heavily on individual behaviors (Borschuk & Everhart, 2015; Mayberry, Bergner, Chakkalakal, Elasy, & Osborn, 2016; Spanakis & Golden, 2013). After years of programmatic and governmental funding for diabetes prevention and self-management efforts targeting communities which are disproportionality impacted, diabetes incidence has continued to rise, and its reporting has continued to focus on individual symptom management markers. This begs the question, why are our efforts to relieve the burden of diabetes not working for those groups most severely impacted?

After the landmark Diabetes Complications and Control Trial (DCCT) was published in 2001, the findings took hold of clinical and medical care communities (Peyrot, 2001). The

DCCT revealed that tighter blood sugar control was correlated with up to a 40% decrease in likelihood of complications (Yi-Frazier et al., 2015). For the first time, it was confirmed that if individuals can more tightly manage their glucose levels, they would be healthier in the long run. The DCCT acted as a catalyst; it shifted the way diabetes care was provided and what it meant to live with it. Standards of care changed, and concepts of empowerment through self-management became trendy. *Activating* patients to adhere to lifestyle prescriptives enveloped the clinical landscape of diabetes, ushering in a new cognitive and mental burden unto those living with the disease. Rather than acquiescing to the inevitability of future complications, persons with diabetes began to ruminate on the possibility of complications *if and only* if they are not able to sustain tight enough control over their glucose levels. The shame, blame, and stigma around diabetes intensified, and the attribution of poor diabetes control latched to willful characters instead of physiological body makeup.

Researchers Chaufan, Constantino, and Davis asked an enticing question in a study of public discourses called "'You Must Not Confuse Poverty with Laziness': A Case Study On The Power Of Discourse To Reproduce Diabetes Inequalities" (2013). Specifically, they asked, "why, then, are health inequalities so resilient, given the extraordinary wealth of knowledge about them and the ostensive collective commitment to their elimination?" (Chaufan, Constantino, & Davis, 2013, p. 145). To address this question, researchers conducted interviews and focus groups with staff members and consumers at a diabetes non-profit organization in a low-income neighborhood in Northern California. Using a critical sociological perspective, researchers performed data analysis with focusing on cause attribution (i.e. what participants identify as reasons for diabetes incidence and for when health outcome measures are not achieved) and references to beliefs about inequitable social contexts as *normal*, *natural,* or

inevitable. Their results contextualize the power of social environment reproducing diabetes-related stigma in the United States (Chaufan et al., 2013). Researchers found that staff who run the organization dedicated to helping low-income persons with diabetes tend to explain diabetes incidence as *a failure of the individual*. Staff persons believe that diabetes is a signal of a defective person who is ignorant of self-care strategies or unwilling to make changes necessary to manage diabetes effectively (Chaufan et al., 2013). Consumers also tended to internalize similar attributions made by staff persons. They themselves believed that if they were better educated and made better choices, their health would be better. When asked about solutions, both staff and consumers pointed toward individualistic education-based solutions rather than social infrastructural ones. Even when prompted during interviews with questions related to structural inequalities, participants reverted back to individual attributions and solutions. They looked at themselves, their habits, their diets, their cultural practices, as the problem that needed to be fixed. This implies that participants believe that the "proper locus of intervention" ought to occur exclusively at the individual rather than the social level (Chaufan, Constantino, & Davis, 2013, p. 161). Even though they are willing to acknowledge social barriers, they ultimately look within to find an answer; they look within to make change. And when considering the trends in diabetes-related care, this is unsurprising.

Persons with diabetes spend approximately 8,000 hours per year thinking about diabetes, though only a few of those are spent within the presence of a health care provider (Hilliard, Sparling, Hitchcock, Oser, & Hood, 2015). Though not an exhaustive list, thinking about diabetes involves self-monitoring blood glucose levels several times a day, administering insulin via multiple daily injection or insulin pump, counting carbohydrates in all food and drink consumed, managing the emotional and physical ups and downs of variable blood glucose levels,

and navigating social stigmas associated with having what is referred to as a 'lifestyle' disease. In part due to the daily demands of self-management, adults with diabetes are at risk of diabetes-distress, which can then negatively impact capacity to employ self-management strategies when needed (Yi, Vitaliano, Smith, Yi, & Weinger, 2008). One way that adults with diabetes have responded to the threat of diabetes distress is to form communities of support both online and in-person (Baek, Tanenbaum, & Gonzalez, 2014; de Vries et al., 2014). And research supports this action.

1.3   <u>**Literature Review**</u>

Research done on online health communities, including those directly related to diabetes, is far-reaching and multidimensional – examining health outcomes, structural network design, and cultural implications. Taken together, the literature points to online health communities as sources of peer support which impact health outcomes, drive and maintain membership, and provide meaning and value to those who participate through either public or non-public action. To arrive at those general conclusions, qualitative, quantitative, and blended methods have been utilized.

After a thorough review, I clustered the literature into three types: 1) outcome-based; 2) structure-based; 3) culture-based. Figure 1 demonstrates a visual diagram of each type and brief descriptors of studies that fell into each.

Figure 1. Visual summary of diabetes online community research by type

Outcome-based	Clinical, concerned with safety, results-focused, quantitative-dominant
Structure-based	Technological and psychological, concerned with usage, deign-focused, blended quantitative and qualitative
Culture-based	Cultural, concerned with meaning of experience, experience-focused, qualitative-dominant
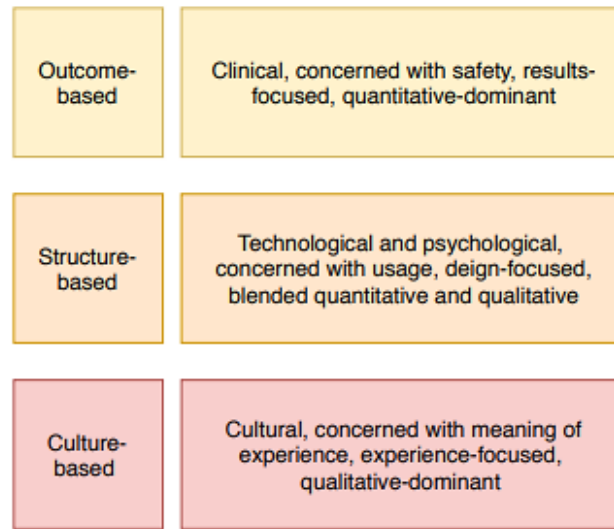
The first type, outcome-based research, focuses on the measured impact of participation on health outcomes, perceived social support, and knowledge acquisition. This type of research emphasizes potential consequences/benefits of participation and tends to utilize quantitative research methods. The second type of online health community research focuses on structural community design. Research of this type examines membership (i.e., who is there), community stickiness (i.e., who stays and why they stay), and social network structures and tends to utilize a combination of quantitative and qualitative methods. Lastly, the third type turns its attention to cultural aspects of online health communities – examining motivation to join, member-to-member interactions, how members make sense of their participation and membership in the community, and how they characterize the community as a moving and potentially growing body. Outcome-based and structure-based research are more common than culture-based research, a possible consequence of diabetes being primarily understood as a problem of the

individual. In fact, almost everything we currently know about diabetes online communities regards only individuals.

1.3.1 <u>What We Know About Diabetes Online Communities</u>

A recent scoping review was conducted to probe and synthesize what is known about diabetes online communities (Litchman et al., 2019). The multidisciplinary team searched serval databases and processed 47 articles spanning academic, health, and computer science disciplines. According to the review, "The 'DOC' is a user-generated term that encompasses people affected by diabetes who engage in online activities to share experiences and support in siloed or networked platforms" (Litchman et al., 2019, p. 22). The review points to several benefits and consequences of participation in DOCs, aligning it with the outcome-based type of research befitting this literature.

Other researchers have found that engagement in diabetes online communities can positively impact A1C (Litchman, Edelman, & Donaldson, 2018; Litchman, Lewis, Kelly, & Gee, 2018), reduce diabetes-related distress (de Vries et al., 2014), and foster support and connection, advocacy, self-expression, information and education, technical support, and humor as a coping strategy (Hilliard et al., 2015; Tenderich, Tenderich, Barton, & Richards, 2018). To paraphrase DOC scholar, Lora Arduser, diabetes online communities are cultural sites that contain a sense of common morality, employ self-protective mechanisms, and exercise a rhetorical vision of life with diabetes in relation to those around them (2011). In this way, social benefits drive community-building public participation (e.g., posting, commenting, up-voting/liking) and non-public participation (e.g., lurking) (Butler, Sproull, Kiesler, & Kraut, 2003). Researchers Zhang, He, and Sang found that members of one large diabetes group on

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Facebook mostly participated to get or give information, though also used the group to build the community and give and get emotional support (2013).

Users who engage with TuDiabetes.org, one long-standing DOC, described it as more than a website – as a space and place for connection and active community (Litchman, 2014). Their interactions follow rules of engagement and are interlaced with behavior-based moral norms (Arduser, 2011). However, other studies have found that even though some users reference their community as *the* diabetes online community, there is no singular monolith making it up. There is no organizing body or clear boundaries that distinguish one DOC from another (Litchman et al., 2019).

1.3.2   Gaps in the Literature

Research on diabetes online communities has largely failed to illuminate socio-cultural elements of diabetes (Johnson & Ambrose, 2006). We lack contextual research which examines the meaning of membership from a socio-cultural perspective, and that defines or explains the collective experience of diabetes. In order to unpack that, we need to identify the narratives that drive and shape these communities. Which discourses of representation are aligned with the dominant popular culture portrayal of diabetes, and which representations counter or resist those narratives? Does the use of narrative impact identity? How do members' identities impact the collective community as a social network? What are users hoping to accomplish by posting diabetes-related content publicly? What are they hoping to change?

By focusing principally on the health and behavior side of diabetes, the cultural side is missed. Thus, my dissertation brings the wealth of information already known about diabetes online communities into dialogue with the cultural elements that have gone overlooked. Specifically, I focus in on cultural elements related to social change as doing so centers my gaze

more directly on the collective experience of diabetes, rather than the individual experience. In the chapters that follow, I intentionally turn away from the health and behavior side almost entirely in order to see people with diabetes apart from those things. I look at three diabetes online communities holistically and produce an atmospheric overview that, for the first time in diabetes literature, considers the collective-experience. I do so within the context of social change.

1.4   Definition of Terms

Four terms within this dissertation warrant thorough defining, as they have been heavily contested, have conflicting definitions depending on the academic field, or simply need to be operationalized in the context of this project. In the chapters that follow, I explore social phenomena related to *community*, *identity*, *narrative*, and *politicization*.

1.4.1   Community

In the field of public health, communities are often defined by geographic boundaries, conceived of as akin to neighborhoods. This pragmatic approach imposes borders, cutoffs, inclusions, and exclusions based on physical location. However, sociologists like Durkheim describe community as a networked society inextricably linked through religious and spiritual structures and institutions maintained through ritual and meaning-making routine. Brint (2001) argues that communal relations influence behaviors and consciousness within individuals regardless of physical location (Brint, 2001). Community is not necessarily about space and place according to these formulations, but about relationships. Social science fields define community more theoretically as well, arguing that community is *a feeling* stemming from a set of relationships between people which foster a sense of belonging (Chavis & Newbrough, 1986).

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However, approaching community as *a feeling* is an oversimplification of a very complex social phenomenon.

We live in a technologically advancing age where communication is progressively moving into digital mediums. Not only are we communicating online, but we are also locating life-partners, purchasing groceries, planning weddings, logging and analyzing health metrics, protesting, forging identities, and so on. In this way, within the internet lives an immense archive of cultural practices, reactions, reflections, mores, and customs unfolding in real-time. We do not just see individual accounts; we see dialogues progressing and regressing rhetoric that color and shape political, economic, cultural, and social life. Groups of people discussing any and every aspect of living, dying, and whatever is in between can be found across social media and media platforms using a single search engine term. As a location of multifaceted cultural exchange, then, the internet serves as a uniquely advantageous site for research examining communities. If an online community can exist, what are its bounds? What distinguishes a community from a group loosely organized by a few leaders with megaphones?

Rather than conceive of online communities through a set of criteria developed by scholars using top-down approaches to research – which introduces a level of colonialism into the research process (Rock, 1988) – the definition of online community I accept throughout this dissertation allows for ambiguous boundaries of a given group/community based on its self-identification (Preece & Maloney-Krichmar, 2005).

For this study, I adapt the definition of online community from Conrad's 2005 work on online learning, which describes an online community "*as a general sense of connection, belonging, and comfort that develops over time among members of a group who share purpose or commitment to a common goal*" (Conrad, 2005, p. 2). This definition, along with an

acceptance of the ambiguity involved in following the self-concept of the group in question, forms a flexible and less oppressive vision of community overall. Rather than *decide for a group* their status as a community based on theoretical criteria, this project will respect the self-concepts of the group/communities in question. Respecting self-concepts also affords participants flexibility in self-definition, which is particularly vital amongst groups that come together based on shared experiences of social marginalization.

Sociologist, Rob Shields, noted in his book *Cultures of the Internet: Virtual Spaces, Real Histories, Living Bodies,* that the internet and its cyberspaces are a particularly productive research context when observing them as an "open frontier for those oppressed by social norms" (Shields, 1996, p. 9). Some online communities are forged because individuals can form a sense of connection to others who have similar lived-experiences of oppression, stigmatization, and marginalization within virtual environments. Socially and culturally marginalized individuals and groups have found support on the internet as a meeting place for connection and as a platform for social change. Sense of community has been shown to impact health across health-related online communities (Berkman, Glass, Brissette, & Seeman, 2000). Autistic persons, for example, use social media platforms to discuss disability as a social construction while reinforcing their collective and individual autistic identities (Parsloe, 2015). In conflict with biomedical discourses, the online Aspie community collectively works to reclaim what is socially regarded as a 'spoiled identity' by celebrating their neurodiversity in the public domains of Twitter, Reddit, the blogosphere, etc. (Parsloe, 2015). I borrow from Parsloe's arguments as I consider diabetes online communities as places of social change. I ask in what areas people with diabetes are seeking change by looking at the narratives are they most frequently countering.

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1.4.2 <u>Identity</u>

Identity takes many forms and flavors in theory and practice. It serves as an organizing principle and is in some cases ascribed and in others avowed. The individual process of identity development, which involves discovering who one is, was theorized to take place most intensely during adolescence (Erikson, 1959). However, identity development extends into adulthood as well as life circumstances and relational roles shift. The construct of identity is too broad to define without breaking down process particulars like agency, communion, redemption, meaning-making, contamination, and exploration (McAdams & McLean, 2013). The concept of identity is further complicated by collective identities and identity development, especially when those collective identities are marginalized.

In Chapter 5, I explore the volatile history of identity politics, situate diabetes identity within the theoretical framing of disability identity, and deconstruct dominant narratives of identity within diabetes online communities. I contend with several questions within Chapter 5, such as: What is the location of diabetes identity, if there is one? Why does *place* matter in the context of diabetes identity? How do the sociopolitical conditions of diabetes impact individual and collective senses of diabetes identity? If there is an identity dynamic in diabetes that reinforces exclusion, rather than inclusion, how does that change the social conditions of the disease state overall? Where do shifts in power happen through the negotiation of identity within diabetes?

1.4.3 <u>Narrative</u>

In its most basic formulation, narrative is how elements of a story are arranged. More specifically, it is the thread of occurrences shaped by a particular worldview. Narratives produce information and knowledge for the listener or reader. The concepts, methods, and definitions of

narrative across academic and health disciplines have varied greatly and evolved over time. Sociological and medical uses of narrative serve a similar purpose, though pull in opposite directions. Both use *narrative* as evidence of meaning-making by individuals and collectives, which can be analyzed and deconstructed to produce knowledge based on lived experiences. However, sociological use of narrative generally works to explain social phenomena and "parse reality into fixed entities with variable qualities" (Abbott, 1992, p. 428). Sociological use of narrative as a methodological foundation of research has been criticized for its over-reliance on the assumption that *story* occurs within recognizable boundaries of time and space – that they represent sequential actions that denote linear causality and interconnection (Abbott, 1992).

Narrative-based medicine, on the other hand, uses narrative as a mediating device to examine the relationship between objective and subjective social dimensions of health and illness (Hurwitz, Greenhalgh, & Skultans, 2004). A physician who uses narrative-based medicine, for example, is pushed to understand their patient first, and problem solve second, rather than the other way around. Thus, it is used by health care providers as a humanizing mechanism that concentrates their efforts on the person, rather than their ailing body (Zaharias, 2018). The ultimate purpose of practicing narrative-based medicine is to improve the delivery of health care by better understanding patient and family stories around health, illness, healthcare, dying, and death (DasGupta, 2018). For this dissertation, *narrative* will be defined using a combination of sociological narrative use and medical narrative use, with one extra twist: social justice.

In the context of disability studies, the use of narrative in research takes on an additional dimension of social justice. Disability studies scholars, Susan Gabel and Susan Peters, describe a topic intertwined with the narrative arch of social justice that cross-cuts all existing disability theory, namely, resistance (2004). Gabel and Peters argue that the theoretical and practical path

forward for disability studies is through a theory of resistance, as it traverses issues of social and economic disenfranchisement, disrupts power structures, and works to transform structural inequalities (2004). Because resistance is inherently political, and the primary narrative of disability is resistance, then disability is political. This perspective is not lost within the walls of academic institutions but rather embedded in the lived experience of many disabled people who have demonstrated actions (e.g., protests) in pursuit of social change (Charlton, 2000).

With that said, the arch of social justice and has been criticized by some disability scholars for being too focused on a certain kind of lived-experience (Barton, 2007). Critics argue that narrative research in disability studies centers too heavily on individuals and groups who have established a form of empowered consciousness, effectively erasing the stories and experiences of less *woke* disabled people. That is, the dominant narratives described within this literature are actually counter-narratives challenging hegemonic discourses and representations of disability as an unfortunate and sad aspect of the human condition. A question of erasure is raised as the stories of disabled persons who do not identify as disabled or who experience only negative sides of disability are left out of concepts of disability based on narrative. As I was formulating this dissertation project, I found myself guilty of this – looking to focus exclusively on the narratives that express a certain level of collective empowered consciousness. Though narratives that resist or counter oppressive hegemonic representations of diabetes are important, they do not tell the whole story.

Therefore, within this dissertation, I use *narrative* to unpack discourses of representation of and around diabetes as told by adults with diabetes who post diabetes-related content online. I consider all narratives, regardless of their alignment with dominant, empowered or less *woke* representations of diabetes.

1.4.4 <u>Politicization</u>

When discussing the topic of my dissertation with those unfamiliar with disability studies, I am routinely asked, "How is diabetes a political thing?" Even many people with diabetes who routinely share personal stories online have asked me this. My answer to these queries has been *because people with diabetes are seeking change.* Underneath my grossly oversimplified usual response is recognition that dominant portrayals of diabetes do not permit for its condition to be politicized.

The social landscape of diabetes, as described at the start of this chapter, diverts all responsibility of diagnosis and management unto to the individuals within which the illness resides. Thus, the condition of diabetes, according to dominant culture, is not a matter of political concern. However, the social conditions of diabetes create external and internal bounds of exclusion. Narratives of diabetes offer reinforcements, disruptions, and deconstructions of those social conditions, warranting an analysis of them through a politized lens (Sakalys, 2000). The purpose of examining how the condition of diabetes is being politicized through narrative and counter-narrative is to critically understand what it means to have diabetes today and legitimize divergent and deviant voices within diabetes populations. The purpose of this dissertation is to marry concepts of resistance found within disability studies to diabetes, squarely positioning diabetes as a politicize-able condition. By redefining what it means for something to be political, we can open "up the possibility for a more radical challenge to such forms of domination and exclusion as racism, sexism, and homophobia than had been possible with more traditional concepts of the political" (Kauffman, 2001, p. 23).

1.5   **Study Designs**

This project design is two-fold: 1) it uses participatory action research approach to co-create an action within DOCs; and 2) it uses an exploratory design to complete a humanistic netnography of three DOCs. These design elements translate into a two-study research project. Though the two studies are methodologically compatible and occur concurrently, they are maintained as separate studies with overlapping content areas to meet the format of this dissertation. All objectives, expectations, and research questions presented here collectively apply to both studies.

1.5.1   **Objectives**

I conducted this dissertation guided by several goals, some of which are action-oriented and others which are knowledge creation/exploration oriented.

Action-oriented goals:

- Facilitate DOC leaders through an action-based workgroup;

- Build capacity within DOCs; and

- Help facilitate a community-generated action.

Knowledge creation/exploration goals:

- Understand the ways in which diabetes is being politicized in online spaces and platforms;

- Contextualize what is known about varying diabetes online communities;

- Understand the extent to which narrative use within diabetes online communities impacts members' sense of connection/connectivity;

- Understand the collective-experience of diabetes using a socio-political lens; and

- Understand what member of diabetes online communities hope will come of posting diabetes-related content.

1.5.2 <u>Research Questions</u>

There are three research questions guiding this research and a number of subsequent probes:

1) If at all, how is the condition of diabetes politicized across social media platforms?

2) What discourses of representation are used across varying online diabetes groups?

   2.1) What dominant narratives are reproduced?

   2.2) What are the counter-narratives?

   2.3) What do interactions between dominant-narratives and counter-narratives look like?

3) What do users expect will come of broadcasting various narratives, be they counter or dominant?

   3.1) What do users hope will come of posting about diabetes on an individual level?

   3.2) What do users hope will come of posting about diabetes on a group level?

1.5.3 <u>Study Expectations</u>

As was disclosed at the start of this chapter, I came into this dissertation with over five years of immersive experience interacting with the population of study. As such, I began this work with some assumptions for what to search look for and what I might find. Because of the possibility of said assumption biasing my work, I recorded them in a fieldnotes journal, which I will discuss at length in Chapter 2. For the sake of full transparency, I now disclose that before I began collecting data, I predicted that the following would emerge:

I. The condition of diabetes is being politicized online by people with diabetes through the use of within-group dominant narrative, and beyond group counter-narrative.

II. Aspects of the condition of diabetes being politicized:

    a. Cost of insulin and other diabetes supplies;

    b. Seriousness of diabetes;

    c. Relentlessness of diabetes;

    d. Diabetes comes in all shapes and sizes; and

    e. Diabetes rules are bendable.

III. There are unifying or binding elements across diabetes online communities based around shared lived experience.

IV. Diabetes identity is built upon a rejection of whole-person acceptance of diabetes (e.g., diabetes is all of me).

2. METHODS

In this dissertation project I conducted two studies concurrently. In study 1, I used generative appreciative inquiry with a participatory action research framework to examine participation in diabetes online communities as a social factor of diabetes health. In study 2, I used netnography to understand the ways in which the condition of diabetes is being politicized in diabetes online communities. Together, the two studies shed light on what is happening in these spaces from a cultural and sociopolitical lens. This chapter is broken down into four sections. Section I briefly offers basic information on the overall sampling, inclusion, and exclusion criteria that was used in both studies as well as the timeline. In sections II and III, I include detailed explanations of all methods used throughout studies 1 and 2, respectively. In section IV, I detail the ethical considerations that formed the ethical boundaries of my wider dissertation.

2.1   <u>Basic Information</u>

It is relatively uncommon for one dissertation to contain within it two separate studies. It was required for this one. Considering what is already known about diabetes online communities, this study needed to fill research gaps in a meaningful way by expanding the research process to directly and actively include the community. Merging netnography with appreciative inquiry was not a feasible option, so I separated overlapping elements, conducted the two discrete studies concurrently, and then synthesized findings across them. Doing one without the other would have left a large research gap unaddressed.

Conducted together, these two studies reveal different aspects of what it means to have diabetes today, through culture, and through action and social change. Table I summarizes all research tasks completed across the concurrent two studies.

TABLE I.
SUMMARY OF RESEARCH TASKS AND OVERALL TIMELINE

Phase	Activity	Description	Participant/Actor	Time
Study 1: Peer Collaborator Group	Intake-Interview	30-minute interview	Individual Peer Collaborators	July 2018 - February 2019
	Community Meetings 1-4	*Discovery, Dreaming, Designing, & Destiny meetings to set search parameters and generate action plan*	Peer Collaborators	January 2019 - May 2019
	Exit-Interview	30-minute interview	Individual Peer Collaborators	June 2019
	Evaluative Survey	5-minute survey	DOC users	August 2019
	In-depth interviews	60-minute interview regarding diabetes and social media experience (x30)	DOCs users	March - June 2019
Study 2: Netnography	Gaining Entrée	Researcher immerses in Twitter and Instagram,	Researcher-as-instrument	Ongoing
	Online data collection (managed using MAXQDA)	1) Archival-data: #dsma on Twitter, Instagram, and MyDiabetesSecret 2) Elicited-data: Structured #dsma chat focus group	DOC users	Ongoing
	Data Analysis & Interpretation	Thematic coding, develop narrative categories, hermeneutic phenomenological analysis	Researcher-as-instrument	Ongoing
	Fieldnotes & reflexivity	Researcher reflections to produce Atmospheric overview	Researcher-as-instrument	Ongoing

Recruitment procedures

      Recruitment procedures looked different depending on the study and platform. Though recruitment strategies will be discussed in the subsequent section of this chapter, Figure 2 demonstrates the recruitment breakdown across studies.

Figure 2. Recruitment procedures breakdown across studies
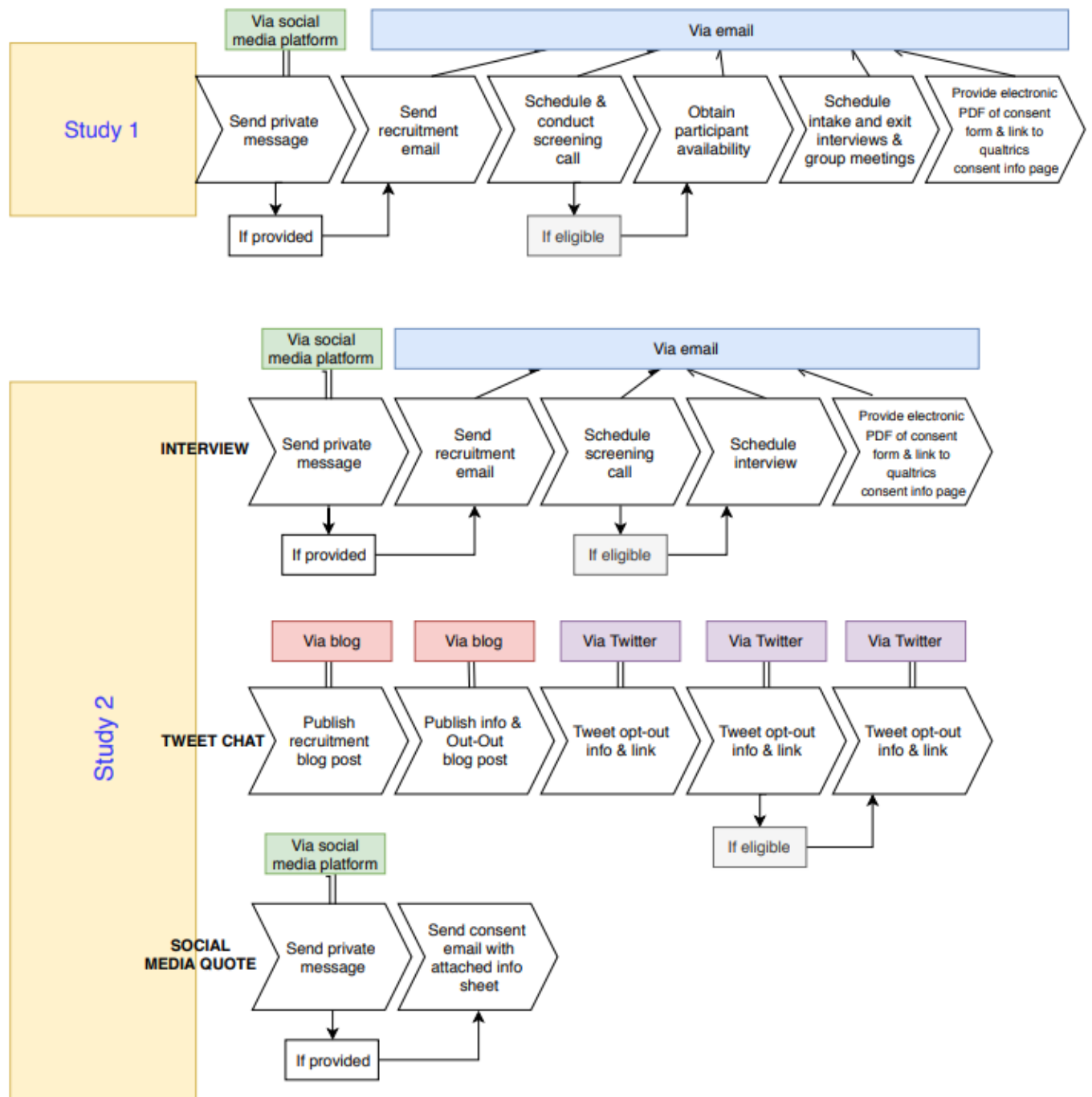
Data collected in aggregate form did not require consent because it is wholly public data which anyone even without an account can access. Aggregate collection is not included in this figure as it does not involve interactions with possible participants.

Inclusion Criteria

- Adults with diabetes (type not specified) ages ≥ 18 who are able to give their own informed consent and also post-diabetes related content online

- Adults who care for someone with diabetes ages ≥ 18 who are able to give their own informed consent and also post-diabetes related content online

- Individuals who are the partner of an adult with diabetes ages ≥ 18 who are able to give their own informed consent and also post-diabetes related content online

Exclusion Criteria

- Anyone aged ≤ 17

- Anyone who is not able to give their own informed consent

- Anyone who does not have a direct connection to diabetes

- Anyone who does not post diabetes-related content online

Screening Methods

I conducted all screening over the phone or email prior to enrolling participants. I asked participants the following questions:

1. Are you age 18 or older?

2. Are you a person with diabetes?

    a. If no, are you the caregiver or partner of a person with diabetes?

3. Do you regularly (at least once/month) post diabetes-related content online?

4. Are you able to provide your own consent to participate in this study?

Excluded or Vulnerable Populations

Minors were excluded from participating in this study in order to eliminate some life-stage variation within the sample and to focus the pilot sample into a specific adult age range. Those who were not able to provide their own informed consent were also excluded from participation. Those without access to the internet were excluded.

Participant Enrollment

I enrolled participants who met the eligibility in the study after they signed the relevant consent form. During the consent process, I informed participants that participation was voluntary and that they may quit the study at any time without influencing their relationship with the research team or University. I discarded records of people who did not meet the criteria so as to not leave any identifiable data. Screening was based on self-report, and I did not conduct any form of medical confirmation. As accepted by the Institutional Review Board (IRB), up to 2,180 participants could be enrolled in this study. Table II shows the breakdown in the total enrollment number if each activity reached capacity.

TABLE II.
TOTAL POSSIBLE ENROLLMENT NUMBERS

Activity	Informed consent?	Phase	Number of Participants
Peer Collaborators	Yes	1	10
Social Media User Interviews	Yes	2	30
Social Media Tweet/Post/Page Quote	Yes	2	40
#DSMA Tweet Chat	Document Waived/ Opt-out only	2	100
Social Media Content	Waived	2	2,000
			TOTAL
			2,180

2.2. **Study 1: Generative Appreciative Inquiry with Community Action Planning**

2.2.1 **Methodology**

The spirit of participatory action research is based on the concept of *participation and change* theorized by Paulo Freire (Khan, Bawani, & Aziz, 2013). According to Freire, change relies on the participation, knowledge, and buy-in of local community members who ought to be "partners in the processes of knowledge creation and social change" (Flicker et al., 2008, p. 288). When we engage community members in the process of praxis (reflexive change-making), "they [may] come to see the world not as static reality, but as reality in process, in transformation" (Freire, 1970, p. 83). Not only are community members included as partners in the research process using this framework, but they also may more directly benefit in many ways, as individuals, as a community and potentially as a social group in society. Participatory action research has been described as a framework which "may also yield research that is more socially relevant, valid, and accessible to people with disabilities and communities alike; qualities which may result in more actions to improve participation opportunities and decrease disparities"

(Hammel, McDonald, & Frieden, 2016, p. 10). I selected the PAR framework for this dissertation because of its inherent criticality and epistemological inclusion of community members within the research process. One method commonly used within the PAR literature is appreciative inquiry.

Appreciative inquiry is "a constructive mode of action research, [which] can unleash a positive revolution of conversation and change in organizations by unseating existing reified patterns of discourse, creating space for new voices and new discoveries, and expanding circles of dialogue to provide a community of support for individuals" (Ludema, Cooperrider, & Barrett, 2001, p. 189). Though appreciative inquiry has traditionally been used as a method of organizational change, its principles and methods can be applied to loosely organized communities and healthcare delivery systems (Cram, 2010). In this study, I adapted appreciative inquiry to meet the needs of a *non-organized community group, that of diabetes online community members who share virtual spaces and networks*.

Specifically, I used the 4D model of appreciative inquiry, which involves four phases: 1) the discovery phase – drawing out the strengths of the community or organization; 2) the dream phase – dreaming up what could be under the best of circumstances; 3) the design phase – community members and researchers co-creating and constructing the ideal; and 4) the destiny phase – co-envisioning a sustainable future which incorporates changes toward the ideal (Ludema et al., 2001). These phases, designed to be iterative and cyclical, have been shown to be useful in health research by shifting "the focus from problems to be fixed to celebrations of successes while acknowledging the power of dialogue" (Trajkovski, Schmied, Vickers, & Jackson, 2013, p. 1230). Appreciative inquiry presents with a unique opportunity to initiate action in collaboration with community members and organizations who have lived-experience

with the social conditions of diabetes and the navigation and management surrounding them in the everyday social and medical worlds.

With that said, there is a variant of appreciative that is slightly better suited for this study. Generative appreciative inquiry (GAI) modifies the appreciative inquiry method by attempting to help members see the group and what it does in a new way, in a way that challenges the social environment around the group and may lead to actual social change (Bushe, 2013). GAI is designed to be transformational through facilitating disruption and "embracing the notion of inquiry as intervention" (Zandee, 2013, p. 84). This method works best when group members are already engaged in reflective practices and are thus primed to challenge the status quo in the pursuit of social change (Schroeder, 2013). Considering the social landscape of diabetes, as was unpacked in Chapter 1, the generative variant of AI was selected because it befits the group of study and because it centers on transformation. Thus, all group meetings were structured around generative appreciative inquiry (GAI) (Cooperrider, Whitney, & Stavros, 2008).

Because generative appreciative inquiry has not yet been adapted to online contexts, this study focuses on exploration of this methodology within virtual elements of connection, such as Google Hangout and via email. Users of diabetes online communities are not bound by physical place, so doing research in person would not have been feasible or realistic, nor representative of this space and the type of connections occurring within it. Furthermore, adapting generative appreciative inquiry to an online context suits the study epistemologically, and also adheres to a foundational tenant of Participatory Action Research (PAR) – to meet the community in the cognitive space and physical place in which they currently reside (Ludema et al., 2001).

In this study, all participant sessions took place over the phone, via email, or over Google Hangouts. Email reminders were sent to all participants before each meeting, and a summative

recap email was sent within a day after each took place to bring back findings and plans to the community and to member check them with participants. If a community member missed a meeting and expressed interest in making it up, an alternative time was scheduled after the group meeting to virtually update them and solicit their input (Birt, Scott, Cavers, Campbell, & Walter, 2016). The participatory action framework is flexible and allows the research to move to accommodate needs identified by group members (Kemmis, McTaggart, & Nixon, 2014).

I audio-recorded all meetings using a detached recording device, then sent the encrypted audio file to be transcribed via a transcription service called [Rev.com](Rev.com) and then destroyed (Rev, 2019). I reviewed a subset of the audio files against the delivered transcripts to ensure accuracy.

2.2.2   Research Questions

Two research questions guided this study.

1) What does engagement with online communities look like as a social element of diabetes health?

2) How can community assets and strengths of diabetes online communities be leveraged to create social change in a community-identified area of need?

2.2.3   Recruitment

Recruitment occurred purposively. I had personally met each of the participants recruited for this study before recruitment began. That prior knowledge of participants attitudes, dispositions, and group behaviors allowed me to form a group I thought would work dynamically together (Dwyer & Buckle, 2009). Additionally, I manually audited potential participants' social media accounts taking into account their current DOC use (e.g., who do they talk to, what do they talk about, etc.), tendencies to be reflexive (e.g., talking about their DOC), and their historical activity (e.g., have they come and gone and if so, why?). Thus, as I formed, I

considered group dynamic, group composition, collective group influence within their

communities, and social media activity. Additionally, I aimed to put together a diverse group that

varied in diabetes type, age, race, ethnicity, and sexual orientation. As I worked through this

recruitment process, I explained in my fieldnotes how challenging it was for me to recruit Peer

Collaborators with Type 2 and parents of children with diabetes, who also had a longstanding

history engaging in diabetes online communities. This challenge is likely the result of my

engagement practices within diabetes online communities. It took me a total of three-months

using email, text, phone, and web-conferencing communications to form the group.

I began preparations for this project several months before any data were collected or

research meetings took place. I did, however, hold a pre-study virtual gathering where I offered a

30-minute presentation on what would happen in the work-group, what participation time and

effort would look like, possible compensation, and what could potentially come out of it. During

this meeting, I asked the participants what title they would like throughout this study. After some

discussion, the group decided on *Peer Collaborators* as their title. I will henceforth refer to these

community members as *Peer Collaborators*.

2.2.4   Meet the Peer Collaborators

Eight Peer Collaborators were enrolled for this study (n=8). Five of the eight attended all

meetings and intake and exit interviews. Two of the eight were unable to continue group meeting

participation after the first meeting but completed the follow-up exit interviews and took part in

the action. One peer collaborator passed away after the last group meeting, so was not able to

complete the exit interviews. When consenting, the Peer Collaborators had the option to use their

real names in this research. All selected that option and voted to be named within this project as

a form of community capacity building. All Peer Collaborators provided a photo and a brief

biography. The PI wrote a biography and selected a photo of Kim Hislop, the peer collaborator

who passed away. Figure 3 introduces the Peer Collaborators.

Figure 3. Meet the peer collaborators

Picture	Bio
	Christopher Snider was diagnosed with type 1 diabetes in 2002. He has engaged in the diabetes online community through a variety of platforms since 2009. Christopher is the Community Manager at Tidepool, a 501(c)(3) nonprofit organization dedicated to making diabetes data more meaningful, accessible, and actionable.
	Karen Graffeo has been living with type 1 diabetes since 1979. She is currently the Program Manager at DiabetesSisters. She has been an active member of the DOC since 2008, when she created her blog Bitter-Sweet. Seven years in a row, Karen has hosted Diabetes Blog Week, bringing together over 150 diabetes bloggers.
	Stephen Shaul has been living with type 1 diabetes since 1991 and has been blogging about life with diabetes since 2012. Steven is currently serving as a member of the State of Maryland's Advisory Council on Health and Wellness, where he is co-chair of the Diabetes committee. In addition, He serves on the 2018 Reader Panel at Diabetes Forecast magazine.
	Kerri Sparling is an internationally recognized diabetes advocate. She is the creator and author of Six Until Me, established in 2005 and remains one of the most widely-read diabetes patient blogs. Kerri is a highly-rated speaker and has presented the patient perspective to audiences around the world. She works to raise awareness for diabetes, patient advocacy, and the influence of social media on health outcomes. Her first book, Balancing Diabetes (Spry Publishing), looks at type 1 diabetes in the context of "real life."

Figure 3 (continued)

Bill Wood [   ] nd motivator that shares his personal challenges living with diabetes while participating in ongoing diabetes research. In 2015 Bill authored an essay "Bionic Pancreas Patient Perspective" in the Canadian Journal of Diabetes.

Beatriz (Bea) Sparks lives with diabetes and has authored multiple diabetes blogs over the last 10 years. Bea has been a voice for type 2 diabetes, fiercely advocating for the reduction of stigma across all diabetes types and community inclusiveness.

Mike Lawson lives with diabetes and is also a digital artist. He has worked at diabetes-related non-profits and written several diabetes blogs in the past. Mike is currently authoring a monthly zine and working in the theater industry.

Kimberly Hislop lived with diabetes and was an advocate for rebranding diabetes across online communities and in-real-life peer support events. She wrote a diabetes blog and participated in Twitter, Facebook, and Instagram diabetes groups. She often was the one voice in the room who advocated for an ideological shift in thinking around diabetes complications and what it means to succeed with diabetes. Kim was a fierce leader and presence in her community, and her loss was felt deeply by them.

2.2.5   Intake Interviews

All Peer Collaborators took part in the intake interview, which was approximately 30-minutes long. I did six Peer Collaborator intake interviews over the phone and two via email. I used the intake interview responses to develop content for the weekly meetings, and cater

activities to the strengths of the group (Ludema et al., 2001). The intake interview guide asked

the following questions:

Q1a. How would you describe yourself?

Q1b. What qualities do you most value in yourself?

Q2. What qualities do you most value in the DOC you participate in most?

Q3. What DOC do you feel most connected to, and why?

Q4. What are the things your DOC does best?

Q5. Why do you post content to your DOC?

Q6. What qualities do you bring to the DOC?

Q7. What do you think will come of posting diabetes-related content to your DOC?

Q8. If you had three wishes for your DOC, what would they be?

The purpose of asking these positively-framed questions at the individual participant level first is

two-fold: 1) to orient the participant toward the unconditionally-positive philosophy and

framework of appreciative inquiry; and 2) to spark reflexivity about their community and their

own valuable contributions to it (Watkins et al., 2001). I provided Peer Collaborators a $10

amazon gift card at the end of each interview for their time.

2.2.6   Community Meetings

The peer collaboration group convened four times, every Tuesday morning during the

month of May in 2019. During each meeting, I led Peer Collaborators through one of the D's of

the 4D model of appreciative inquiry. Figure 3 shows a visual overview of the specific overall

meeting structure and process adapted from the original 4D-model (Ludema et al., 2001).

Figure 4. Visual overview of adapted 4D-model of appreciative inquiry
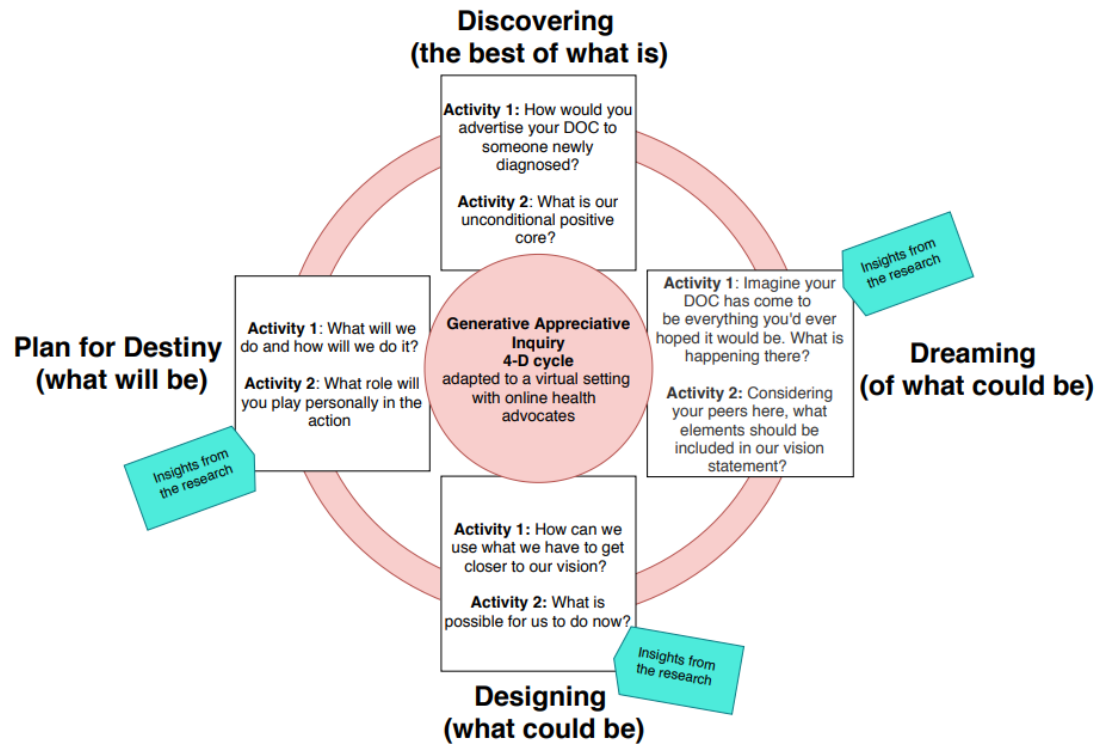
Community Meeting #1: Discovery Phase – 60-90 minutes

Purpose: To explore what gives life and the best of what is; appreciating what already exists; and

begin to inquire *what are our stories*? What is our unconditional positive core?

Education: Introduce the wider study; Explain PAR and Netnography; Introduction to

Appreciative Inquiry 4-D model; and Introduction to dominant-aligned, neutral, and counter-

narrative examples. Introduce the concept of politicization.

Activities:

1. Group Introductions:

  a. Name, platform(s), relationship to diabetes, something you think others in this

   group do not know about you

2. Introduction to the purpose of the discovery phase; share insights from intake

  interviews

3. Advertising Exercise – Peer Collaborators were asked, imagine you are trying to sell

  engagement in a DOC to someone who doesn't know it exists. What are the two

  greatest selling points you would highlight?

4. Core challenge – Peer Collaborators were asked to think about the selling points

  everyone listed and decipher what of those strengths, capabilities, and collective

  assets is the most essential to the group at its best. To assist with the thinking around

  this, I presented Peer Collaborators with an image of a spherical core. Figure 4 shows

  the image I presented to Peer Collaborators.

Figure 5. Spherical image used to demonstrate core challenge
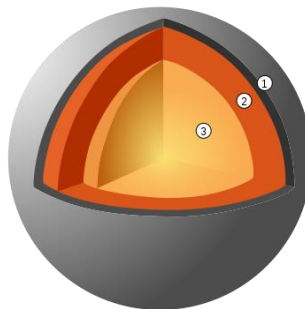
5. Summative discussion – Summary of what had been said across Peer Collaborators, drawing out points of connection and differences in perspectives. I invited Peer Collaborators to respond and reflect further on their identified positive core versus others' ideas.

Community Meeting #2: Dreaming Phase – 60-90 minutes

Purpose: To explore what might be and envision results and impact; imagining, inquires: what do we really care about? What do we really want to change? What do we want for our community? What is the greatest potential of our influence?

Education: Recap results and activities from meeting 1, reintroducing goals of appreciative inquiry; introduce purpose of the dreaming phase; discuss emergent theme of identity via the phrase "diabetes is a part of me, but it doesn't define me." What does this mean to you? Why do you think people claim that?

Activities:

1. Re-Introductions: name and answer the following question: If a movie was made about you, what genre would it be and what actor/actress would play you?

2. Discuss an emerging theme from data collected so far; ask for reflections (e.g., "When you heard that, did anything resonate?" or "How about the opposite, did anything seem weird or off, or surprising?").

3. Dream Scenario – Peer Collaborators have five minutes to type individual responses to the following prompt: "*It is 2028 and you've just woken up from a long sleep. As you look around, you see that while diabetes has still not been cured, your DOC has become everything you've ever hoped and wished it would be. What is happening? How is it different? What are DOC members doing that is making a difference?*" (adapted from

37

Cooperrider, Whitney, & Stavros, 2008). All group members share and reflect on things they heard in common amongst other peers in the group.

4. Crafting a vision statement – I introduced Peer Collaborators to tenants of a vision statement: that it should be provocative, push boundaries, spark interest, be grounded in reality, be achievable within 10 years, and be affirmative and unconditionally positive.

5. Summative discussion - I summarized what had been said across Peer Collaborators drawing out points of connection and differences in perspective. I then invited Peer Collaborators to reflect on the working visions statement and how it felt to collectively draft it.

Community Meeting #3: Designing Phase – 60-90 minutes

Purpose: To merge the best of what is and what might be; to design social architecture; discuss co-construction and innovation to build a blueprint; generate a list of possible actions

Education: The purpose of the designing meeting; concept of social architecture explained (e.g., what are the strengths and assets of the community that build it up – like group identity, projects, or programs) (Ludema & Fry, 2008); and elements of a blueprint are broken down (e.g., steps one could take to leverage the strengths and assets identified) (Calabrese, Hester, Friesen, & Burkhalter, 2010).

Activities:

1. Finalize vision statement – Peer Collaborators weigh in and discuss the vision statement, once conversation resided, yes-votes are recorded individually

2. Discuss an emerging theme from data collected since last meeting; Peer Collaborators offer reflections (e.g., "Does it seem different than last week?" or "Did it seem to help clarify issues raised from last week?")

3. Designing social architecture – I asked Peer Collaborators to create two lists covering materials the community has that can help move it closer to a value articulated by their vision as well as the social materials (further assets and strengths) the community needs to help move it closer to the vision (adapted from Cooperider et al., 2008).

   a. I assigned each Peer Collaborator a social value that was brought up during the first two group meetings (e.g., collective power, inclusiveness, leadership, connection, cohesiveness, celebration, compassion, and transformation), and then asked each person to construct a list of social materials the community currently has and a list of the materials the community currently needs to move closer to that vision. To help facilitate their thinking, I also provided a list of materials or design elements that possibly make up the social architecture of their DOC.

   b. Design elements provided to Peer Collaborators: "*social responsibility, education, vision and purpose, culture, group identity, communications, leadership, celebration, and connectivity, roles, responsibilities, projects, programs, policies, rewards, technology, information, processes, language, laws, schedules and so on…*"

   c. After each peer collaborator shared their lists, common themes were discussed.

4. Craft possibility statements/provocative propositions - Peer Collaborators bridge the *best of what is* and *what might be* by writing a possibility statement that is provocative, grounded in reality, affirmative, and desired (called provocative prepositions) (Ludema et al., 2001). Everyone shares and reflects on the common threads between their possibility statements.

5. Brainstorm actions – I asked Peer Collaborators to brainstorm ideas, no matter how big or small about what actions could be done in the communities to move it closer to the vision. I asked them not to worry about what was realistic or achievable, but rather to use this brainstorm to have fun imagining.

6. Summative discussion – I summarized what had been said across Peer Collaborators, drawing out points of connection and differences in perspective.

Community Meeting #4: Destiny Phase – 60-90 minutes

Purpose: To explore and decide what will be; celebrate accomplishments; select action from action brainstorm from meeting 3; design specifics of action implementation; discuss how to empower, improvise, and sustain; design evaluation

Education: The purpose of the destiny meeting is explained with examples; action selection is explained as needing to be some combination of the following: exciting, realistic, feasible, socially relevant, and measurable.

Activities:

1. Recap of meetings 1-3 – I summarized what had happened since the beginning of the first meeting in the form of a story, highlighting distance traveled and accomplishments of the collective.

2. Action selection

   a. I led Peer Collaborators through the brainstormed action list they made during the design meeting; then, I asked them to discuss, negotiate, and select an action based on what is realistic, exciting, feasible, socially relevant, and/or measurable.

   b. Organize for action

      i. Create plan timeline

40

ii.　Designate responsibilities

　　　　iii.　Identify available resources

　　　　iv.　Identify resources still needed

　　　　v.　Select preferred forms of action evaluation

　　　　vi.　Name the project

3. Write action commitments – I asked Peer Collaborators to each write a personal action commitment which clearly stated what responsibilities they were taking on related to the action. All statements began with "I will."

4. Let's celebrate – Peer Collaborators shared what had changed for them since the start of this appreciative inquiry process – specifically if and how their respective DOC engagement has changed over time (adapted from Whitney & Trosten-Bloom, 2010).

5. Summative reflections – Peer Collaborators reflected on their overall experience with the group process. Specifically, they shared one thing that they learned about DOCs in this process, something they questioned as a result of the process, and a way in which their ideas and thoughts about DOCs broadened.

Each of these meetings and the intake and exit interviews were audio-recorded and transcribed using Rev.com (Rev, 2019). Rev.com ensures that all files are securely stored and transmitted using TLS 1.2 encryption, the highest level of security available. All hired transcriptionists signed strict confidentiality agreements, and never shared the files or personal information with anyone outside of Rev. I made efforts to keep the identity of the participants hidden during the interview so as to not leak identifiable information to transcribers at Rev (e.g., asking Peer Collaborators not to use last names).

2.2.7 Exit Interviews

The appreciative inquiry design is a flexible method, allowing for the objectives and activities of each meeting to shift to accommodate the desires and progress of the group members (Whitney & Trosten-Bloom, 2010). This flexibility extended into the intake and exit interview processes. At the end of meeting 4, Peer Collaborators expressed concern over being overwhelmed with their diabetes advocacy and work overload over the impending months. To respond to this, I acknowledged their concern and assured them that it was okay to only do what they could, given their time restraints. I also converted the exit interview to an exit survey to accommodate their busy schedules and reduce the overall burden of participation. The exit survey was developed and disseminated via UIC Qualtrics following all accessibility standards (Qualtrics, 2005). The survey asked questions regarding reflections of the appreciative inquiry process and expectations for the planned action. A copy of the Exit Interview survey can be found in Appendix A.

2.2.8 Content Data Analysis

All data analyses were iterative (DiCicco-Bloom & Crabtree, 2006). I began data analysis after the intake interviews were complete and continued throughout the 4D meeting cycle, posting findings, and member checking these with the Peer Collaborators throughout the process. This process allowed the study to build on itself, inching closer to a study form and topic that was socially relevant to and met the needs of the community (Carter et al., 2007). I used axial coding to code all the meeting transcripts using the MAXQDA software (VERBI, 2016). I started by reading each transcript as I got it in full. Then I read it a second time, this time marking the text with colors and ideas (McSherry, Timmins, de Vries, & McSherry, 2018). As more meetings occurred, I went back to each prior meeting transcript and did a code comparison. As categories,

themes, and subthemes and reflections emerged, I verbally shared them with the group, starting with phrases like "It sounds like you said…" and then asking, "Does that sound right?" This collective reflexivity captures the spirit of PAR and breaks down the tendency toward interpretive errors (Cornwall & Jewkes, 1995; Tanabe, Pearce, & Krause, 2017). It also serves as a form of member checking during the data collection process, thereby increasing the rigor of the study (Birt et al., 2016).

In addition to the analytic procedures, I used a foundational guiding analytical framework to interpret the data. I chose critical theory because it draws on the wider social context to which group members belong – deepening the interpretations (Grant & Humphries, 2006) and because it has been underused in appreciative inquiry research (Dick, 2009).

2.2.9   Evaluating the Action

At the end of Meeting 4, Peer Collaborators were asked how they would like to measure and evaluate the *success* of the campaign. After some discussion, they decided they wanted me to track the social media metrics one week after the launch of the campaign using a social media search engine. To do this, I used a publicly available search engine that specifically searches social media platform. I used https://www.social-searcher.com/ at the one-week post-campaign launch. I recorded the total number of posts, shares, likes, and top shared posts across Twitter, Facebook, and Instagram and then emailed Peer Collaborators in real-time during the campaign.

As a follow-up, I developed and sent out an anonymous evaluative online survey to community members who may have been engaged in the campaign using UIC Qualtrics following high accessibility standards set forth by Qualtrics (Qualtrics, 2005). A copy of the evaluative survey can be found in Appendix B. The purpose of this survey was to gauge knowledge of, interest in, and reflections on the generated action.

2.3   Study 2: Netnography

2.3.1   Methodology

Ethnography is a method designed to allow for a movement beyond surface readings of what is happening into interpretations of why things are as they are, the purpose to gain an understanding of a deeper truth underlying human interactions and culture (Paulsen, 2009). Ethnographers use flexible combinations of naturalistic participant observation, in-depth interviews, fieldnotes, thick description, and member checking (Iacono, Brown, & Holtham, 2009). Through these methods, ethnographers venture to produce writings that reflect cultural truths and beliefs, drawing a social critique in the process (Clifford, 1986). I, thus, chose to pursue ethnography for this dissertation project because of the deep dive it allows, the variety and flexibility of methods available, and the capacity it has for social critique.

Netnography, a neologism combining *internet* and *ethnography*, has been described as a systematized and pragmatic approach which takes into account ethical and procedural elements specific to ever-shifting cultures and groups with online configurations. It is formally defined as a "specific set of related data collection, analysis, ethical, and representational research practices, where a significant amount of the data collected and participant-observational research conducted originates in and manifests through the data shared freely on the Internet, including mobile applications" (Kozinets, 2015, p. 79). Netnography, then, uses a set of practices to explain how online group interactions and behaviors and the people and artifacts within them relate to existing or new theories about the social environment.

Though netnography was invented by a scholar in consumer marketing and communications, its applications extend far beyond these fields. Netnography has been applied to research spanning health, business, and academic fields (Kausel & Hackett, 2016; Kozinets,

2019; Langer & Beckman, 2005) and explored as a critical research method used to explore social hierarchies, power structures, and identity (Bertilsson, 2014).

To paraphrase Kozinets, there are six fundamental differences between ethnography and netnography:

1) alteration of communication – there is a more performative nature to online interactions and self-representations that requires scholars to acknowledge how interactions and communications between people and groups are altered to fit the *place* of social media;

2) access to groups – the hybridity of public and private connections in online groups adds challenges of access to individuals, groups, and cultures;

3) archiving – all social media interactions are automatically archived and remain findable via search engines making later data analysis not reliant on researcher memory;

4) analysis – finding, capturing, curating, and coding online social data require research skills that move far beyond ethnographic ones;

5) ethics – conducting online research is relatively novel in the academic research world, making the ethical considerations and legality of data collection thorny at best, and an ever-shifting arduous task at worst; and

6) colonization of online spaces – so much of social media has been colonized by corporations and organizations for marketing purposes that impact the ways people interact online with one another and researchers (2010).

Another fundamental difference between ethnography and netnography revolves around the blending of audiences. When analyzing social media posts, researchers must take into

account that a single post could be intended to speak to multiple audiences or none at all. In traditional ethnography, recorded interactions are more deliberate; thus, the analysis of them may be more direct.

Netnography then produces unique challenges and requires distinctive skills which set it apart from traditional ethnography. With that said, variations of netnography stipulate further considerations. Specifically taken up in this dissertation is the consideration of conducting netnography in online groups who discuss sensitive topics, like health and illness, or the subversion of medical advice. Those considerations led me to develop three criteria which guided this work.

As a scholar in the field of disability studies, I chose to pull three criteria from the corpus of netnographic work upon which to guide my use of netnography which are relevant to the central epistemology of disability studies. I used these three criteria as self-checks within my fieldnotes in order to produce a more just academic process and result. Figure 5 shows a summary of the criteria I developed and used herein.

Figure 6. Summary of netnographic evaluative criteria

Negates Othering
Reduces, rather than expands space between researcher and population of study

Self-Awareness
Author(s) reflects on their own positionality, background, and theoretical perspectives

Anslysis with Story
Analysis goes beyond categorization, drawing and interpreting meaning from data to form larger picture
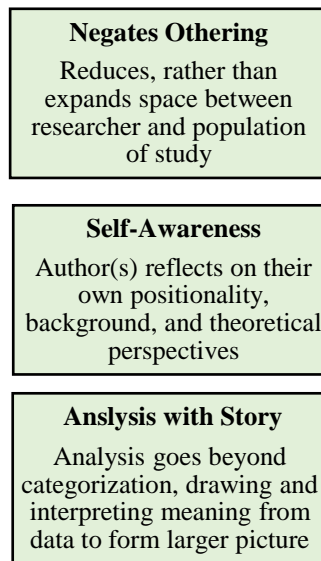
The first criterion I developed to guide the use of netnographic methods in this study is: N*egates Othering*. When a researcher immerses themselves in the community or group of study, the social and hierarchal boundaries between *us* and *them* begin to dissolve. According to disability studies scholar, John Davis, the dissolution of said boundaries begins when participants are valued as experts of their own experience (2000). This negotiation of power relations between the ethnographer and participant requires both parties to immerse in a bi-directional knowledge exchange, a tenet lodged within the netnography canon as well (Costello, Mcdermott, & Wallace, 2017). Davis argues that the ethnographer ought to "exchange their knowledge with disabled people in hope that it will contribute to their fight against oppression" (Davis, 2000, p. 202). Further, Davis reasons, the ethnographer's writing should, to some extent, counter hegemonic discourses which reproduce systems of oppression through knowledge. In line with Davis's approach, I place a high value in the merits of an online study using netnographic

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methods on the basis that negates, rather than reinforces or expands, the distance between the researcher and the researched. This is of particular importance in online spaces where oppressed groups likely have found respite through chosen, rather than ascribed identities.

The second criterion developed is: *self-awareness*. Central to netnographic methods and principles is the process of reflection. According to disability studies scholar Corbett O'Toole, disclosing one's positionality in text is an opportunity to dismantle the knowledge-production-related power structures maintaining social inequalities faced by disabled people (2013). However, this criterion also includes the use of reflexive methods throughout a study which calls into question and highlights the researcher's beliefs, disciplinary convictions and arcs, and goals for producing new knowledge. The taking and use of fieldnotes is one method ethnographers have employed in online settings which provides a richness to the data available for analysis while also drawing the predilections of the researchers out for discussion (Emerson, Fretz, & Shaw, 2011). Robert Kozinets, author of *Netnography: Redefined*, recognizes the difficulty of "holding up a mirror to ourselves" as instruments of research (Kozinets, 2015, p. 95). Reflexivity is not built into every field of research, but it is in disability studies. This dissertation will hold reflexivity as a standard of rigor, especially considering the study is centered on a group facing stigmatization.

The third criterion developed to guide this netnographic work is: *analysis with story*. This criterion accepts the merits of complex data analyses. This criterion requires the PI to consider many questions related to interpretation and ordering of data. Does the study point to findings that are contextualized to the local virtual setting? Does the author situate the findings within the wider culture and relevant cultural theories? Because ethnography so heavily emphasizes the voices of participants, the researcher's ability to weave data narratives into a story is paramount.

To paraphrase, the story is a crucial element of ethnography because it allows for a complex rather than reductionist cultural interpretation of social phenomena (Kozinets, 2015, p. 206). The thick description which paints and forms that cultural interpretation is what breathes life into the ethnography (Bowler, 2010). I developed this criterion in response to recently-published health-related online ethnographic studies which fail to move beyond the categorization of discussions. That is, they fail to interpret beyond the content itself. This criterion required me to do more than simply describe what already exists and move into the territory of asking why things are as they are and what it means that things are as they are. Effective use of netnographic methods involves "an explicitly human window into the rich communicative and symbolic world of people and groups as they use the internet, the web, and social media, leaving its traces and transmissions for us to discover and decode" (Kozinets, 2015, p. 80).

Using these three criteria as guidelines, I was able to methodologically and philosophically ground the selected methods in a way that complemented the disability studies social justice framework.

2.3.2   Research Questions

The overarching research question guiding this study was: *How is the condition of diabetes being politicized by people with diabetes online?* This research question went through several iterations at times expanding to broaden and at others contracting to narrow in scope and vision. Following with netnographic practice, I was constantly attempting to expand my awareness around the fact that my quest for and perspective of the data was biased to meet the call of the research inquiry (Kozinets, 2015). This is to say, because my research question focuses exclusively on content related to the way diabetes is being politicized, my search for social media content will naturally exclude a mass of potential data that could also tell a part of

the cultural story of diabetes online communities. I made use of fieldnotes to question this built-in data collection bias, questioning on several occasions, "What would it mean to include content like this? What does it mean that it isn't a part of the story?" For example, when excluding posts related to experiences with diabetes technology, I reflected in fieldnotes: "*This is an important aspect of diabetes identity – relationship to technology. But it doesn't fit the criteria and research question. It feels weird to exclude, but I have to do this. Note to Self: you can always research this specifically later.*"

To answer the research question, I used several netnographic research activities throughout study 2. Both retrospective (elicited) and prospective (aggregate) data were collected. I used a combination of gaining entrée, participant observation, interviewing, tweet chat as focus group, aggregate data collection, atmospheric analysis, and reflective fieldnotes to generate the forthcoming netnographic articles.

2.3.3 <u>Gaining Entrée</u>

The online groups examined for this study are those in which I had been engaged in for five years prior to any conceptual development of this study. I was entrenched in the diabetes-blog scene and used Twitter, Facebook, and Instagram to engage with diabetes online communities as early as 2013. I started my first diabetes blog, called Unexpected Blues, in 2013, without the express intention of studying the groups it ultimately exposed me to. In 2015, however, when I was accepted into graduate school, I realized I wanted to somehow study what was happening online in and around these groups, so I started looking at interactions, conversations, and behaviors in a more systematic way. I started asking clarifying questions when I saw patterns, a form of member checking via community-engagement and participatory co-creation of knowledge (Masuda, Zupancic, Crighton, Muhajarine, & Phipps, 2013) years

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before the formal parameters for this study were approved. I became a recognized member within an ever-expanding and ever-shifting diabetes online community who wore many hats. This relational process involved constant negotiation and renegotiation as my place within the group evolved from a layperson to researcher (Costello et al., 2017). I felt my willingness to share fade and my desire to listen intensify. Around the fall of 2016, I began tracking hashtags, linking them to other hashtags, and falling down rabbit-holes into social media doldrums you must be looking for to find. Though not in all, in many, I offered an affirmative voice – words of encouragement and expressions of my humility. I traversed diabetes online communities spanning social media platforms getting to know the userbase and content streams this way – absorbing how they differ across demographics and platforms. Though the intention with which I gained entrée changed over time, I've maintained a critical eye. While it could be argued that I could never produce an *etic* perspective of what is happening in diabetes online communities as a result of my close affiliation with the group of study, I can consciously take a step back as many insider researchers have done (Dwyer & Buckle, 2009; Richards, 2008). Gaining entrée for me, then, followed a naturalistic course, developing slowly, cautiously, and with intention. Along a similar vein, though it is challenging to negotiate between roles (effectively code-switching), my pre-established insider-status serves as a strength within the participatory action research philosophy (Dwyer & Buckle, 2009). As will be detailed herein, I checked the potential biases and preconceived notions I brought with me in a reflexive fieldnotes journal.

2.3.4   **Participant Observation**

Participant observation in the groups in focus for this study looked partially naturalistic and partially contrived. At its most naturalistic, it looked engaging with users I had already had regular contact with around their tweets and posts discussing representations of diabetes. At its

most contrived, it looked like me reaching out to strangers asking them to clarify their positions around a recently posted representation starting with "I'm studying X and wondering if you might say more about that." In addition to fluctuating levels of naturalness, the participant observation looked different depending on the social media platform I used. For this study, I used participant observation on my:

a) Personal blog via www.TheChronicScholar.com: This blog existed before the genesis of this project. It was not designed to be a research blog, but rather a community blog to engage with people with diabetes and those who care for them. On two occasions I elicited comments from community members, asking for reflections, etc. Their comments were entered into my fieldnotes journal only. The comments were never quoted directly, nor referenced. All comments entered into the fieldnotes journal were stripped of any identifiers of the commenter. They were entered into the fieldnotes to assist with my own reflexive practice. On the Chronic Scholar blog, however, I did introduce the study and my intentions with collecting data. It was my hub for sharing information about and iterative process for the netnography. It was also the location of information about the tweet chat focus group, which will be detailed herein.

b) Twitter: I used my personal diabetes-focused twitter account @Heather_RoseW to engage with the #dsma community (an established DOC which will be detailed herein). I used my account organically as a pre-existing member of that community and also as a PhD student in academic twitter circles. I participated in several tweet chats around #dsma, #HCSM, #HealtheVoicesChat, and #WhyWeRevolt. At the time of this submission, I had 3,334 followers, demonstrating a large and growing social network on Twitter.

c) Instagram: I used my Instagram account @heatherrosewalker organically as a pre-existing member of an Instagram diabetes community. Throughout this process, I grew my network of connections by following hashtags, following diabetes-related accounts and users, and posting text photos asking for input about the community.

Across all platforms, I always prefaced my participant observation with disclosure of my position as a researcher. I was direct and private messaged on several occasions to explain my intentions and in one case, my research questions. Every time asked, I gladly offered more information and sent them to my blog, which contained the most detailed study-related information. This helped to increase the transparency of the research in online spaces (Green, Polazzi, O'Loughlin, & Traverso, 2016).

2.3.5   Aggregate Data Collection

Over the course of a year, I systematically and purposely reviewed and stored publicly available social media data that met a pre-set list of criteria. To be included, the post had to do all of the following:

1) present or react to a representation of diabetes;

2) come from a person with diabetes, a care partner to someone with diabetes, or a healthcare provider of someone with diabetes; and

3) be explained through story/personal experience.

However, aggregate data collection also varied depending on the platform in question, a method supported by theory and practice (Madianou, 2015). While there was likely some cross over, these three platforms differ across content, demographics, stickiness and retention, frequency of posts, bonding, and cohesiveness. It was imperative that data be collected in a way that meets the

platform. For example, Twitter data can be aggregated via a spreadsheet in a readable format, whereas Instagram data cannot.

Up to 2,000 individuals were set to be included in this research activity. There was no compensation for this activity. I collected archival/aggregate data from:

1. *#DSMA weekly tweet chats* –very sticky (same members returning and staying); growing user base; self-identifies as users of "*the* diabetes online community"; type 1 dominated, but not exclusive; offline (in-real-life) meetups. I was very familiar with this group and had met several users in-real-life prior to the study beginning. Many already knew about my research from community grassroots engagement.

2. *#DiabetesCommunity & #T1Dawareness, & #T2D on Instagram* – medium stickiness; demonstrates cross-pollination of diabetes narratives between type 1 and type 2 diabetes (T1D & T2D). Members reference each other occasionally. I had already met a few of the users who seem to be leaders/influencers in this group.

3. *MyDiabetesSecret Tumblr* – not sticky, <u>anonymous</u> user-based submitting diabetes-related secrets; demonstrates contention between type1 and type 2 groups. Also seemed to be a place for people to express deeply personal thoughts about living with diabetes. There was no risk of identification because user posts are anonymous.

I stored all archival data in my secured UIC box drive in password-protected files. Identifiers were attached to the data as all data collected in the form of photos, text, and page is wholly public data on Twitter, Instagram, and the one Tumblr page (none of which require a person to have an account to collect data). On a few occasions, I took a screenshot of a relevant social media post using my mobile device if I happened upon it when not in a data grabbing session. When that happened, I would move the screenshot into my UIC box drive within 24

hours, then delete the photo from my mobile device. All data saved in the Box drive was transferred into MAXQDA, a data storage, and analysis software used throughout all studies in this dissertation (VERBI, 2016).

After I started preliminary archival data analysis, I identified specific posts, photos, tweets, and content that demonstrated emergent themes (Finfgeld-Connett, 2014). In line with the Twitter Terms of Service and with my ethical principles, I reached out to the authors who produced the content seeking permission to quote it. I did this by Direct Messaging (DM) each person and asking if I might send them an email. Because sending a message on the three platforms does require a person to have an account, this point of contact required a waiver of consent. If they provided their email address, I proceeded to email them with my UIC email address using Institutional Review Board approved recruitment documents. If they did not provide an email address or if they never responded to an email, I either did not use the item or mixed around words in a way that made it untraceable but maintained the meaning behind it. At the end of this chapter, I will return to ethical considerations and provide a detailed explanation of the ethical parameters used throughout the wider dissertation.

2.3.6 <u>Tweet Chat as Focus Group</u>

As a form of elicited data collection, a tweet chat was hosted, which replicated previous research (Chai, Ranney, Boyer, Rosen, & Lewis, 2017). The tweet chat was organized and lead in ways similar to a focus group. Though in-person focus groups are not constrained by word counts, they are constrained by group dynamics. Focus groups require the researcher, or group members to set ground rules and establish the possibility that they may interrupt if participants are talking over each other or a dominant participant is taking over time and not giving others a chance to equitably share their own story (Krueger & Casey, 2015). Conversely, in a tweet chat,

all participants share their responses at the same time then respond to and retweet the responses of others, so tweets build on each other. A tweet chat as focus group also allows for much higher participation rates and for asynchronous responses to roll in after the dedicated hour has ended (Chai et al., 2017). This method is particularly high-yielding when hosted through an already established weekly twitter chat. Thus, I used this method with one such established group: #DSMA.

Diabetes Social Media Advocacy (#DSMA) began its first weekly tweet chat in 2013 and has, barring a few missed weeks, remained a steady location of communal gathering for people with diabetes online. Spearheaded by powerhouse advocate, Cherise Shockley, #DSMA has been described as a lifesaving hour of connection and peer support (Hilliard et al., 2015). Because I had participated in and even hosted #DSMA so many times in the past and personally met Cherise Shockley over a dozen times, she allowed the opportunity to host #DSMA for an hour-long tweet chat focus group.

I hosted the #DSMA tweet chat focus group on April 24, 2019, for one hour starting at 9 pm EST. I pre-arranged six questions posted them with recruitment and study information a week before the chat on my community blog, www.TheChronicScholar.com. I hosted the tweet chat in real-time, question by question, as would occur in an in-person focus group. A blog post with information about the study and an opt-out procedure was tweeted from my personal account, and the host (@diabetessocmed) account several times before, during, and after the tweet chat. This activity was set to enroll a maximum of 80 participants. Figure 7 demonstrates the tweet procedures, questions, and timeline of the chat.

Figure 7. Tweet chat as focus group chat guide
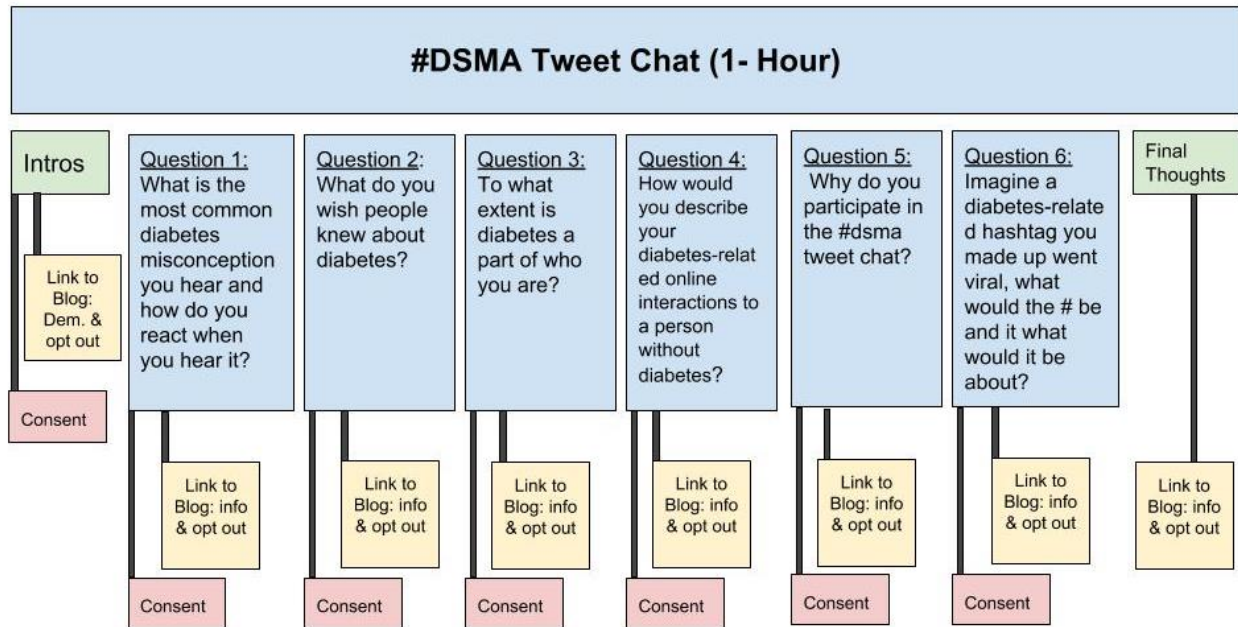
I archived all tweets, retweets, and response-threads using MAXQDA and Symplur (Audun, 2019; VERBI, 2016), two online tools for data capture and analysis.

2.3.7   In-Depth Interviewing

Twenty people were selected to interview based on an audit I conducted of their social media profiles. I purposively recruited interviewees from diverse backgrounds who share varying narratives of diabetes online. To maximize variability within the sample of invitation to interview was based on the following criteria: frequency of diabetes-related posts, audience/follower type and size, type of diabetes, ethnicity, gender identity, social media platform preference, age, and level of personal sharing. When I began recruiting, I was started with a strategy to include some users who share dominant narratives (e.g., If you have diabetes,

you just need to eat well, and you will be fine), some who share counter-narratives (e.g., diabetes is a complex condition that plays out differently for everyone), and some who remain relatively neutral (i.e., they do not take a position either way). However, as I began auditing profiles, I found that very few individuals polarized to either type of narrative, but rather, shared a combination of dominant and counter-narratives at different times. Thus, my recruitment strategy shifted to focus primarily on the criterion listed prior. I kept close records in my fieldnotes of how each interviewee was selected so that it was clear I had not just cherry-picked people I already knew or narratives with which I agreed. Each interviewee was provided a $20 gift card honorarium for their time.

As is common in in-depth interviewing, the interview guide remained flexible to accommodate participant responses and data processing (Seidman, 2006). The interview guide used in the last interview, thus in its last iteration, contained the following questions:

(1) Why do you post content online about diabetes?

(2) Overall, what is your goal for posting about diabetes?

    PROBE: What do you hope to gain, personally?

    PROBE: If you do not hope to gain anything personally, what is your main

    motivation to keep doing it?

(3) How would you describe your online self/persona?

    PROBE: How do you hope your followers see you?

    PROBE: How do you think your followers see you?

(4) Next, I'd like to ask you about a specific post you made, [shows or describe post] in

    which you [said/photographed] [describe post]. Can you tell me a little more about it, and

    what it was like to post that?

PROBE: What led to you decide to post that in particular?

PROBE: Who were you hoping would see the post?

PROBE: What were you hoping would come of the post?

PROBE: In what ways were you satisfied or not satisfied with the result of posting it?

(5) To what extent is diabetes a part of who you are?

PROBE: Who or how does diabetes require you to be?

(6) Is there a diabetes identity?

(7) If you had the opportunity to go on the Ellen show to talk about diabetes, but you could talk for 1 minute, what would you say?

PROBE: Of all the things you could share on the Ellen show, why would that be what you said?

The purpose of the user interviews was to gain a richer understanding of various narratives used. Questions of motivation to post, conceptions of online persona, stories behind specific posts, and high-stakes diabetes narratives were asked. Conducting these interviews also served to triangulate the data by directly asking users what posting about diabetes means to them, why they do it, and what they hope to gain (Brace-Govan & Demsar, 2014). In other words, asking these questions directly served to challenge, confirm, and or bring depth to the interpretations and analyses I was doing of the aggregate data (Birt et al., 2016). Though not initially in this interview guide, I added questions about diabetes identity to reflect results from the tweet chat and preliminary data curation (Kozinets, 2017). I added these questions because nearly all tweet chat participants answered the question "to what extent is diabetes a part of you" the same. Considering my dissertation is framed around the use of narratives, I felt a need to unpack this further. When reflecting on the tweet chat data, I wrote in my fieldnotes,

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This is a grand narrative – the idea that diabetes is integrated with self, but not

fully. Is it a partial acceptance? Or is there something more happening here.

I'm wondering if I explore this further, or if I just interpret it as is? On a

personal level, I may not get another dedicated opportunity to research diabetes

identity. Could I add a question or two to the interview guide? It could be a

powerful area the explore that has been underexplored in the lit.

Acting on my reflexive thought-process, I added the questions of diabetes identity. The

result was fruitful, as an entire chapter of this dissertation is now dedicated to *diabetes identity*.

The interview questions shifted throughout the interviews as interviewees reached saturation on

certain questions and themes (Constantinou, Georgiou, & Perdikogianni, 2017; Morse, 1995).

For example, the first seven interviewees answered the Ellen question (regarding grand

prioritization of diabetes-related issues) exactly the same. It was moved up in the interview guide

to determine whether or not I was priming interviewees to all respond in the same way; a

strategy used to self-check researcher bias (Krefting, 1991). After three more interviewees

answered similarly despite the positional movement, I relocated the question back to the end.

I audio-recorded all interviews and sent them to be transcribed using Rev.com (Rev,

2019). Rev.com ensures that all files are securely stored and transmitted using TLS 1.2

encryption, the highest level of security available. All transcriptionists have signed strict

confidentiality agreements. A signed non-disclosure agreement between Rev.com and myself

was included in the ethical review process, which will be described toward the end of this

chapter.

2.3.8   Self-Reflective Fieldnotes

Using fieldnotes throughout the narrative analysis to capture my reactions and personal reflections, I often applied the content to my own experiences (Kulavuz-Onal & Vásquez, 2013). I wondered if this was something I'd seen or was it something new? I categorized things I expected and things I was surprised by personally. Sometimes that came in the form of the actual post, or via responses to a post. I started writing fieldnotes when I began brainstorming about which community members I intended to ask to be in the Peer Collaborator group for study 1. I have kept a journal of my actions as well as my reactions to content and intuitions about research processes. Researcher reflexivity has been identified in qualitative research literature as a tool for increasing the validity of a study with qualitative elements (Creswell, 2003). Researcher reflexivity in the form of fieldnotes is also an integral aspect of netnography, and humanist netnography in particular (Kozinets, 2015). This iterative processing is argued to increase trustworthiness of the findings as well as decrease bias by offering the researcher time and space to process and support pre-conceived notions of the subject matter (Emerson et al., 2011).

2.3.9   Member Checking

Member checking, when thorough, provides validity to the methodology used and helps demonstrate and increase the trustworthiness of the findings produced (Koelsch, 2013). There are several layers of member checking built into this study. First, I prompted all interviewees in the consent form to indicate their willingness to be contacted via email regarding study findings. For those who consented to that, I followed up via email with either a copy of a manuscript in which they were quoted or a graphic that showed concepts I was developing based on the data (Buchbinder, 2011). Second, during study 2, I shared developing insights from study 2 with the Peer Collaborators and asked for reflections. Because the two studies were happening

concurrently, this process of member checking was relatively seamless. I did not share raw data with the Peer Collaborators to ensure the privacy of social media users. Third, I used my community blog (The Chronic Scholar) to post about ongoing analyses to give community members something to react to. However, I was selective about the type of findings to share, so as to not hurt community members or their sense of being in the community (Krefting, 1991). Doing this last form of member checking was also important for me to maintain the relationship and rapport I have with individuals across DOCs.

2.3.10 Data Analysis

All netnographic data collected throughout study 2 was filed systematically into MAXQDA and analyzed using several rounds of manual and computer-mediated coding (VERBI, 2016). Hermeneutic analysis was chosen over other forms of analysis for the netnographic data because it calls for iterative coding and recoding of data (Kozinets, 2015) and because it is "interpretive and concentrated on historical meanings of experience and their developmental and collective effects on individual and social levels" (Laverty, 2003, p. 25). It also requires the researcher to deconstruct their interpretations – taking a mirror to one's personal biases and assumptions that go unacknowledged and unquestioned in other forms of data analysis. Additionally, a case has been made for the use of Hermeneutic analysis in research involving disability and social conditions around disability (Kavanagh, 2008). Hermeneutic analysis involves calling into question pre-understandings of disability that, if unchecked, may unknowingly subscribe to oppressive hegemonic and reductionist understandings of what it means to live with disability (Kavanagh, 2008). It also involves the use of persuasive prose, metaphors, and analogies that reveal the way the researcher has made sense of the data

(Kozinets, 2015). Not only does using hermeneutic analysis befit the population of study, but it also draws out pre-understandings and biases of the researcher.

2.4.   __Ethical Considerations__

Conducting research in an online setting comes with a particular set of ethical standards which have been debated within various fields since the internet was identified as a research site. In fact, Internet Research Ethics is and has been a steadily growing field since the early 1990s (Buchanan & Ess, 2008). According to a relatively recent report on the ethics of conducting social media research from a market research standpoint, ethical research in online spaces involves:

- Researcher and research purpose disclosure and transparency;

- Informed consent as online data is extremely difficult to keep anonymous ;

- Open dialogue with participants about their fears and qualms with their data being used for research purposes; and

- Multiple opportunities to opt-out (Evans, Ginnis, & Bartlett, 2015).

Meeting these ethical standards would present challenges in a study using primarily retrospective inquiry and data. However, as general guidelines, they offer a good starting point. Missing from the list is the process of gaining approval from the researchers Institutional Review Board (IRB). Because the ethical grounds of conducting social media-based research is in a state of flux, doing so before beginning a study such as this one is paramount.

In one systematic review of ethical standards in social media research it was found that there is no set of online ethical standards because each online group differs in terms of content, level of sensitivity, and place on a spectrum of private and public (Kantanen & Manninen, 2016). However, the Association of Internet Researchers has recently updated an ethical guide to

internet research (currently in version 3 – though at the time of this dissertation is available to members only). The Internet Research: Ethical Guidelines 3.0 considers new and unfolding "changes and developments in technological, legal, and ethical context that shape internet research" (Brake et al., 2019, p2) and ultimately points to a basic ethical approach which looks at ethics on a case-by-case basis with a particular interest in reflexivity. Following this logic, the ethical decisions I made for this study reflect and respect the culture of the groups observed, and in some cases go above and beyond typical standards of consent for social media research.

Informed consent is vital when it comes to using online social media data because every post disclosed in a publication or presentation, even if left anonymous, can be traced back to the author. For the most part, rather than move words around or the like, I elected to disclose direct posts, but only those for which the author has given permission (Townsend, Wallace, & Harte, 2015). This required a brief online consent form which was approved by the IRB with the study application. Seeking consent to reuse online social media quotes disrupts the oppressive power structures that discredit laypersons and deny credit to patient authors as a form of paternalistic forced protection (Roberts, 1981). When gaining permission was not possible, or if the author wished to remain anonymous, I either shuffled words so the original post could not be located or did not use the quote at all.

For two of the communities (all but MyDiabetesSecret which is anonymous), I participated in the communities and was forthright about my positionality, always leading with disclosure. I learned and followed community rules out of respect of users and the rituals and customs of the group (Nind, Wiles, Bengry-Howell, & Crow, 2012).

According to the netnographic framework, ethical netnographic practice involves: "stating your name, being honest, using your existing social media profiles, following personal branding

principles to represent yourself, asking permission when needed, worrying about terms of service if necessary, gaining clear consent for interviews, citing and giving credit, and concealing and fabricating when necessary" (Kozinets, 2015, p. 159). To paraphrase Kozinets, the founder of netnography, the rules of data collection on the internet are flexible and require researchers to reflexively ask themselves legal, philosophical, and academic ethical questions regarding the nature and specific context of the research they intend to conduct. Taking it up as an ethical position, I critically examined whom this research serves and asked myself "how can my writing and publications give voice to those who might otherwise remain silent" (Keim-Malpass, Steeves, & Kennedy, 2014, p. 1690). While collecting and analyzing data and writing up results, I believed it was my ethical responsibility to not only do no harm but to serve.

Prior to beginning this study, I submitted an application to the University of Illinois at Chicago's IRB for approval. Because UIC does not yet have a standardized approach to the ethics of conducting online ethnographic work, several correspondences between myself and the IRB occurred via email and over the phone. After three rounds of revisions, approval was obtained on April 10, 2019.

3. GENERATIVE APPRECIATIVE INQUIRY

3.1 Abstract

The exploration of social factors involved in diabetes health is a growing topic area across research fields and domains. Participatory action research, an underused framework within this literature, has the power to illuminate social factors as they are prioritized across the communities. This study looks specifically to diabetes online communities, unrestricted by physical space and place, to ask *where would you like to seek change*? Using generative appreciative inquiry (GAI), this study unpacks *how* and *why* participation in diabetes online communities can be seen as a social factor influencing health by people with diabetes, while also exploring how these communities can leverage assets and strengths to create social change in community-identified areas of need. Eight Peer Collaborators took part in this two-month, action-oriented workgroup research study, the result of which was a social media listening campaign designed to improve inclusiveness and sense of belonging within diabetes online communities. The action, entitled the "I Hear You" campaign, was planned over the course of 4-meetings and carried out by Peer Collaborators thereafter. The process and resulting campaign are analyzed using a critical theory lens and discussed in relation to community engagement as a social factor influencing diabetes health. Findings suggest that *sense of inclusion* within existing online networks of support is a social factor of diabetes health and is deserving of further research.

3.2   Introduction

The social conditions of diabetes have been examined in academic and clinical research and public health for decades at local and global scales. Social determinants of health models have been utilized to demonstrate close associations between sociopolitical and economic factors and diabetes wellness (Cummings et al., 2018; R. J. Walker, Smalls, & Egede, 2015; Zahid Ansari, Carson, Ackland, Vaughan, & Serraglio, 2003). Similarly, peer support has been found to impact self-efficacy, patient activation, and diabetes distress (Dale, Williams, & Bowyer, 2012; de Vries et al., 2014; Heisler M., 2007). Overall, the literature on social elements of diabetes self-management and health point toward diabetes populations as collectively complex and capable of growth on micro and macro scales. With that said, while the complexities of diabetes are acknowledged broadly, nearly all research covering diabetes health implicitly and uncritically utilize a medicalized model/lens. That is, most studies rely on an unquestioned assumption that the problem of diabetes lies within individuals (Donoghue, 2003). In part, because the study of diabetes has been routinely medicalized and located within individuals, a narrative around the condition has solidified – one that is highly problematic.

To further complicate the social landscape of diabetes, popularized narratives of diabetes compound the issue – they show diabetes as a simple disease that can be put into remission if people just cared enough about their bodies to eat healthier and be more active. This reductionist narrative lends itself to a culture-wide phenomenon of surveillance, judgment, stigma, and blame. Adults with diabetes have reported that the experience of stigma interferes with their emotional life, their social life, and their diabetes management (Liu et al., 2017). They feel generalized and misunderstood and address such perceptions using storytelling and contextualization (Bock, 2012). That is, they collectively generate counter-narratives to disrupt

popularized ideas of what it means to have diabetes. With that said, the process of changing the mind of the public around an issue is very slow. Along the way, adults with diabetes continue to feel stigmatized by popularized narratives. They continue to feel unheard and misunderstood, in part evidenced by the dialogue of the experience of stigma playing out across dozens of diabetes online communities (DOCs) (Hilliard et al., 2015). Because DOCs are a hotbed of discussion around various representations of diabetes across popularized narratives and counter-narrative, we focus on them here in this study.

The term DOC has been defined as a "user-generated term that encompasses people affected by diabetes who engage in online activities to share experiences and support in siloed or networked platforms" (Litchman et al., 2019, p. 487). Across social media platforms, including but not limited to Facebook, Twitter, and Instagram, people with diabetes congregate to converse and share deeply personal social experiences of daily living (Tenderich et al., 2018).

The content in and outcomes from participation in diabetes online communities have been explored in health, academic, and computer science fields (Litchman, Edelman, & Donaldson, 2018; Newman, Lauterbach, Munson, Resnick, & Morris, 2011; Warshaw & Edelman, 2019; Wild, 1981; Zhang, He, & Sang, 2013.). One scoping review unpacked 47 recent articles covering what is known about diabetes online community usage (Litchman et al., 2019). Across studies, authors found an emergent theme of "shared experience," which mediated various forms of social support. Furthermore, the shared experience was a social factor of health that extended beyond individual diabetes symptom management. However, the scoping review leaves open the question of *why* and *how* shared social experiences, particularly those discussed in online forums, facilitate social change beyond individual diabetes-specific symptom

outcomes[2]. Social movements, for example, have been initiated and carry through across DOCs. Hashtags like #IWishPeopleKnewThatDiabetes and #DayOfDiabetes are meant to bring those deeply personal stories being shared to non-diabetic audiences, effectively raising awareness of social and personal factors faced by sharers. Two social movements that unfolded in parallel across DOCs, aggregated under #WeAreNotWaiting[3] And #OpenAPS, have been the subject of a number of studies (Choi, Hong, & Noh, 2018; Lewis, Swain, & Donner, 2018; Omer, 2016). Both movements were generated in support of citizen scientists who hacked diabetes devices and open-sourced the code and process so that others may do so as well. Research teams have found mostly positive sentiment across #WeAreNotWaiting and #OpenAPS movements (Litchman et al., in press), that peer mentoring is an altruistic and rewarding mechanism occurring organically within them (Crocket, 2019), and that uptake of the technology shared through the movements may positively impact diabetes health (Litchman et al., 2018). While DOC-initiated social movements have been studied, no studies on the topic have taken a participatory approach. How would what we know about these DOCs change if we were to include them in the research design process? What social factors would they focus on? What elements of social health would they prioritize? What questions would they want answered?

The purpose of this study is to explore/understand how shared social experiences within diabetes online communities (DOCs) shed light on diabetes health and wellness, in general, and to challenge overly medicalized, patient-blaming narratives of diabetes, in particular. We sought out to explore social elements of diabetes health within the context of change-making. To do

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[2] Further, the scoping review authors recommend researchers employ participatory research strategies moving forward to "increase the social validity and usability of the knowledge produced by the work" (Litchman et al., 2019, p. 487). These methodological and content gaps are addressed in this project.

[3] The hashtag was, in its inception, a protest directed at device manufacturers to deliver more advanced products to the market and the United States Food and Drug Administration urging them to speed up their process of approvals.

this, we shift toward a research methodology that democratizes the research process and facilitates change, participatory action research.

For this study, then, we used generative appreciative inquiry (GAI) - a participatory action research approach - with a purposive sample of identified thought leaders in DOCs. These thought leaders provide both an in-depth understanding of the lived experience of diabetes as well as membership in individual DOCs while also having the breadth of knowledge of the landscape of DOCs as a whole.

3.3　　Methodological Approach

Participatory action research is based on the concept of *participation and change* theorized by Paulo Freire (Cahill, 2007; Freire, 1970; Khan et al., 2013). According to Freire, change relies on the participation, knowledge, and buy-in of local community members who can and should be "partners in the processes of knowledge creation and social change" (Flicker et al., 2008, p. 288). Not only are community members included as partners in the research process in this approach, but they also may directly benefit as individuals and as social communities or groups. Participatory action research has been described as an approach which "may also yield research that is more socially relevant, valid, and accessible to people with disabilities and communities alike; qualities which may result in more actions to improve participation opportunities and decrease disparities" (Hammel, McDonald, & Frieden, 2016, p. 10). Though many may scoff at the conflation of disability and diabetes, we argue that such reactions are indicative of deeply embedded oppressive dominant narratives, to which we will return.

Appreciative inquiry is "a constructive mode of [participatory] action research, [which] can unleash a positive revolution of conversation and change in organizations by unseating existing reified patterns of discourse, creating space for new voices and new discoveries, and

expanding circles of dialogue to provide a community of support for individuals" (Ludema, Cooperrider, & Barrett, 2001, 189). Though appreciative inquiry has traditionally been targeted at organizational change, its principles and methods can be applied to social communities and systems, such as online conversations and forums (Cram, 2010).

Generative appreciative inquiry (GAI) refines the appreciative inquiry method by supporting members to see the social group and what it does in a new way that can also challenge societal and health norms, beliefs and attitudes surrounding diabetes (Busche, 2013). GAI is intentionally transformational actively facilitating *disruption* of a status-quo space, hence "embracing the notion of inquiry as intervention" (Zandee, 2013, p. 84). GAI is ideally suited for group members who already engage in reflective practices and are thus primed to challenge the status quo in the pursuit of community capacity building and social change (Schroeder, 2013). The participants recruited for this study demonstrate engagement with reflexive practices across their social media channels, as well as at speaking events across the country.

In this study, we adapted GAI for the online contexts and specially, focused on the application of virtual, online elements of social connection. Adapting generative appreciative inquiry to an online context suits the study epistemologically because it meets the community where they gather virtually, and also adheres to a foundational tenant of PAR – to focus on the needs that the community prioritizes (e.g., resources, emotionality, belonging, etc.) (Ludema et al., 2001).

3.4   Research Questions

Two research questions guided this study.

1) What does engagement with online communities look like as a social element of diabetes health?

2) How can online community assets and strengths be leveraged to create social change in

community-identified areas of need?

This exploratory, mixed-methods study was designed to answer the research questions.

The year-long research process involved the establishment of an advisory committee of diabetes

community members, and the adaptation of generative appreciate inquiry and the 4D model.

This study was approved by the Institutional Review Board of the University of Illinois at

Chicago, where the first author was located. All methods used were approved, including the

option for Peer Collaborators to opt to use their real name. All Peer Collaborators chose to do

just that and will be credited by name throughout this article.

3.5   Methods

3.5.1   Establishing Peer Collaborator Group (Sample)

True to the principles of PAR, foundational work for this study to ensure community-

relevance, interest, and direction began several months prior to formal meetings and data

collection. A purposive sample of thought leaders were recruited based on the results of a manual

audit of their social media accounts as they met the following criteria: 1) historical, social media

use in at least one DOC; 2) varying perspectives toward the community; 3) have written

reflexively about their DOC in a blog or micro-blog; and 4) have come and gone from their

respective community groups. When selecting participants, we also aimed to recruit individuals

who knew each other prior to engagement with this group (meaning they had previously

interacted either online or in-person at some point). Using these considerations, we brought

together a potential advisory committee of community members online for an informal planning

discussion, led by HRW. During that discussion, we gauged interest in the workgroup,

introduced principles of the research, and asked community members what they would like to be

called (Campbell, 2010). Verbal expressions of interest and availability were recorded, and community members expressed a preference to be called 'Peer Collaborators,' which we will use henceforth in this article. Eight of the ten Peer Collaborators who participated in the planning discussion went on to complete the study. Once we obtained IRB approval for this study, interested Peer Collaborators were re-contacted, and continued interest and willingness to participate in the study was assessed. Interested Peer Collaborators completed the informed consent process.

3.5.2   <u>Doing Generative Appreciative Inquiry</u>

Over the course of one month, Peer Collaborators were convened to discuss strengths and assets across DOCs in order to design an action. By deeply immersing into community experiences, Peer Collaborators collectively appreciated the best of what is, envisioned what might be, and took a step toward that vision by generating an action with implications for social change (Whitney & Trosten-Bloom, 2010). Figure 4 (repeated from the methods chapter) visually breaks down the entire adapted GAI 4D-Model we used throughout this study, including topics, research-related add-ins, and activities. This visual is adapted from the original 4-D model put forth by Ludema, Cooperrider and Barrett, in 2001 (Ludema et al., 2001).

Figure 4. Visual overview of adapted 4D-model of appreciative inquiry

Discovering (the best of what is)

Activity 1: How would you advertise your DOC to someone newly diagnosed?

Activity 2: What is our unconditional positive core?

Plan for Destiny (what will be)

Activity 1: What will we do and how will we do it?

Activity 2: What role will you play personally in the action

Generative Appreciative Inquiry 4-D cycle adapted to a virtual setting with online health advocates

Dreaming (of what could be)

Activity 1: Imagine your DOC has come to be everything you'd ever hoped it would be. What is happening there?

Activity 2: Considering your peers here, what elements should be included in our vision statement?

Designing (what could be)

Activity 1: How can we use what we have to get closer to our vision?

Activity 2: What is possible for us to do now?

Insights from the research

Each square within the circle demonstrates one session. The first session was the Discovering session, and the rest happened sequentially counter-clockwise from there. Something that made this adaptation unique was that it occurred within a wider project focused on diabetes online communities. Our lead author was concurrently conducting a netnography (ethnography of online culture) of three DOCs and was sharing insights from the user-interviews and social media analysis taking place at the same time (Kozinets, 2017). On three occasions, we offered Peer Collaborators high-level emergent themes coming from that work and asked them

for reflections. The netnographic insights fed into the decision-making process during meeting 4 in which Peer Collaborators chose and planned an action.

After the group meetings concluded and as Peer Collaborators were following through with their action commitments, we sent out a mixed-methods exit interview survey which included quantitative evaluations of their experiences on a 5-point Likert-scale and well as open-ended qualitative questions. A copy of the exit survey questions can be found in Appendix A.

3.5.3   Data Collection

Using the 4D model of GAI, our lead author facilitated a virtual action group with four sessions (i.e., all research activities took place via phone, email, or google hangouts as determined by the group). We audio-recorded, for the sole purpose of transcription, all meetings using a detached recording device. All audio recordings were transcribed via a transcription service and then destroyed. A sample of the transcripts was compared to audio recordings to ensure accuracy. The transcripts, along with fieldnotes, were used in the analysis process.

3.5.4   Accommodations Made

 At every opportunity, we attempted to accommodate Peer Collaborators (Tanabe et al., 2017). Email reminders were sent to all Peer Collaborators before each meeting, and a recap email was sent within a day after each took place. Two times throughout, a Peer Collaborator missed a meeting and expressed interest in making it up, at which point an alternative time was scheduled to update them – a flexibility afforded by the PAR framework (Kemmis et al., 2014).

3.5.5   Analysis

Within 24 hours of the receipt of each transcript, we uploaded the text document to MAXQDA, where we iteratively coded them. The lead author (HRW) first read each transcript in full, and then a second time making notes and marking initial codes. Using a fieldnotes

journal, she then made observations and interpretations (Emerson et al., 2011). This process was repeated after each of the four meetings and then again after the action was launched by Peer Collaborators. With each subsequent meeting, HRW did an axial reading of the previous transcripts, comparing differences in the codes, drawing themes between them (Boeije, 2002). This constant iterative coding procedure alongside the keeping of a fieldnotes journal increased the trustworthiness of our interpretations through triangulation (Krefting, 1991; Morse, Barrett, Mayan, Olson, & Spiers, 2002) and also served to meet a gap in health-related qualitative literature published recently (Kegler et al., 2018; Raskind et al., 2018). We selected this inductive analytical trajectory in order to constantly compare codes and themes across meetings, as the topics evolved from discussion to action planning, and involved increasing negotiation between Peer Collaborators.

We used critical theory to extend our understanding and interpretations of what unfolded within this study. Using this critical theory approach, coined as a Critical Appreciative Process (CAP) when used in the context of appreciative inquiry, required we consider elements of human emancipation and social transformation in such a way that challenges the social realities around the condition of diabetes (Grant & Humphries, 2006). Epistemologically, using critical theory within GAI is fitting as it, too, reflects a socially constructed world (Grant & Humphries, 2006). We also selected critical theory to address an area of weakness identified in appreciative inquiry research – that it has tended to be soft, fuzzy, and uncritical (Dick, 2009). Critical theory also extended our analysis, allowing for deeper opportunities for reflexivity. Because our lead author, HRW, has lived-experience with diabetes and has personally participated in some of the online groups represented by Peer Collaborators, this deeper level of reflexivity was vital (Bergold & Thomas, 2012).

Lastly, we used SPSS to analyze the Likert-scale quantitative questions asked in the exit interview evaluation survey (IBM Corp., 2018). We ran descriptives and frequencies on all quantitative questions.

3.6   Results

3.6.1   Participant Descriptives

There was some attrition within the peer collaborator group. Two people who had started didn't finish due to scheduling conflicts and competing life demands. It is possible the two who dropped out did not feel welcome, or heard, though this was not reflected in their exit surveys[4]. With that said, those Peer Collaborators were still included in all email correspondence, including planning details leading up to the action. As the action rolled out, eight of the nine Peer Collaborators participated in the action. The Peer Collaborator who did not participate in the action passed away between the time the action was created and when it rolled out. Her passing may have impacted the way the action was led by Peer Collaborators and possibly the way the community responded to it, though it was not within the scope of this study to measure that.

Four of the seven participants who took the exit survey had participated in a workgroup intending to create an action before, and three had not. Of the four Peer Collaborators who did have experience with action-directed workgroups, three had participated in three or more other workgroups, and one had participated in one other workgroup.

3.6.2   Discovering the Best of What is: Unconditionally Positive Core

After co-creating this list, Peer Collaborators were asked to prioritize the best of what is in their DOC. To stimulate reflection, the PI showed a drawing of the earth with the core

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[4] I might guess they may have felt tokenized as one of them was the only person with type 2 diabetes and the other was the only parent of a child with diabetes. I also recruited them right before the groups started and they might have been less invested in the action-group as a result.

exposed and facilitated an adapted *unconditionally positive* core activity (generally there is no

image provided in this stage. The PI provided one to stimulate thoughts about what is most

essential, and most deeply embedded). Peer Collaborators were asked to identify the most

foundational essence of the best of what is. This activity was difficult for most Peer

Collaborators, though all came up with something. Peer Collaborators identified the following as

elements of the unconditional positive core of DOCs: people, frustration/toughness, compassion,

broken pancreases, personal vulnerable health connection, chronic illness, and help for self. Of

the seven who participated in this activity, three of them think of situation as the core. This group

understands that what connects people and holds them together is the fact that they have

diabetes. However, other Peer Collaborators interpreted it differently. To them, what connects

people and holds them together are the emotions that arise as a result of having diabetes. To

them, it is about the compassion and emotion shared between members. Some community

members also interpreted this activity to be about process. For example, one Peer Collaborator

said that at its essence, people go online to meet others with diabetes because they want to help

themselves, but when they have been there a while, they move beyond themselves and begin to

participate for the sake of the community.

In a follow-up discussion during meeting two, common themes within their individual

positive cores were pulled out by Peer Collaborators, and the unconditional positive core was

identified as ***people sharing vulnerability and compassion with purpose***. This was selected

because many Peer Collaborators located *action* within subsequent layers of the positive core.

They felt that under every connection, conversation, and story shared was a drive to change

something, whether it be attitudes of diabetes by the public, or an individual's personal

willingness to try a new therapy.

3.6.3 <u>Dreaming of What Could Be - Vision statement</u>

During meeting two, Peer Collaborators were lead through a dreaming activity in which they were asked to imagine their DOC five years into the future where their community has become everything they ever hoped it would be. They were asked the following question: "*It is 2029, and you've just woken up from a long sleep. As you look around, you see that while diabetes has still not been cured, your DOC has become everything you've ever hoped and wished it would be. What is happening? How is it different? What are DOC members doing that is making a difference?"* This conversation was the most difficult for the group emotionally of any activity because they were confronted with the challenge of realism. Peer Collaborators felt it was difficult to imagine their community being ideal within ten years because they felt they were so far from ideal now.

They described their communities as lacking inclusiveness and not being representative, and also not effectively leveraging their collective power for good. Specifically, Mike Lawson – DOC artist, YouTuber, and podcaster - started this discussion by sharing that for him,

> It would be great to know that this diverse space is also teaching us how to coexist with diverse sets of people. So allowing me to coexist with people who are poorer than I am, or just living a more complicated life, will be great. And then I also wrote something about collectively lobbying our legislators, so that we're being represented, in whenever government we live in. But something collectively bringing us together and using that power, because there's power there that's really untapped, I believe.

In response to this, Chris Snider, DOC non-profit leader and podcaster, said in his future ideal DOC,

The Type-1 Type-2 divide no longer exists. That everyone is each other's

advocate rather than the mob mentality. It's more of a collective consciousness

of pragmatism. Somewhere in there, I feel like there's a connection to what

Mike said, about everybody operating, truly operating for the greater good.

As the other Peer Collaborators continued to share, the need for more inclusive, diverse, and

cohesive community became apparent.

Deepening the conversation, Peer Collaborator, Kimberly Hislop – long-time DOC

advocate, described a lack of voices in diabetes online communities who speak openly about

diabetes-complications. Throughout the group meetings, it became ever-clearer that what it

means to succeed with diabetes was too narrowly defined across DOCs. In their experience, Peer

Collaborators mostly saw and interacted with posts which featured diabetes success as either

time-in-range (controlled numbers) or having no complications. Creating an inclusive

community was not just about welcoming people from diverse sociopolitical, economic and

ethnic backgrounds, but also about more widely defining diabetes success so that those with

complications do not feel judged and blamed-out of participation or engagement. During the first

meeting, Kimberly was acknowledged for being a voice and support to others with complications

in diabetes online communities, to which she responded, "Yeah, but where is that person for

me?"

Two common threads within every ideal DOC dreamed up regarded inclusion and a

reduction of within-group judgment - especially around the conversation of complications. And

so, at the end of meeting two, a first draft of the vision statement was written to reflect this.

Then, each week, Peer Collaborators refined their collective vision statement and after a few

more discussions finalized it. It said:

Our vision is to create a more unified community of people with diabetes that

embraces and relies upon empathy, respect, and appreciation for similarities

and differences of our unique diabetes experiences; aspiring for improved

individual and collective outcomes.

3.6.4   Designing What Could Be - Aspiration Statements

As a follow-up to drafting the vision statement, during meeting three Peer Collaborators

were asked to use their responses to build an aspirational statement starting with "we will..."

Table III shows the aspiration statements written by each peer collaborator, verbatim.

TABLE III.
ASPIRATION STATEMENTS

Aspiration Statement
We will build a diverse group of leaders who will use their collective experience and available resources to positively impact the lives of those living with and affected by diabetes.
We will listen to our community as a whole without prejudice so we can better represent diabetes to the world and change the narratives around this disease.
We will find, support, and promote non-whites CIS-gender people with diabetes in order to create a more representative and inclusive diabetes community.
We will celebrate ordinary people living with diabetes in order to support and build the community we're trying to create.
We will come together as a united group of people with diabetes in order to harness our collective power to improve our individual and collective outcomes.
We will use or harness the passion of our diverse, educated community in order to change the world for people with diabetes with our collective power.

Each aspiration captures elements of the finalized vision statement while showing the unique priorities of each Peer Collaborator. While all focus on fostering an environment where people feel welcome and included, Peer Collaborators see multiple paths to get there. Some believe that we get to an inclusive environment by elevating diverse leaders. Others believe we get there by listening to and celebrating members not traditionally acknowledged.

These aspirations, collectively, led to a short brainstorming session in which Peer Collaborators were asked to brainstorm without limits. Peer Collaborators had a difficult time with this; however, acknowledging and recognizing that all Peer Collaborators involved in this working-group also worked full-time jobs, and had many other commitments. Being asked to brainstorm without limits wasn't appropriate for them, considering the fact that most of their advocacy work was done in free time. While their participation in the work-group was paid, their labor of actually doing the action they chose was not. This set realistic boundaries for the actions they brainstormed.

3.6.5 <u>Planning Destiny of What Will Be: The Action</u>

The action designing process occurred during meeting four following the action brainstorming session in week three. Community members negotiated and prioritized options collectively. And, in the final meeting, Peer Collaborators designed their action, the result of which was to host a brief social media *listening campaign*. The following comment by peer collaborator, Karen Graffeo - DOC blogger and non-profit leader, initiated the conversation which developed the concept of the *listening campaign*:

> I feel like people need to feel like they're being heard. And that we're
> addressing not just what our small group thinks are the needs, but what the
> entire community thinks are the needs. So, I think that might help us be more

successful if it would be more inclusive. But it was one of those things because

we put a lot of content out there, but there's not always confirmation that you're

being heard. Or that your story is resonating in somebody. And I really like the

idea of checking in on our community, but I think this is also an opportunity to

magnify voices that don't always get magnified. Or bring to light stories that

aren't old stories. And the idea of listening and oh I hear you kind of thing is,

and your story matters, everyone's stories matter regardless of how big or how

small. And if there's a way that we can use our position as people who have

audiences to help magnify some of the people that are able to reach out to other

people. That's good community, and that's good service.

Karen's comment exemplified a common trend throughout these meetings, in which Peer

Collaborators recognized their wider communities and attached value to inclusivity.

Other Peer Collaborators were then asked to weigh in. The first, Kerri Sparling - DOC

blogger and traveling speaker, explained that the idea of a *listening campaign* was "conceptually

born from when Chris Snider came up with the idea to have everyone go and read the comments

on somebody's blog to prove that you were out there listening." For fellow Peer Collaborators,

this reference helped to ground the idea in a historical example of a similar community-generated

action of which they had all been a part. The next comment came from Kimberly Hislop who

agreed, then added that it would work to actively include "the community we're trying to reach,"

and then ended by expressing support of the idea saying "I do like that, I'm on board." Without

prompting, Peer Collaborators collectively negotiated and built momentum around the idea of a

listening campaign. In response to Kim's concur, Mike Lawson, widened the conversation by

expressing his support for a *listening campaign* as a foundation tool in creating change. He

explained, "Looking at these actions, I sort of see, like my brain for some reason started prioritizing what should come first? What could come next? And I feel like listening would be kind of a first step anyway. Kind of like getting a better understanding of who's out there, and you know. Who has energy they're willing to give? It feels like a nice first step." Lastly, Stephen Shaul moved the conversation from a conceptual one to a practical one. He added, "Listening campaign, yeah, I love the idea of listening campaign. Honestly, I have a little trouble figuring out how most of these things on this list, happen. How we're going to make those happen, but I love the idea of a listening campaign. I think it's a terrific idea."

From there, logistics of the campaign were discussed and debated. As some Peer Collaborators requested clarity, others provided examples to ground the conversation. Their shared historical participation in diabetes online communities strengthened the clarity of the multiple moving parts being discussed. Peer Collaborators weighed potential elements of the campaign, collectively eliminating options that were not feasible or realistic. The discussion slowly moved toward the generation of goals and a list of materials needing to be collected and met to pull off the campaign. As the Peer Collaborators were talking, the PI was making a list of elements in a PowerPoint slide which all Peer Collaborators could see.

After the compiled list was saturated, Peer Collaborators wrote action commitments reflecting that list. The personal action commitments recorded verbatim are listed in Table IV.

TABLE IV.
PERSONAL ACTION COMMITMENTS

Personal Action Commitments
I will help craft language specific to our listening campaign prior to [August] 1st. And then once this campaign launches, I will share voices from the diabetes community using our common agreed-upon methods. Whether you know hashtag, image, etc.
I can absolutely connect to helping craft some of the language that we use in sharing. That I can do, and I can also commit to sharing other people's stuff as promised.
So at launch, I will share and re-share as appropriate by the committee. And after launch I will be meaningfully engaged with the community on an on-going basis, that's beyond this campaign, but I'm feeling disconnected, and that's on me too. So I'm going to try and do more than just like pictures and leave a comment here or there.
I will share content on [August] 1st and moving forward. I will ask others to share, and I will support the campaign as needed. So if there's anything between now and [August] 1st, if there's any holes or whatnot, I can be there.
I will share from my personal accounts on a daily basis. And I will identify people in our relations that we'd like to have onboard and reach out to them.
I will share the idea specifically and broadly after the [August] 1st deadline. So I'll ask specific people to kind of go on board, but then I'll also just broadly kind of like share it. I'll work with others to make a text-based image or images to communicate the idea. And then the last one is kind of after [August] 1st, I will include the hashtag in my daily social media browsing. And then I'll just kind of amplify these voices or join conversations that are out there. If I know the people or if I don't know the people. Just kind of doing the listening.

The Deliverable

Peer Collaborators designed a social media campaign to acknowledge and celebrate

stories already being told across diabetes online communities, called the "I Hear You"

Campaign. This *listening campaign* was designed to let people with diabetes of all types and

from all backgrounds know they are being heard. It serves to acknowledge what people are

already doing and the work they have already put in to share their stories. This campaign

recognizes that online engagement requires time and energy and that many people with diabetes

who do so around diabetes do it to ensure diabetes online communities (DOCs) are places of support and mutual understanding.

A minimalist image was created and used for the campaign. Figure 8 shows the image in the context of an Instagram post by a popular diabetes non-profit DiabetesMine.

Figure 8. Community-generated image shared during the #IHearYou campaign

Photo

I hear you.

Liked by ~~allysonshughes and 4 others~~

diabetesminenews We at DiabetesMine are writers, journalists, fellow D-peeps, & where necessary advocates. We want to share your story and the value of your message with the world. Of course, we also live with diabetes ourselves. And that means we have a window into understanding and identifying with your story, and no matter what that may be, we're in your corner. Not every day is perfect, but we are here to be your sounding board and safe landing place should you need one. To connect you with information and others in he Diabetes Community as you might need. You are not alone. #IHearYou #DOC

2 hours ago

Peer Collaborators devised a clean image with appealing minimalistic visual elements. The campaign image in thin font pictured above reads, "I Hear You." The campaign was developed to create positive change for DOCs by acknowledging those who go unheard and lifting up voices often missed, a strength of the community as it is. Peer Collaborators envisioned the campaign fostering inclusion and appreciation across DOCs. The "I Hear You" campaign launched on August 1, 2019[5].

3.6.6 <u>Evaluation of Group Experience</u>

When asked how similar this GAI workgroup was to others they've participated in three reported *somewhat different*, and one said *very different.* Finally, all four Peer Collaborators who had been involved in action-based workgroups in the past reported that this GAI workgroup experience was much more satisfying compared to the other groups. One peer collaborator added that "What matters most is how invested the group members are. In the other group I worked on, the members missed most meetings and did not make participation a priority." While two of the group members did not attend a majority of the meetings, there was a sense of collective participation and engagement within the group. For example, one Peer Collaborator reflected, "It was great to engage with other like-minded folks and listen to their conservative and different input" and another said, "That the folks involved in this group were actually collaborating and working in pursuit of a common goal that benefits the diabetes community, not a specific individual or group."

When asked how the campaign did justice for DOCs, Peer Collaborators explained that the "I Hear You" campaign did so by giving everyone a voice; reinforcing the idea that 'you are

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[5] It is not within the scope of this article to break down the metrics and descriptives of how the campaign was perceived. However, they have both been collected and written about in Chapter 6 of this dissertation with other hanging results. These results will likely become publishable papers after this dissertation is complete.

not alone'; centering on a need for people's stories not only to be told, but to also be understood and appreciated; having a clear powerful message; helping unite the community; having a low bar of entry; and trying to be inclusive. These thoughts indicate that Peer Collaborators see justice for their community as the antithesis of isolation by exclusion. To them, the "I Hear You" campaign served their communities at individual and community-wide levels.

Peer Collaborators were also asked to evaluate their experience with the design of the meetings, the group dynamics and group composition, their expectations of the campaign, and to what extent the campaign upholds the values of the collective vision statement drafted in week two. Table V shows question responses reflecting these categories.

TABLE V.
PROCESS EVALUATION FOR PEER COLLABORATOR GROUP

(N=7)

Item	Min	Max	M	SD
Appreciative Inquiry Approach				
Facilitated active discussion	6	10	8.43	1.62
Informed collective vision statement	7	10	9.14	1.07
Led the group toward actionable plans	6	10	8.86	1.68
Fostered co-ownership of the action	7	10	9.43	1.13
Group Composition				
There was a diversity of opinions	5	10	8.14	1.95
There was a wealth of knowledge	5	10	9.29	1.89
I was able to learn from fellow group members	5	10	9.29	1.89
I heard perspectives I hadn't heard before	4	10	8.86	2.19
Personal Experiences				
I felt safe sharing my opinions	7	10	9.57	1.13
I felt safe sharing my experiences	7	10	9.29	1.25
I felt heard in the group	4	10	8.71	2.36
I felt heard by the group	4	10	8.71	2.36
I felt welcome in the group	4	10	8.71	2.36
I felt valued in the group	4	10	8.86	2.19
Group Facilitation				
I was often directly asked to give my thoughts and opinions	4	10	8.57	2.51
The flow of the meetings made sense	4	10	8.71	2.36
The group process was managed properly	7	10	9.14	1.46
I was told what to expect for each meeting ahead of time	6	10	9.00	1.73
I had a clear understanding of what the group was supposed to accomplish as a whole	2	10	8.14	2.97
Expectations of Deliverable				
The action we designed corresponds with the expectations I had of what this group would be	2	10	8.00	2.89
I have a clear understanding of what I am supposed to do for the I Hear You campaign	3	10	8.29	2.63
I believe I can meet the action commitment I wrote in meeting 4	3	10	9.00	2.65
The action I helped co-design represents values I uphold	5	10	9.29	1.89
The action I helped co-design represents values upheld by the community	5	10	9.29	1.89
The action we developed will help move DOCs closer to the vision statement	1	10	7.43	3.41
Vision Values Upheld in Deliverable				
Unifies community	5	10	8.83	2.04
Embraces empathy	6	10	9.33	1.63
Relies upon empathy	5	10	8.86	1.86
Respects differences	4	10	9.00	2.24
Appreciates differences	5	10	9.00	1.91
Respects similarities	5	10	8.43	1.90
Appreciates similarities	4	10	8.57	2.30
Aspires for improved individual outcomes	5	10	8.57	1.99
Aspires for improved collective outcomes	6	10	9.00	1.73

All Peer Collaborators reported that they were often asked to give their thoughts and opinions during group meetings (N=7), fostering a sense of collective participation which was reflected in the exit surveys.

Group dynamics

All Peer Collaborators reported that they thought the group dynamics were managed properly (somewhat agree n=1, 16.7%, strongly agree n=5, 83.3%), and that the group dynamics allowed for discussion that was active (somewhat agree n=1, 16.7%, strongly agree n=5, 83.3), supportive (somewhat agree n=1, 16.7%, strongly agree n=5, 83.3%), and collaborative (somewhat agree n=1, 14.3%, strongly agree n=6, 85.7%). The majority also reported that the group dynamics allowed for inclusive discussion (somewhat agree n=1, 14.3%, strongly agree n=5, 71.4%), though one somewhat disagreed (n=1, 14.3%).

All Peer Collaborators strongly agreed that they were able to meaningfully contribute (n=7). When asked to elaborate on their contributions, Peer Collaborators shared the following:

- "1) I was an active participant in each discussion, prompted by both the organizer and other participants. 2) I was able to engage with the organizer outside of the scheduled meeting times to further contribute. 3) Each week, takeaways included my input."
- "Sharing my perspectives while hearing/making room for others' perspectives, reminding our group to think about who was NOT at the table with us, respectfully sharing 14+ years of experience in this particular advocacy space."
- "Open discussion, called on to engage. Proactive input."
- "I was directly asked my thoughts, all members took into account what I said, we all worked well as a group."

- "Added opinions, provided insight into decisions I was uniquely privy to, supportively cheered on others."

- "Being able to project my experiences; Providing the space for other people to contribute was an important part of the process; Allowing the ideas of others complement my own."

- " 1)Voiced my opinion without having to agree with everyone 2) Contributed ideas 3) Asked questions."

One peer collaborator offered the following comment on their experience, "I've always known that I've made friends with some very smart, very passionate patient advocates, but being able to collaborate with them has helped reinforce what we all bring to the table. It's exciting to engage with these folks on a somewhat regular basis to see where we complement each other."

Sense of collective ownership

Throughout the evaluative exit interview, all Peer Collaborators reported they saw themselves in the listening campaign they designed (somewhat agree n = 2, 28.6%, strongly agree n=5, 71.4%), and that they saw the community in the campaign (somewhat agree n = 2, 33.3%, strongly agree n=4, 66.7%). However, one peer collaborator reported that they did not see the community in the campaign (somewhat disagree n=1, 14.3%).

Expectations of Deliverable

Peer Collaborators expressed mixed feelings around the action generated throughout the workgroup process. When reflecting on the experience and action before the campaign launched, some Peer Collaborators felt encouraged by the collaboration, while others felt a little sad or skeptical that the action wouldn't make a difference. Several Peer Collaborators described the root of their skepticism stemming from the knowledge that other Peer Collaborators might be too busy to do the campaign justice. Others rooted their skepticism in the general pace of social

media, considering the possibility that the campaign may not "get above the noise." And did you decide to do anything about these concerns or try to adapt the action to address them?

Action Evaluation

In a relatively short discussion after planning the action, Peer Collaborators decided they wanted to evaluate the action based on the number of posts linked to the correlating hashtag (#IHearYou). The PI tracked use of the hashtag on Twitter, Facebook, and Instagram for one week after the launch of the campaign. Within a week, 285 tweets, 48 Instagram posts, and 102 Facebook posts were shared using campaign hashtag. HRW was contacted by a Spanish-speaking parent of a child with diabetes and asked if the campaign image could be translated into Spanish to read "Te Comprendo." The PI created and shared that image, and the campaign was propelled by Spanish-speaking communities as well. The PI sent out two emails to Peer Collaborators after the campaign launched to check in on progress and reflections. Three Peer Collaborators replied with expressions of surprise – they were happy with the turnout and how their community made it their own. One Peer Collaborator reflected that while the numbers were decent, it seemed like it only reached the usual "in-group" folks. To them, the campaign didn't reach those who aren't heard.

3.7   Discussion

Participants in this study were purposively chosen because of their ability to see beyond their own personal experiences, reflecting on and clearly articulating trends and patterns happening in these online spaces across the community and people within it. They had all been a part of community-driven, and in some cases, corporate-driven approaches to creating change within diabetes communities. Their collective vision statement honed-in on inclusivity and celebration of difference as the two main arcs of change, which also serves to demonstrate a

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prioritization of issues facing people with diabetes in these communities at large. They recognize that DOCs are not always inclusive, and don't always celebrate differences in management styles between people, and chose to focus on those with their action. This recognition can also be seen as a reflection of the relatively narrow approach to diabetes symptom management popularized in the United States (Bock, 2012). Though many social factors of diabetes health have been researched, the primary symptom management tools provided to patients still revolve around willpower and the individual's ability and willingness to change their self-management behaviors (Ho, Berggren, & Dahlborg-Lyckhage, 2010; Powers et al., 2017).

Peer Collaborators' vision statement also serves as an expression of a desire for a community more representative of the broader American population – inclusive across socioeconomic-, racial-, ethnic-, gender, and sexual orientation-, disability-, and educationally-based boundaries. Litchman et als. (2019) scoping review and gap analysis of diabetes online communities found that very few studies are capturing these diverse populations in their samples (e.g., non-white/non-middle-to-upper-class populations). While our finding here could indicate that research designs have failed to recruit people from underrepresented populations, it could also indicate that DOCs are still in the early stages of creating a welcoming space for them. Or, when considered more systemically, the lack of diverse representation within diabetes online communities could be a sign that people in more marginalized groups have access to fewer resources to connect with these online groups (e.g., time, internet connection, etc.).

The social implications of the broad lack of diversity and desire to create a more inclusive online environment within DOCs mimic the trajectories of other social movements. For example, some social media movements in the last few years have been called out using the moniker "too white" through hashtags like #DiabetesTooWhite or #DisabilityTooWhite. Those

in underrepresented groups point to lack of representational voice within the social movements that apply to them. Disability studies, a field built around bringing social justice through critical analysis, has been argued to have whitewashed disability history and voice too (Bell, 2017). This trend, though not surprising, echoes a much wider systemic societal issue of exclusion from innovation and community capacity building. Peer Collaborators argue through their vision statement that in order for their DOCs to be the best they can be, more diverse representation is needed.

Through the development of the action, Peer Collaborators began to operationalize and create change around the issue of *inclusion*. However, their focus slightly shifted. Instead of focusing on bringing more diverse populations into the community, Peer Collaborators decided to elevate voices who were already in the space, but who might otherwise have gone underacknowledged. The listening campaign was described by Peer Collaborators as a good first step toward creating a more welcoming environment for everyone. By highlighting the voices that are not often heard, Peer Collaborators felt they were amplifying the diversification of the story of diabetes online. That is, they were doing their part to broaden what it means to have diabetes and the stories told to illuminate that meaning.

DOC support – which has been shown to decrease diabetes distress (Barrera et al., 2002), increase sense of diabetes empowerment (Litchman, Edelman, et al., 2018), increase patient activation (Kokkodis & Lappas, 2016), and in some cases improve A1C (Litchman, 2014), is a social factor that lends itself to positive changes in overall health and mental health.

The design of the listening campaign also appealed to the idea that being heard is a factor of mental health and diabetes-well-being. If the listening campaign helped community members feel heard, it might have also positively impacted their mental health and overall diabetes well-

being. When considering the advancement of research on the health implications of participating in diabetes online communities, Peer Collaborators in this study pointed to the importance of researchers inquiring about representation within DOCs. Future research ought to explore how underrepresented groups navigate DOCs, to what extent they feel represented and welcome, and the barriers and supports impacting their participation.

If DOCs are spaces where people with diabetes can access tools and support to manage the physical and emotional demands of life with diabetes, but there is an issue of access keeping some groups on the margins of those spaces, then we can shift our thinking to see access to them as a health disparity – and one that is acknowledged and prioritized by community leaders.

This study has demonstrated that community assets and strengths can be leveraged to create social change in community-identified areas of need by involving community members in the research process and purposively including community members that are in different positions to represent different voices within the community and to take actions. Using methods like generative appreciative inquiry and participatory action research allows for the objectives and activities of each gathering to shift slightly to accommodate the desires and progress of the group members (Whitney, Kaplin, & Bloom, 2010). In an online community group faced with physiological and social adversity along with technology issues such as internet trolling, a focus on *emphasizing what works* rather than what doesn't likely cultivated a more satisfying experience for Peer Collaborators. Peer Collaborators were recognized as expert navigators throughout and across these community groups, which likely drew out more open and flowing discussion. The composition of the group led to a workgroup experience that extended beyond individual experience and into honoring and respecting the wider communities.

3.7.1 Limitations

There were a few limitations of this study. First, the data was only direct-coded by the lead author. Co-authors were consulted and asked for feedback on the preliminary analysis, however. Another limitation of this study was the resulting composition of the group. We selected the Peer Collaborators based on how they demonstrated a reflexiveness around experiences in DOCs. We wanted a group that was used to looking inward and seeing all sides of the unfolding culture within these online groups. While that side of it worked well in our study, our Peer Collaborators also had many conflicting responsibilities. Some had to join meetings from their offices at work, and others were scheduled to help run large-scale diabetes conferences during the time between group meetings, action planning, and action implementation. Some Peer Collaborators expressed feeling the action would not be as impactful because so many of them were too busy to give their time to the action. If this study were to be replicated, we would suggest researchers find a team of individuals who have reflexive tendencies and who have the time to dedicate to performing the action.

3.8 Conclusion

In this study, we have explored how engagement in online communities can be seen as a social element of health in the context of diabetes by bringing community members to the table. To do that, we lead the community through the generation of new community action. Peer Collaborators designed and implemented an action that upheld personal and community values and served to acknowledge and affirm existing members of their respective communities. As evidenced by discussions across all four meetings in which Peer Collaborators listed examples of similar projects and actions historically done in their communities, there is a strong willingness on the part of community members to work on creating a more inclusive and welcoming

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community for all. Community members who are eager to address these issues head-on ought to be supported and brought to research and decision-making tables. GAI is a particularly fitting method for engaging such thought-leaders in DOCs to create an action that seeks to further strengthen DOCs by amplifying diverse voices from within the communities with the long-term goal increasing diversity in representation and voice. Thus, future research ought to consider the role of inclusiveness and diversity within a support network as a social element of diabetes health.

4. POLITICIZING THE CONDITION OF DIABETES ONLINE: A NETNOGRAPHY

4.1 Abstract

We live in a social environment that understands diabetes as a consequence of gluttony and inactivity – an individual problem rooted in personal knowledge, choice, and will. This broadly accepted narrative effectively acts to depoliticize the condition of diabetes en masse. Our study calls this depoliticization into question – inquiring into the culture of diabetes online communities (DOCs) across three social media platforms, looking for an answer. We use a combination of netnographic methods to ask *how* the condition of diabetes is being politicized online. We gaze deeply into narratives and find that in direct opposition with the broadly accepted narrative, *diabetes is mainly politicized* through the sharing of personal stories online. Online, people are connectively *rebranding* diabetes as an unrelenting, difficult, yet manageable condition. They share vulnerability with humility, working to challenge and ultimately change the minds of those without diabetes and those with it who subscribe to the broadly accepted narrative.

4.2 Introduction

> It has been said that you cannot kill an idea, but it is even more difficult to see
>
> a new idea get a hearing in the community of men. - Francis H. Cook

Stories demonstrate an unfolding practice of meaning-making and reveal and frame beliefs about the human experience. Stories perplex, confound, and create dilemmas; calling for acknowledgment of complexity and appreciation for shades of grey. It has been theorized that storytellers face unique obligatory social pressure to tell a story that is worth telling in a manner that meets the storytelling conventions of her audience (Polanyi, 1981). Though it could be

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argued that social media has, to some extent, diffused that obligatory social pressure, it has in other ways intensified it. We can post pictures of our meals, share a quip about an interaction, tweet incomplete thoughts. Social media allows the mundane and unremarkable parts of life to be told as an ever-unfolding in-real-time performative life story. However, pressure to increase likes and shares, retweets and upvotes, and followers and friends, effectively monetize that mundane storytelling and with it the intertwined experience of sharing. In a digital world overflowing with competing stories, how can one ever feel heard?

Storytelling on social media around issues of social justice and voice have been trending in social science and social media research. With social media movements like #BlackLivesMatter (Rickford, 2016) and #MeToo (Jaffe, 2018; Mendes, Ringrose, & Keller, 2018), the collectivization of storytelling has transcended historical conventions of the craft. Collective storytelling to generate critique and challenge oppressive power structures often originate organically as users connect around a shared experience of marginalization (Parsloe & Holton, 2017). Though studies on social media movements have become trendy across academic disciplines and domains, few published studies take a more holistic look to the groups from which social media movements spur. Even fewer examine the culture of the groups who elevate deconstructed perspectives of wide-reaching social justice issues.

For this study, we took an in-depth look into the use of narratives across three diabetes online communities/groups, focusing on how users talk about conditions of diabetes and ensuing representation. We inquired: How do individual storytellers' narratives intersect? How and where do they connect? And how does their *collective* and *connective* action color or shape the culture of the group? How do the stories told about diabetes generate critique and challenge oppressive power structures?

Most studies of chronic illness narratives rely on the assumption that storytelling about illness and disability is first-and-foremost about coping (Woods, 2007). It is a simple undertaking to amass hundreds of articles discussing the health outcomes related to participation in online health communities for *sick people*. In this study, rather, we consider collective storytelling as a medium for social change – a radical shift in perspective from what has come before.

4.2.1   Defining Politicization

 "Liberation is thus a childbirth, and a painful one. The man or woman who

emerges is a new person, viable only as the oppressor-oppressed contradiction

is superseded the humanization of all people. Or, to put it another way, the

solution of this contradiction is born in the labor which brings into the world

this new being: no longer oppressor nor longer oppressed, but human in the

process of achieving freedom." *(Freire, 1970, p. 49)*

After the civil rights movement in the US, the concept and construct of politics shifted. The nature and purpose of politics took on new meaning, connecting personal experiences to social change more than ever before (Kauffman, 2001). Rather than focus on transforming representations of marginalized populations and groups, the focus shifted to transforming civil rights, espousing civil equality, increasing access to education, work, and power within policy and government (Kauffman, 2001). When disabled activists began work in political advocacy in the 1960s, they were simultaneously working to forge a collective identity which required outsiders to acknowledge those who claim that identity as within the realm of the polity (Anspach, 1979). Even today, despite immense advocacy efforts, disabled people do not have equal access to political processes. In 2016, there was a reported 62.7 million disabled people

considered eligible to vote in the United States, accounting for approximately 17% of the voting population (Schur & Kruse, 2016). However, only 16.0 million reported voting in the November 2016 election (Schur & Kruse, 2016). Issues of erasure from political deliberation have not been resolved, indicating that persons with disabilities are still not seen by mass culture and its political institutions as political actors. Disabled people have expressed that existing as a disabled person is a form of political engagement because they are constantly dispelling commonplace notions of disability (Walker, 2020).

Politicizing the condition of disability, then, can look like intentional political activism or it can conversely look like just existing in public in a way that challenges dominant conceptions of what it means to be disabled. "The politicization of matter previously viewed as external to politics, according to this view, opens up the possibility for a more radical challenge to such forms of domination and exclusion as racism, sexism, and homophobia than had been possible with more traditional concepts of the political" (Kauffman, 2001, p. 23). It should be noted here that diabetes has been depoliticized to the point that many would contest the notion of diabetes qualifying as a disability. Though the Americans with Disability Act (ADA) Rehabilitation Act of 1973 recognized persons with diabetes as protected by the legislation, it remains a subject of debate within and beyond diabetes communities.

Dominant thought and consciousness have yet to recognize the politics of diabetes. The social landscape of diabetes diverts its diagnosis and management to individuals inflicted with it. As a result, the condition of diabetes, according to dominant culture, is not a matter of political concern. However, as we argued at the outset of this chapter, the social conditions of diabetes create external and internal bounds of social and societal exclusion. Narratives of diabetes offer

reinforcements, disruptions, and deconstructions of those social conditions, warranting an analysis of them through a lens of politicization (Sakalys, 2000).

The purpose of this study is to examine how the condition of diabetes is being politicized through narratives and counter-narratives to critically understand what it means to have diabetes today and legitimize divergent and deviant voices within diabetes populations.

4.2.2   Research Query

Through several iterations, we decided on one broad overarching research question for this netnographic study: *How is the condition of diabetes being politicized by people with diabetes online?*

4.3   Methodology

Netnography, a neologism combining *internet* and *ethnography*, offers a systematized and pragmatic approach that takes into account ethical and procedural elements specific to ever-shifting cultures and groups within online contexts (Kozinets, 2015). Netnography is formally defined as a "specific set of related data collection, analysis, ethical, and representational research practices, where a significant amount of the data collected and participant-observational research conducted originates in and manifests through the data shared freely on the Internet, including mobile applications" (Kozinets, 2015, p. 79).

Though netnography was invented by consumer marketing and communications scholar, Robert Kozinets, its applications extend far beyond the field. Netnography has been applied to research spanning health, business, and academic fields (Kausel & Hackett, 2016; Kozinets, 2019; Langer & Beckman, 2005) and has been explored as a critical research method used to explore social hierarchies, power structures, and identity (Bertilsson, 2014).

Netnography produces unique challenges and requires distinctive skills which set it apart from traditional ethnography. With that said, variations of netnography stipulate further considerations. For this study, we considered the specifics of conducting netnography in online groups who discuss sensitive topics, like health and illness, and who are socially marginalized.

4.3.1   No Excuse to Not Engage

When an author immerses themselves in the community or group of study, the social and hierarchal boundaries between *us* and *them* begin to dissolve. According to disability studies scholar, John Davis, the dissolution of said boundaries begins when participants are valued as experts of their own experience (Davis, 2000). This negotiation of power relations between ethnographer and participant requires both parties to immerse in a bi-directional knowledge exchange. Davis argues that the ethnographer ought to "exchange their knowledge with disabled people in hope that it will contribute to their fight against oppression" (Davis, 2000, p. 202). Further, Davis argues, the ethnographer's writing should, to some extent, counter-hegemonic discourses which reproduce systems of oppression through knowledge.

Central to ethnographic methods and principles is the process of reflection (Paulsen, 2009). According to disability studies scholar Corbett O'Toole, disclosing one's own positionality in the text is an opportunity to dismantle the knowledge-production-related power structures maintaining social inequalities faced by disabled people (O'Toole, 2013). However, this criterion also includes the use of reflexive methods throughout a study which call into question and highlight the researcher's beliefs, disciplinary convictions and arcs, and goals for producing new knowledge. The taking and use of fieldnotes is one method ethnographers can employ in online settings which provides a richness to the data available for analysis while also drawing the predilections of the researchers out for discussion. Robert Kozinets, author of *Netnography:*

Redefined, recognizes the difficulty of "holding up a mirror to ourselves" as instruments of research (Kozinets, 2015, p. 95). Reflexivity is considered in this study as a standard of rigor.

Because traditional ethnography emphasizes the voices of participants, the researcher's ability to weave data narratives into a story is paramount, allowing for a complex rather than reductionist cultural interpretation (Kozinets, 2015, p. 206). The thick description which paints and forms that cultural interpretation is what breathes life into the ethnography (Bowler, 2010). Effective use of online ethnographic methods involves "an explicitly human window into the rich communicative and symbolic world of people and groups as they use the internet, the web, and social media, leaving its traces and transmissions for us to discover and decode." (Kozinets, 2015, p. 80).

4.3.2   Researcher Positionality

Because the frameworks used in this study emphasize reflexivity on the part of the researcher, the majority of researcher activities involved community immersion and the keeping of active and rich fieldnotes. As a multidisciplinary research team, we bring varying expertise spanning academic, clinical, and communications fields that benefit the work. Additionally, the first author has had diabetes since 2001 and has been engaged in diabetes online communities since 2012. Her experience as a community member has served to illuminate, challenge, and in some cases affirm diabetes phenomena appearing across disciplines. The research questions, study design, and data analysis use our collective positionalities as tools of the research (Dwyer & Buckle, 2009; Richards, 2008). Reflexive practices, like fieldnotes, were instituted throughout this project to acknowledge tensions, subjectivities, and biases throughout the work, and to increase the overall trustworthiness of the findings (Emerson et al., 2011). Additionally, HRW maintained a community blog called The Chronic Scholar (www.thechronicscholar.com)

through this study and attended community twitter chats bimonthly to sustain community relationships via #DSMA.

4.4   Methods

This study used a plethora of netnographic methods including but not limited to gaining entrée, participant observation, in-depth interviewing, tweet chat as focus group, aggregate data collection, reflective fieldnotes, and several rounds of member checking. Many of these methods were used concentrically, rather than in a linear fashion. Table VI concisely breaks down the approach and all data collection processes we used throughout this study, including the approximate time periods.

TABLE VI.
SUMMARY OF DATA COLLECTION METHODS USED

Method	Description
Gaining entrée	Fall 2012-ongoing
	In August 2012, HRW joined several DOCs as a participant (TuDiabetes.org, Diabetes Blog, & Twitter). In 2015, HRW decided to research some of these groups and started disclosing the intention to do so to community members. Thus, gaining entrée followed a naturalistic course, developing slowly, cautiously, and with intention based on our team's prior levels of engagement within the groups selected.
Participant observation	January 2016-ongoing
	We used upfront and full disclosure across the social media channels and accounts that we used to make contact about the study (Twitter & Instagram). The first author's diabetes community blog (www.TheChronicScholar.com) was used to share and disclose specifics of the project, including opportunities to participate and opt-out, and primary findings as they emerged throughout the study. The series of blog posts shared during the study can be found in Appendix C.
Fieldnotes & reflexivity	August 2018-September 2019
	HRW kept a digital fieldnotes journal as a tool for increasing the validity of the study. Within this journal, she recorded assumptions, reactions to observed interactions, developing expectations, moments of surprise, excitement, and sadness were recorded as they occurred.
Aggregate data collection Twitter	March 2019-September 2019
	Using a pre-set list of criteria, we systematically and purposively reviewed and stored social media posts (going back 4-years) from three platforms using MAXQDA. Posts had to: 1) present or react to a representation of diabetes, 2) come from a person with diabetes, a care partner or healthcare provider to someone with diabetes, and 3) be explained through story/personal experience.
	We collected #DSMA weekly tweet chat data from 2010 to September 2019 using a data analytics tool, Symplur. Additionally, using Symplur, we collected tweets aggregated under #IWishPeopleKnewThatDiabetes, #DayofDiabetes, and #T1DLooksLikeMe.

Instagram	We manually collected data aggregated under #DiabetesCommunity & #T1Dawareness, & #T2D; The profiles of users who posted photos with these tags were manually audited, and reflections were recorded into the first author's fieldnotes.
MyDiabetesSecret	The administrator of the MyDiabetesSecret Tumblr page was approached and provided the research team with access to the full 6-year history of anonymous posts made by people with diabetes across diabetes online communities.
	In addition to these systematic data collection parameters, screenshots were also taken advantageously when a post that meets the criteria crossed HRWs social media feeds.
Elicited data collection	April 2019 - June 2019
Tweet chat	In line with previous research, the tweet chat was organized and lead in ways similar to a focus group via an already established weekly community tweet chat run by Diabetes Social Media Advocacy (#DSMA). The chat was conducted on April 24th, 2019, for one hour starting at 9 pm EST. Six questions were pre-arranged and posted with recruitment and study information a week before the chat on HRW's community blog. HRW hosted the tweet chat in real-time, question by question, as would occur in an in-person focus group. A blog post with information about the study and an opt-out procedure was tweeted from the PI's personal account and the hosting account several times before, during, and after the tweet chat.
In-depth interviewing	We selected 20 people to interview spanning Twitter (7), Instagram (9), and MyDiabetesSecret (4). We used a purposive sampling method based on the frequency of diabetes-related posts, audience/follower type and size, type of diabetes, ethnicity, gender identity, social media platform preference, age, and level of personal sharing. A semi-structured interview guide used was developed through several iterations based on conversation between authors. The detailed interview guide can be found in chapter 5. Each interviewee was paid $20 for a 60-minute interview. All interviews were audio-recorded and transcribed verbatim using a transcription service (rev.com). A subset of the transcripts was verified by listening to audio recordings for accuracy.
Member checking survey	After all data had been manually analyzed, a 2-minute evaluative survey was created and disseminated across HRWs social media channels relevant to the study (Twitter, Instagram, and community blog). Users were asked to rate the frequency by which they see each of the 24 identified narratives used across their diabetes online community.

4.4.1   Data Analysis

From April to June 2019, all data (text and photos) were analyzed using hermeneutic analysis. This form of analysis was chosen over other forms because it calls for iterative coding and recoding of data (Kozinets, 2015) and because it is "interpretive and concentrated on historical meanings of experience and their developmental and collective effects on individual and social levels" (Laverty, 2003, p.25). It also requires the researcher to deconstruct their preconceptions while taking into consideration personal biases and assumptions that go unacknowledged and unquestioned (Dwyer & Buckle, 2009). Additionally, a case has been made for the use of hermeneutic analysis in research involving disability. Hermeneutic analysis involves calling into question assumptions of disability that if unchecked may unknowingly subscribe to oppressive hegemonic and reductionist understandings of what it means to live with disability (Kavanagh, 2008). It also involves, to paraphrase the inventor of netnography, the use of persuasive prose, metaphors, and analogies that reveal the way the researcher has made sense of the data (Kozinets, 2015). Hermeneutic analysis, then, both befits the population of study and draws out pre-understandings and biases of the researchers. HRW recorded reactions to and reflections of data in fieldnotes during data collection, during designated periods of data analysis, and during the writing stage of this research.

4.4.2   Data Organization - Narrative Modes

Four narrative modes (external dominant, internal dominant, external counter, and internal counter) were identified early in the data collection process, which helped to organize all types of data. Because the modes are not mutually exclusive, one story could apply to or make use of two or more of the modes at one time. See Table VII.

TABLE VII.
USE OF NARRATIVE MODES FOR ANALYSIS

Mode	Description	Exemplar quotes
External dominant narrative	External dominant narratives codes were applied to stories and posts that demonstrated a narrative that was in line with society-wide hegemonic representations of diabetes	"When I stopped eating the junk and started the gym, I reversed my diabetes."
Internal dominant narrative	Internal dominant narrative codes were applied to stories and posts that demonstrated a narrative that was in line with dominant within-group representations of diabetes	"Diabetes is a part of me, but it does not define me."
Internal counter-narrative	Internal counter-narrative codes were applied to stories and posts that demonstrated a narrative that was directly opposing dominant within-group representations of diabetes	"Diabetes does sometimes limit me, and that is okay too."
External counter-narrative	External counter-narrative codes were applied to stories and posts that demonstrated a narrative that was directly opposing society-wide hegemonic representations of diabetes	"Eating too much sugar doesn't cause diabetes."

4.4.3 Member Checking

Member checking processes took place between May 2019 and July 2019. To triangulate all findings, we conducted member-checking in 4 unique ways: 1) we posted preliminary findings on HRWs diabetes community blog and Instagram account and solicited feedback; 2) we sent first draft copies of this manuscript to 12 interviewees for feedback; 3) short descriptions of emergent thematic categories were emailed to three interviewees asking for anything that was missed; and 4) as mentioned in the summary of data collection methods, a community survey was created with a list of 24 narratives (across counter-modes) that were found across all platforms considered for this study.

This level of member checking was conducted to ensure the social validity of the findings (Seekins & White, 2013), to increase the potential trustworthiness of emergent themes (Birt et al., 2016), to disrupt hierarchies of power in traditional research between researcher and participant (Caretta, 2016), and to triangulate the data and researcher interpretations (Morse et al., 2002).

4.4.4 <u>Participants</u>

Considering this netnography had multiple streams of data, collecting demographic information was not possible beyond the interviews. However, the number of posts which met criteria and the number of people from which those posts came was recorded. Figure 9 shows the participant breakdown by data type, platform, and activity.

Figure 9. Participant breakdown across platform and activity

Elicited

Tweet Chat	Instagram
789 Tweets	1,093 Posts
(N = 105)	(N = 382)

Interviews	My Diabetes Secret
(N = 20)	947 Posts
	(N = unavailable)*

Member Checking Survey	Twitter
(N = 115)	3,109 Tweets
	(N = 1,679)

Organically Occuring

Total
5,884 Posts/Tweets
(N = 2,301)
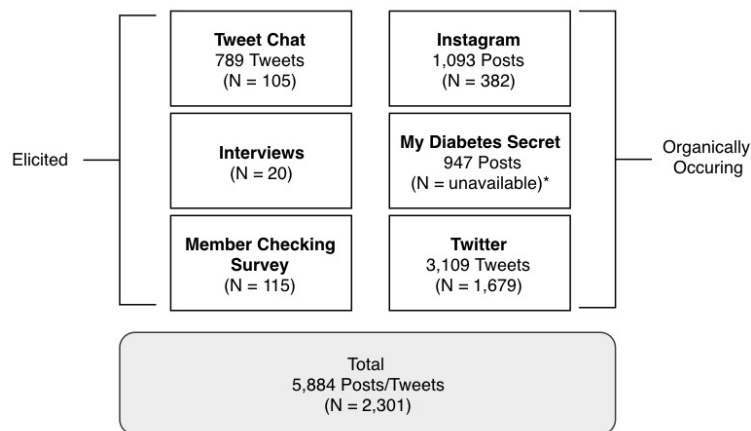
* My Diabetes Secret is an anonymous site, thus counting number of unique authors is not possible.

4.5   **<u>Results</u>**

Twenty-four narratives and counter-narratives emerged across DOCs. Rather than focus on the number of posts attributed, attention was paid to the salience of the posts. If commenters exclaimed how much a post resonated with them or a way in which a post changed their mind about something, it was earmarked. Users were asked to rate the frequency by which they see each of the 24 narratives used across their diabetes online community. The survey garnered 125 responses. Table VIII shows the results.

TABLE VIII.

PERCEIVED FREQUENCY OF NARRATIVES IN DIABETES ONLINE COMMUNITIES (N = 125)

Narrative Quote	M	SD
Type of diabetes does not define one's level of engagement in self-management	1.92	1.18
Diabetes has shaped me into a better person	2.52	1.13
Diabetes does not discriminate	2.62	1.31
Diabetes does not control me, I control it	2.63	1.07
It is a myth that people with diabetes don't take care of themselves	2.70	1.29
I have diabetes, but it does not have me	2.82	1.16
Diabetes makes me stronger	2.82	1.21
Diabetes comes in all shapes and sizes	2.84	1.23
Having diabetes doesn't mean I am a sick person	2.85	1.20
Living with diabetes is possible if you put in the work	2.86	1.24
Type 1 and type 2 should have different names	2.90	1.31
You can't understand what it is like to have diabetes if you don't live with it	2.91	1.25
Diabetes is not a joke	3.06	1.30
Me too	3.08	1.54
Diabetes is a very serious disease	3.13	1.04
Diabetes does not limit me	3.21	1.05
People don't understand diabetes, but they need to	3.33	1.16
The emotional toll of diabetes is immense	3.34	1.25
People with type 1 didn't cause their diabetes	3.49	1.26
Living with diabetes is really hard	3.60	1.17
You are not alone	3.63	1.25
Diabetes sucks	3.77	1.10
All people with diabetes deserve access to affordable insulin	3.98	1.15

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4.5.1 <u>Atmospheric Overview</u>

Use of all four narrative modes directed to the group and beyond build its textual culture. Across diabetes online communities and groups exist norms, processes of normalization, evolving shared language, and processes of group identification. Hive-mind narratives emerged as tools of both inclusion and exclusion and accommodated within-group counters when they were kindly presented. Users describe their DOCs as places where they can *let it all hang out* – where they can show and see the reality of diabetes unfolding in real-time. There is a sense of relief produced by *being around* people *who get it*. The purpose of connection for many is to create a movement within oneself from a feeling of isolation to one of support and understanding and then to replicate/inspire that movement for and within others.

Across all platforms, the most common argument made about diabetes through narratives was that diabetes is misunderstood. Users describe mass-misunderstanding as stemming from ignorance, stereotypes, stigma, and or cruelty. Regardless of the root identified, people with diabetes use social media to challenge several representations that, to them, reproduce systemic misunderstanding by the general public around the cause, treatment, and risks of diabetes. Generally, there is a connective attempt to create change built around narratives of inspiration, overcoming, advocacy, myth-busting, and self-control. Despite DOCs appearing to be relatively cohesive, the sense of belonging within the collective varies widely among user-groups. Across all groups observed, users took breaks from social media, announcing publicly to provide friends and followers with a reason, justification, and a timeframe for return. They describe being burnt out from *correcting people* – from educating. Many eventually trickle back in, but not all.

DOCs tend to be cultures focused on thriving through *performing vulnerability*. The vulnerability is connectively valued – in some cases held up as a requirement for inclusion. However, performed vulnerability is measured and relatively controlled. That is, it is used within parameters that go just far enough to challenge the status quo of diabetes representations, but not so far as to generate pity or concern. There is room for temporarily 'giving up' across these groups but doing so is heavily dissuaded. Thus, the vulnerability in no way extends into the realm of *surrender*. Quite the opposite, the only white flags drawn are those which call attention squarely to the seriousness of the disease, essentially politicizing the condition of diabetes.

In the face of feeling profoundly misunderstood, people with diabetes are coming out in droves to share stories which connectively argue for three primary things: 1) recognition of the incredibly difficult work they do every day to survive; 2) access to life-saving medications and supplies like insulin is a *human right*; and 3) a *rebranding* of diabetes as a serious disease for which no person is to blame. The userbases of DOCs, explored herein as connective rather than collective communities, however, do not always see eye to eye.

4.5.2   Troubles in Paradise

Through rounds of iterative analysis, it became clear across groups that users frequently traveled through a reflexive process – effectively evaluating their community on issues of inclusion and exclusion. There is, what some users call, an "*it-group*" who have more followers and online engagement and more opportunities to participate in beyond-internet activities (e.g., pharmaceutical companies hold advocacy summits and are selective about invitation lists). Those who see themselves as outside of the *it-group*

describe it as a clique. To them, DOCs revolve too much around the "popular kids". DOC users express feeling left out and at worst, unwelcome. Across the three platforms, this was most outrightly discussed on the MyDiabetesSecret Tumblr page. Due to the anonymity, it is likely that users felt both safe and emboldened to share their raw opinions about exclusionary aspects of the group culture. One author wrote,

> "I hate how elitist the diabetes community has become. You have international and national events and conferences, and it's always the same bloggers who attend. It's always the same bloggers who get to trial freebies before they get released. It is completely unfair that these people are handed things on a plate when others trying desperately to make a difference have to self-fund everything. The costs of which prevents them from attending the events these other people get to attend where they get free travel, free hotel, and free admission."

This author clearly holds resentment toward those termed "influencers", reflecting a perhaps similar stratification across social media today. It is also clear that this author has a desire to travel to in-real-life events and to have access to new products, but without the financial help *influencers* receive, the cost of doing these things is prohibitive. The first author (HRW) reflected on this in fieldnotes putting forth a set of questions, "Who gets elevated? Who doesn't? More about personality or resources? About likeability? About commercialization of self? What drives who gets the offers and who doesn't?" To answer, HRW looked back through data in search of something that might shed light.

Within the MyDiabetesSecret userbase are also defenders of diabetes online communities who directly address posts that take a more critical perspective of the group. Many highlight the positive health outcomes they have personally gained. And most talk

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about moving from a sense of isolation to a sense of connection. They tend to express gratitude for what exists. One author additionally expresses a need to offer credit to leaders in the group. They said,

> "I've seen a few people post about "the cool kids" in the DOC, and wonder if they've really stopped to think about what that looks like. Those people got to where they are because they have the ability to communicate their story in a way that people find value in. Most don't do it for any kind of compensation - if anything, it costs (in all ways - money, time, energy, sleep), but if they do, I say good for them. I guess some people just like to tear down what others build, but that shade of green doesn't look good on anyone."

To this author, the answer to what drives offers revolves around the ability to convey a story or narrative. They also go on to argue that resentment of influencers is rooted in envy. However, we cast doubt on this conclusion. While this author is correct to say that sharing one's story costs a person in terms of money, time, energy, and sleep, it is also true that some people have more of these resources to spare than others. To see who gains influencer status as more dependent upon the ability to communicate and less dependent on access to resources and tools is to leave unquestioned the fact that influencers across these diabetes online communities are fairly homogenous. Influencers in the spaces observed are mostly white upper-to-middle-class folks, meaning that many minority groups are vastly underrepresented.

The two quotes here draw upon another area of contention across the groups observed, which is the claiming of community. This claiming of community plays out as a form of both inclusion and exclusion and is indicated by users' tendency to refer to a

diabetes online community as *the* diabetes online community (*the DOC*). This may reproduce the exclusion of individuals who haven't made a direct connection within the group self-identifying as *the one*, and likewise, whole groups at a time. At this point, the research could have taken a turn to question: Which groups are a part of *the DOC*, which are not? And what signifiers make a group fall within or outside of *the DOC*? Do multiple groups feel as though their DOC is *the DOC*? What is the cultural and social implication of a community claiming stake in an identifier? However, these questions lie beyond the scope of this study. What is pertinent is to consider if and how the condition of diabetes is being politicized in different ways between users who identify with *the* DOC, *a* DOC, or neither of the above.

Across the three platforms observed, those identifying themselves as a member of *the DOC* more frequently promoted narratives that disrupted internal dominant narratives. These internal counter-narratives were most evident around discourses of complications. The dominant story around diabetes complications emphasizes avoidance through tight control using a mechanism of celebration. For example, a common experience shared across platforms is the outcome of annual eye exams. For example, several users posted photos of their dilated eyes and some text reading something akin to, "Another year without diabetes-related eye complications. If I can do it, so can you." These statements are one-part celebration and one-part encouragement. Commenters frequently cheer on the author, describing the story as inspiring and even heroic.

While stories such as these function to build some up within the group, it also knocks others down: those who *do* have eye complications related to diabetes. In this way, the dominant narrative functions to exclude those who arguably need the most

support. And more often than not, the users who call out this exclusionary dynamic are those who identify with *the DOC*. These users kindly point out that exclusion based on complications is neither direct nor malicious. They acknowledge the need to share feelings of success but ask for tenderness toward those who succeed in ways other than the avoidance of complications. Three leaders across platforms, all who identify as members of *the* DOC, champion this more critically-minded perspective: Renza Scibilia (@Diabetogenic), Chris Aldred (@GrumpyPumper), and Kim Hislop. Kim Hislop, who passed away due to diabetes complications in June of 2019 advocated for the community to expand upon its concept of diabetes success. Some others across the groups observed have done so as well, however, have not been as well-received, nor as frequently shared or retweeted. It is clear that some lesser-known users who talk about diabetes online feel, at times, unheard and at worst, ignored. While the conversation around diabetes complications online has moved the needle for many, it too, has elements of exclusion. Questions are raised of to whom does the megaphone go and as a result who goes unheard? What subsets and subtopics across these platforms are championed or dismissed?

Early on in the data collection process for this study, our lead author wrote in her fieldnotes, "people with type 2 seem to feel unwelcome, underrepresented, and even victimized by people with type 1 – major trouble in paradise". As it turns out, much of the exclusion described within communities is type-based. One author said of her experience on Tumblr,

> "When I was diagnosed with T2D, I realized I would be alone because
> I'm only 22. All the pamphlets given to me were for elderly people.
> Everyone I know who has t2 diabetes is at least 50 or older. I thought I

could join the Tumblr diabetic community to meet other diabetics my age for support, but instead, all I see are T1 diabetics attacking T2 diabetics because they don't have it "as bad" as T1 does. I just wanted to feel like I wasn't a freak but surprise…I was wrong."

Exclusion is reproduced most frequently through the use of external counter-narratives which function to manage stigma through defensive othering. Some interviewees talked about this aspect of the story unfolding largely from parents of children with type-1 diabetes. Crusaders for the cause, parents, often deflect blame of diagnosis by creating distance between their child and the stereotype. Among groups of parents across all platforms, this rhetoric is most common; however, it isn't constrained to them. Over the last three years, there has been a shift in rhetoric. Rather than the within-group dominant narrative reading, "I have type-1 diabetes, which means I have the type of diabetes that didn't cause this", it now reads closer to, "I have type-1 diabetes, but no one with any type of diabetes is to blame." While this shift in consciousness is happening across all platforms observed, the progress is not happening fast enough or with enough momentum to retain a majority of people with type-2, as is evidenced by authors sharing grievances in the form of anonymous posts, via MyDiabeteSecret. The secrets shared on MyDiabetesSecret around representational type imbalance are many, and all reflect a level of vulnerability observed across Twitter and Instagram as well.

4.5.3   The Art of Vulnerability

Vulnerability was practiced wilfully across all diabetes online communities observed, though it took on slightly different shapes depending on the platform. For MyDiabetesSecret, where users remain anonymous, more explicit vulnerability was

exhibited. A short time after its launch, Chris Snider – the creator of the site, was

compelled to add pages dedicated to suicide prevention. In 2016, he said that it was

difficult to moderate because it was "pretty dark stuff". The Tumblr page provides a

space to be unreserved and to unearth deep-seated feelings about the challenges of living

with diabetes. Many authors describe having to take a drug to survive yet it could be

lethal at any moment. By doing this, they show vulnerability and mortality, but also a

sense of control. One author explores this,

> What people don't seem to realize is that every day, we have to make
> the conscious decision to stay alive. For "normal" people, life is the
> standard, death the outlier. For diabetics, for anyone with a chronic
> illness, life only happens if we choose to fight. Every morning, I have
> to decide that today I am going to keep myself alive. Every night I have
> to agree to wake up, so I don't die. And it's so easy to not. A click as
> you unplug your pump, shattering glass as you break your insulin vial,
> the refusal to eat when you're low. For everyone else, they have to go
> out of their way to die. We have to go out of our way to survive.

This sense of control also wrapped itself around letting one's sense of control go,

in a semi-controlled way. The following quote demonstrates:

> Sometimes I play hypo roulette. Dial a number on my pen and inject
> without even looking. I don't know why I do it but it gives me a buzz
> not knowing what will happen. Will I be high? Low? Unconscious?
> Who knows? I don't care anymore.

While the readings of these posts could stop at threats of suicide, they could also

be read as demonstrations of power. When we principally consider the latter, we see a

glimmer of politicization. In a moment of extreme vulnerability, users link their suicidal

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thoughts to a profound injustice. They draw attention to the fact that they are forced to be responsible for their life and mortality in a way that able-bodied people simply are not. In so doing, they call for recognition of the work they put in to survive and the incessant attention they pay to a disease they feel few people see. Made more profound by the anonymity, users secrets call for this recognition not on a personal level, but a collective level. This politicization may at times be unintentional, but salient none the less.

The condition of diabetes is more directly politicized using the art of vulnerability across Twitter and Instagram. Users, who regularly use their real name have constructed a form of vulnerability that is designed to both inspire and inform. Many can strike a balance between letting the hardest parts show, while also appearing strong, confident, and in power of their health. Users who were interviewed said they talk about the challenges of diabetes on social media to be authentic and *real* and to show others with diabetes they are not alone. When asked about non-diabetic followers, a resounding emphasis was placed in exposing how hard diabetes really was. In one interview, Kylene Redmond (Instagram: @BlackDiabeticGirl), said,

> "Most people think that if you take your pill or insulin, whatever, you're just good. They don't see the mental part, the emotion. How hard it is. Diabetes isn't simple, and oh my god, people need to see what we do every day, just to, you know, just stay alive."

People with diabetes (mostly type 1) make use of hashtags like #DayOfDiabetes, #IWishPeopleKnewThatDiabetes…, and #T1DLooksLikeMe to share stories of daily life. They showcase the minutia of their *real* lives and experiences online to communicate the seriousness of the disease to outsiders and normalize the harshness of it to those on the

inside. Kylene and others like her share an ontological view that there is *one real reality*.

They connectively share an understanding that said reality is messy, filled with hardship,

and burdensome. Diabetes requires people to be responsible when they hope for freedom

and attentive when they hope for rest. However, it is within these forced pockets that

people describe the development and logic of *strength* and *hope*.

Perhaps more palpable, the art of vulnerability is performed in a contrary, though

complementary, direction. Users share their thought-evolution to illuminate personal

transformation. In some cases, they out themselves for having once been ignorant or

misinformed about diabetes to preface a tale of growth. Users, then, showed past

vulnerability to highlight current strength and in so doing, put out a call to action. They

urge their followers to *see the light*, so to speak. They highlight hope and strength which

can be gained from doing the trying emotional work of thinking about diabetes critically.

This sometimes looked like seeing the silver linings, and sometimes like claiming a sense

of *diabetic pride*. Across Twitter and Instagram, the users with the most followers tended

to show an evolution of thought while being upfront about current challenges. Thus,

when a person shows both sides of diabetes, then they are perceived to be painting a more

realistic picture of it for others. Vulnerability is performed, rather than used, in this way.

Further, that performance is likely rooted more in intuition than in deliberate strategy and

driven by a hope of coming across as relatable and *real*[6] Rather than as calculated and or

thoughtfully *unevolved*.

The art of vulnerability is, thus, utilized to bring salience and power to

representations of diabetes that directly counter mainstream representations of the disease

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[6] What constitutes reality is a contentious issue in the worlds of academia and philosophy. To consider the question of what is really real, here, however, is not within the scope of this paper.

as easy to manage and not serious (which are perceived by users as a reductionist smokescreen of imagined futures). By being vulnerable, but not too vulnerable, they connectively work to change the representation of diabetes as a disease for the lazy.

4.5.4   Channelling Goldilocks

Because diabetes is so frequently misrepresented, users in diabetes online communities often rise up against them using their social media influence. However, just as with vulnerability, there is a normalizing force within these groups herding users toward a middle way. When addressing a person, post, or story that misrepresents diabetes, there is a pressure not to ride in, sword wielded, like Mel Gibson in Braveheart. Many users believe that running and shouting across the field toward your enemy doesn't yield results across diabetes online communities; it just tells your horsemen to find another leader. So, there is a pressure within these groups to approach misrepresentations like a game of chess, strategically and 10-steps ahead. Unlike other disability groups which err on the side of radical, most advocacy that is accepted within the DOCs observed is polite and diplomatic. Strategically expressing moderate deviance (a combination of nonconformity, dissent, and disruption toward mainstream representations) is preferred among people with diabetes and also by the clinicians and parents who have joined the conversation. When asked about her online persona, diabetes advocate Brianna Wolin (Twitter: @breezygfreezy) said,

> I try not to get overly aggressive or overly complaining or overly out
> there. Because I want people to feel like they can engage with me. I
> feel like sometimes there are people in the community who always feel
> like they're on the offense, and it's hard to ever want to talk to them.
> And I want to be opposite of that.

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Deviance or nonconformity then is seen as ideal when it is moderate: too little and you aren't doing enough, too much and you're causing trouble. What's more telling, is that generally, the "popular kids" act as sheepherders in the process of normalizing how diabetes advocacy is done online. The leaders or influencers tend to communicate more strategically and in more analytical terms than reactive knee-jerk words. This trend was observed primarily in type-1 dominated groups, a possible indication that this within-group pressure to normalize the right amount of nonconformity may act as a mechanism of exclusion. Figure 10 visually depicts this normalizing pressure built into advocacy efforts across the diabetes online communities observed along with examples of each level.

Figure 10. Process of normalization of advocacy
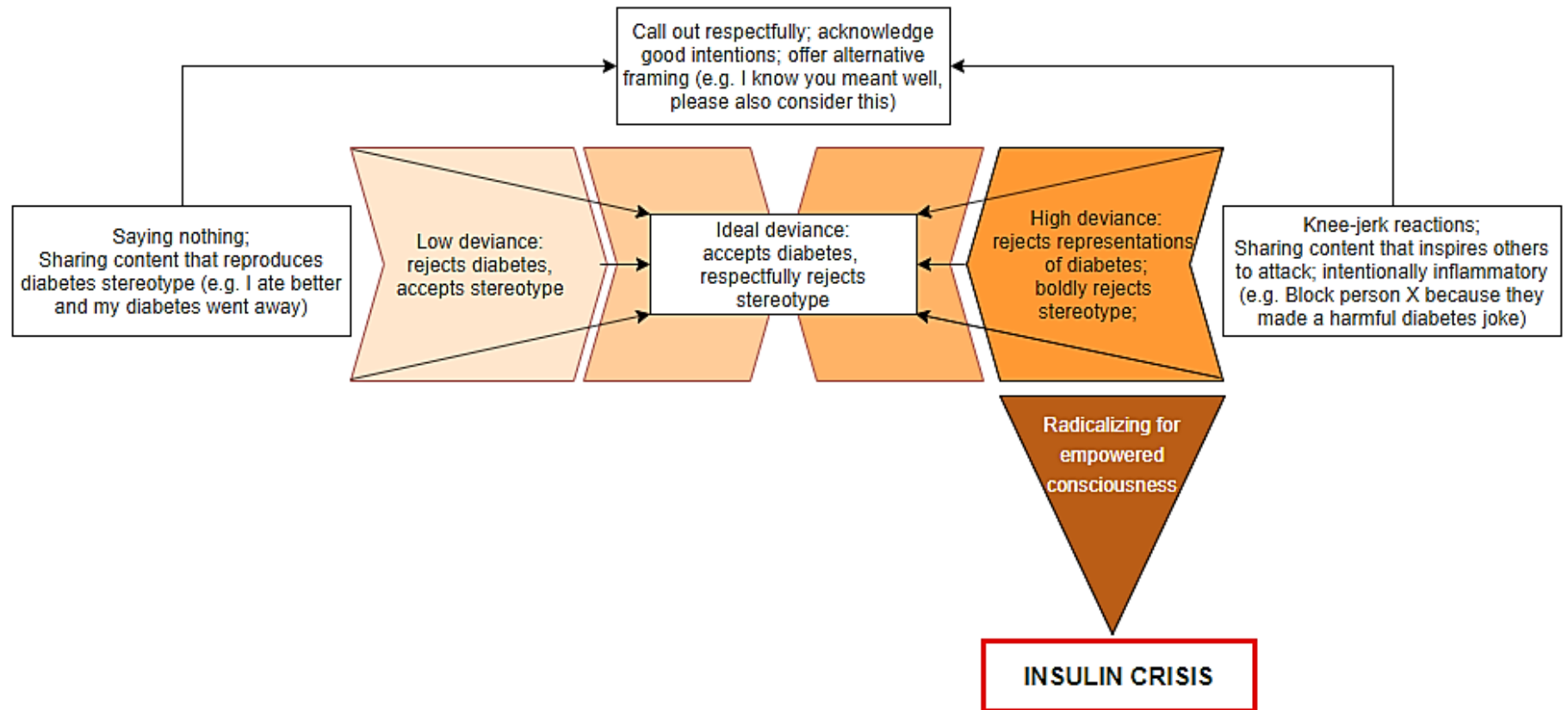
Conversely, current conversations and interactions around the insulin crisis challenge this construction. As is modelled in Figure 9, users of DOCS are in pursuit of a more immediate type of *collective* change. They are radicalizing – and the relative dominant narrative is shifting away from polite deliverance of disruptive messages. Instead, users are taking more risk in their social media posts. They are raising the stakes. When discussing the insulin crisis, for example, users share images and articles about individuals who have died due to a lack of access to affordable insulin. They are contacting news outlets with broad audiences like The Guardian or The New York Times to request coverage of trips to Mexico and Canada – countries where insulin is affordable.

On Twitter and Instagram, users rally around a central hashtag: #Insulin4All. #Insulin4all has transcended the bounds of a social media campaign or movement into an on-the-ground grassroots one. Users who most actively engage with #Insulin4All use the hashtag in their usernames and bios, and in some cases offer advocacy resources like newsletters (Twitter: @lollydaggle) or blog posts covering news and opportunities (Twitter: @StephenST1). The insulin crisis is serving as a platform for individual advocates who are *connectively* engaged in various issues to transform into *activists* with a *collective* organized agenda of social change. In this way, the condition of diabetes is being directly politicized as *lethal without access to medication*. The stakes being set by users around this issue, then, are *life or death*. The normalizing forces and pressures seen across other issues in these groups are not present in this one. Rather, the more extreme, the better. When interpreting these themes of advocacy, our first author wrote in fieldnotes, "What do folks prefer and why? Why is the terminology shifting here?".

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HRW then used her Twitter account to find out. Figure 11 shows a screenshot of the

Twitter poll HRW tweeted on July 31, 2019.

Figure 11. Preferred role/title twitter poll
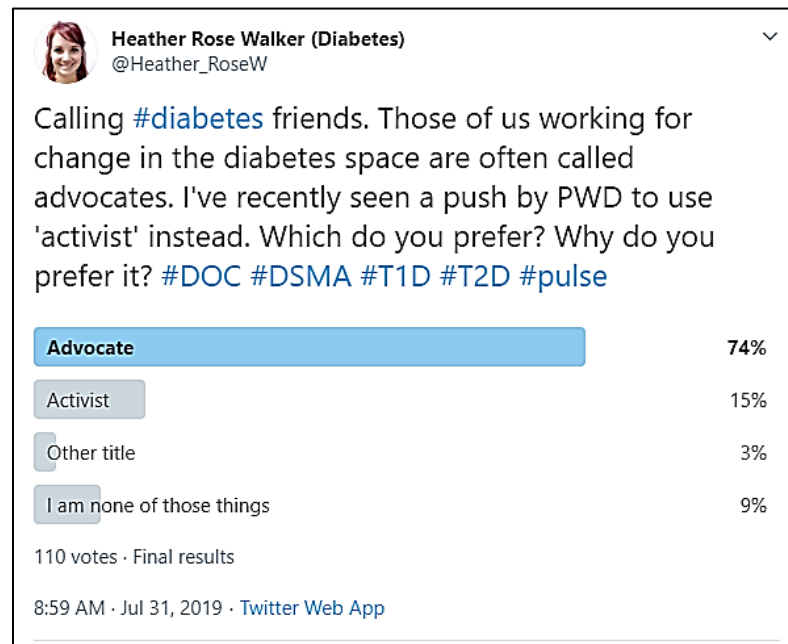
Those in the advocate camp expressed preference for advocate because, to quote

Melissa Lee (Twitter: @SwetlyVoiced), "to advocate is to speak for the people who

aren't privileged to stand in the moment where I'm standing." She differentiates this from

activism, which to her, is about action. Many others echoed Lee's tweet, further stating

that activism is a negative term usually perceived of as aggressive, extremist, and propaganda-like. However, those in the activist camp expressed preference for activist because, to quote Hannah (Twitter: @Lollydaggle), "I am a textbook activist. I'm here to get political on insulin with the goal of systemic change. I'm on the ground and getting stuff done. I advocate too for myself and others in contexts, but I consider advocating more of a support function. I'm also an organizer." Hannah differentiates advocacy from activism in a way complimentary to Lee's tweet. She describes activism within the parameters of a specific goal, insulin affordability. Then, states that advocacy is perhaps more general and more supportive of singular others, rather than of the whole. And lastly, those who selected *I am none of these things*, shared that they feel boxed in and constrained by labels such as these. Conversely, several responded by saying they are both.

The responses, while limited to Twitter, do showcase how the pressure to normalize advocacy efforts transcends into the space of titles. People felt that calling oneself an activist was too aggressive and could potentially create a situation in which their work would not be seen or heard by outsiders. As mentioned before, the insulin crisis serves as an outlier to the general process of making change in these communities, as suggested by Hannah's tweet. In addition to the insulin crisis, other individuals directly argue against the normalizing force in diabetes advocacy, and they generally come out around *events*.

After seeing a secret shared on MyDiabetesSecret about a historical DOC event, our first author wrote in her fieldnotes, "Mrs. Manners!!! – that gossip columnist who advised giving shots in a bathroom instead of in front of people who are eating!, very

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controversial, indeed." While HRWs historical knowledge of this DOC event was sparked, the details didn't become clear until a subsequent search engine search of the event details were explored.

The 2014 Mrs. Manners event shook diabetes online communities and caused internal debate regarding the *right way* to advocate. Mrs. Manners, an advice columnist for the Washington Post, offered advice to people with diabetes that was poorly received. She argued when on an airplane, people with diabetes ought to check their blood sugar (which requires drawing about a microgram of blood) in the bathroom. Users across blogs, Twitter, Facebook, Tumblr, and the like, came up in arms against Mrs. Manners' advice, metaphorically kicking and screaming. Some users, however, announced reservations with this approach, arguing that coming out ablaze in this way wouldn't accomplish anything. And cyclically, others resisted. A follow-up post on MyDiabetesSecret demonstrates a reflexive process around the incident, in which the author calls for more compassion and understanding from fellow users of diabetes online communities. The author said,

> "Wow. "Miss Manners" has us all in a tizzy, doesn't she? Here's the thing… When we read her post yesterday, most of us probably felt annoyed or frustrated. A little angry at the ignorance we face all the time as PWDs. BUT… when people blogged or tweeted rude comments "to" Miss Manners, they weren't really addressing her directly. They weren't looking a 75-year-old lady in the face and saying, "Fuck you!" What they were doing was expressing their thoughts to their community, people they thought would understand. Just like you come home from work and say to your spouse, in the comfort of your home, "My boss is an asshole," but you'd never actually say that to his/her face. Please don't judge people for how they

feel, and how they expressed it. None of us is better than the other.

We're all in this together."

When considering the Mrs. Manners incident and several similar events which have unfolded as micro-dramas across diabetes online communities since it contends that there is pushback from all sides. Not only does advocacy and change-making occur across diabetes online communities, but it occurs within a complex web, connected through shared experience, but disjointed by internal pressures to create change in the *right way*. With that said, some users across platforms continue to politicize the condition of diabetes as they see fit through social media, even when they doubt having potential impact.

4.5.4 <u>And So, I Shout into the Wind</u>

During the interviews, it became evident that users endure putting out opinions and ideas despite feeling like they are 'shouting into the wind'. Even one Instagramer, Mike Natter (@Mike.Natter) who had over 86-thousand followers at the time of the interview, expressed this feeling. Users interviewed all expressed this sentiment, wondering, "*am I making a difference, or am I shouting into the wind?*" They question their impact, sometimes thinking it is probably not much, but they continue to do it anyway. They continue to post about diabetes online because they feel a need to *say it somewhere*.

One interviewee who shared a similar sentiment, Molly Johannes, wrote a blog post called "Dia-Feated" about three months after our interview with her. In this blog post, which was widely shared across Twitter, Johannes describes feeling particularly beat down by diabetes that day. She went on to extend this feeling of defeat to her blog. She wrote:

I feel defeated in terms of this blog: I feel like nobody else really cares about it except me. This is fine in some ways because one of the reasons why I write this blog is because it's a form of therapy for me. But in other ways, this makes me sad because another reason why I started Hugging the Cactus was to make a positive impact, somehow, on the diabetes community that I love so much. But it's hard. There are many bigger, louder, more important voices in the online space that simply have a better reach than me. These people know how to connect with their audience in a way that makes a more profound impact than I ever could. Lately, I'm asking myself, "why bother" a lot more than I'm saying to myself, "keep it up".

People with diabetes across Twitter reached out to her after her post went live through tweet, retweets, and even direct messages. She received words of support and affirmation, a trend from similar posts across all platforms observed. The perception that one is *shouting into the wind* is a theme that transcended platform, diabetes type, and level of popularity (e.g., follower count). It suggests that people with diabetes talking about the condition online have an underlying feeling that perhaps the mind of the public is too big to change, at least in the way that change is being attempted now.

4.5.6 Rebranding Diabetes

Users are using social media to change mainstream ideas about what it means to have diabetes. They are urging the masses to look at diabetes differently. They want recognition of the work they do every day to survive and access to the tools they need to continue living. They are connectively and collectively fighting for access to life-saving

medications and supplies like insulin, calling it out as a *human right*. They are pressing

the public to see diabetes as a serious disease for which no person is to blame, regardless

of type. This overall rebranding is not a concentrated effort, but a connective one

unfolding through an evolution of empowered consciousness. Persons with diabetes do

not see themselves as the one-dimensional characters the mainstream representation of

diabetes makes them out to be, so they are pushing back against it.

4.6   Discussion

En masse, the results from this study indicate that the condition of diabetes is

being politicized across social media platforms, but that the primary mechanism of

politicization is *connective* rather than *collective*. This suggests that attempts to enact

social change are occurring at the level of individuals, rather than of a collective group

(Bennett & Segerberg, 2012). While *connective* action can be generated by decentralized

groups of individuals, some scholars have critically questioned how and if that action can

create lasting change (Nekmat, Gower, Zhou, & Metzger, 2019). However, it has been

argued that in marginalized groups, social media as a conduit of connective action has a

high potential to transform into collective action (Mccluskey, 2014). We posit that such a

transformation is underway within these online groups.

Four primary findings were developed from this study that hold socio-political

implications. First, this study found that DOC users perceive there to be a hierarchal

structure across DOCs, potentially influencing the effectiveness of the forms of

politicization identified herein. Many studies on social movements point to a need for a

collective organizing body to put in the work to achieve actions (Rao, Morrill, & Zald,

2000). They suggest that when there are strong divisions or fragmentations within a

group, patterns of participation change, likely decreasing the saliency of the actions carried out, if any (Bennett, 2012). Despite perceived hierarchies, however, DOC users have connectively rallied around the insulin crisis, suggesting that the power of said hierarchies to dissuade users from participating is only as strong as a weak agenda. Said another way, when contending with a substantive and immediate threat, DOC users do seem more willing to overlook fragmentations. But, what was happening before the insulin crisis became a national issue in the United States? What will happen once this threat is dealt with to the extent that some feel alleviated? When we considerer hierarchal fragmentation in the broader context of representational dialogue in DOCs, we see that the diffusion of individual's messages and hopes for change are partially hindered. Social network analysis has been used in this regard to show, however, that certain topics, when activated, serve as bridges to improve the diffusion of ideas flowing from activist groups online (González-Bailón & Wang, 2016). We propose that a bridge already exists in DOCs in the form of shared vulnerability.

Thus, second, this study found that DOC users have captured an art of vulnerability, sharing highly-personalized stories to draw power toward people with diabetes by attending to the complexity of the disease. While in the past primary aspects of the condition that have been politicized revolve around raising awareness of the various types of diabetes (a form of stigma-management that creates further division and validates the stigmatized image (Ezzell, 2009), efforts of politicization have more recently lent themselves to widening the concept of disease complexity to include those disparaged by pervious type-fragmentation. This transition toward inclusion demonstrates an unfolding evolution in *empowered consciousness*, and subsequently a *collective*

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transformation. Users are beginning to both understand and more urgently communicate that they are living a politicized existence, the social conditions around which need recognition and change.

Users across the three platforms use stories to describe a messy reality, but one that is both simplified and demonized in mainstream representations. This follows suit with research on diabetes and perceived stigma (Liu et al., 2017). Users publicly expressed frustration with being forced to live a life that is generally interrogated, one in which their character is called into question because of a diagnosis. Previous research has alluded to how this conflation leads to internalized stigma (Chaufan et al., 2013); however, none has yet pointed to how people with diabetes are connectively or collectively fighting back. Users in this study experience this social adjudication so intensely that they are willing to broadcast corrective messages across social media even when their gut tells them no one is listening, that they are *shouting into the wind.* Users share incredibly personal information to unearth an emerging experience of a politicized existence; users are connectively working toward a common goal: to *rebrand* diabetes.

Third, then, this study found that DOC users are primarily politicizing the condition of diabetes by demanding a *rebrand*. Back in the early 2000s, the fast-food chain McDonald's attempted a rebrand with some success. After becoming known for unhealthy foods, McDonald's began marketing salads, bags of sliced apples, and even burger patties with a higher percentage of meat. They wanted to break away from the negative association with unhealth and move toward an association with a more complex menu offering healthy items. While comparing DOCs with a corporation whose market value exceeds $161 billion (Macrotrends, 2019) may be like comparing apples and

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oranges, the McDonalds story sheds light on how the DOCs rebrand is unfolding. DOC users are calling for diabetes to be seen as a complex disease with more signs of health than unhealth. They want to be seen for what they do, to be recognized for the hourly effort and self-care required for them to simply survive. Instead of salad and apples, people with diabetes are adding signs of health like concentrated self-observation, the desire to continue living, and continuous hardship to complexify their metaphorical menu.

In the current social landscape of diabetes, academic, mass-media, and political forces are continuing to only listen in ways determined valuable from the top down. As researchers, clinicians, scientists, it is imperative that we ask why people with diabetes are calling for a rebrand? Is it to personally escape the character-attributed stereotype condemning them to a life of adjudication (Tak-Ying Shiu, Kwan, & Wong, 2003)? This study suggests that yes, that is one reason. However, this study also indicates they are doing so in pursuit of a grander goal, being heard and understood. Many are using the only medium they have, social media, to air grievances and make corrections one post at a time. And while the airing of grievances may not be seen as a political act, it can be compared to clicktivism – activism performed through the click of a computer mouse, which has recently been argued as such (Kozinets, 2019). These forms of politicization may not exhibit a likeness to what we generally consider such, but that doesn't mean it isn't so. It is with a sense of sarcasm that we rhetorically ask, are there any decision-makers listening? These findings indicate a strong need for research to return to the drawing board, to (perhaps for the first time) attempt to *hear* those living with diabetes and to *see* diabetes as worthy of entrance to the political world.

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Perhaps a more direct comparison than McDonald's, HIV/AIDS communities and voices have fought and largely succeeded at rebranding both what it means to be HIV/AIDS positive, and what the goals of diagnosed individuals should be (Lloyd, 2018). To get there, however, HIV/AIDS communities have had to strongly implement rights-based actions through collective on-the-ground organizing (Smith & Whiteside, 2010). HIV communities have also had to fight for a shift in rhetoric around the disease – calling out prejudiced and narrow-minded assumptions about what it meant to be HIV/AIDS positive (Hirtle, 2015). The paradigm has shifted, as HIV/AIDS is no longer conceived of as 'gay plague', but rather as a chronic disease (Fee & Krieger, 1993). While their fight is nowhere near over, conditions have improved thanks to the concentrated efforts of activists and the media and policymakers who listened.

The work of DOCs does deviate from what has helped rebrand HIV, but we would argue that users in DOCs seem well-primed for moving forward. There may not be a recipe for change that will work for every marginalized community, but there are steps that can be taken to aid in their pursuit of change.

Knowing how diabetes is being politicized online and the barriers perhaps thwarting pursued change sets the stage for what can be done moving forward. This work adds to the literature on diabetes online communities which, until now, has not extended into the realm of politicization and social change. To further extend this new area of DOC research, the unfolding activism involved in the insulin crisis ought to be further unpacked, as the richness and complexity was only grazed in our work. How is the insulin crisis transforming what it means to act across these groups? How is the insulin crisis impacting diabetes identity in these groups? Similarly, the cultural and political

divide between type 1 and type 2 individuals ought to be thoroughly explored as well. How do these divides impact the efficacy of change efforts?

One potential path forward calls for researchers to further unpack whether or not the connective idealized form of advocacy being pressurized in DOCs, as was found in this study, is efficacious toward political gains. The present study is limited in scope, as it was only able to *identify* that users are connectively rather than collectively participating. Further research is needed to ask directly, does this form of politicization work? Is there a pathway within it to impact health policy and beyond?

4.6.1   Limitations

While the research design, search parameters, and analysis approaches were developed by multiple scholars with expertise across disparate fields, data curation, and analysis was performed by only one researcher (HRW). Additionally, HRWs positionality may be called into question as a bias. While we have presented a strong case which highlights insight over bias, this justification may not be accepted in fields of study less acquainted with justice-oriented qualitative research. Lastly, because it was not within the scope to define the boundaries of diabetes online communities, this study was not able to fully consider if the groups observed met guidelines for community-ship offered by other scholars. More research needs to be done to define the boundaries of online groups dedicated to diabetes with a more critical eye paid to classifications of *community*.

4.7   Conclusion

This study used rigorous methods to uncover how the condition of diabetes is being politicized across three social media platforms. Findings from this cultural

exploration reveal that persons with diabetes are using social media to create change, suggesting they do not feel heard within the current social landscape of diabetes. This article draws attention to this problem and urges researchers, clinicians, policy-makers, and scholars to shift their frameworks of inquiry toward the social, toward justice-oriented emancipation-driven contexts and sense-making.

5.   DIABETES IDENTITY: A MECHANISM OF SOCIAL CHANGE

5.1   Abstract

Identity in diabetes has been considered across studies, but only as it pertains to or bares influence on diabetes-related outcomes and self-management practices. This narrowness within diabetes literature toward the individual has left what is known about a possible unified *diabetes identity* relatively unexamined. Through 20 semi-structured interviews, I ask adult diabetes online community users to contemplate, *is there a diabetes identity*? What results is a reflection of a wider landscape of diabetes that focuses on individuation. However, some interviewees described a particularly socially aware empowered consciousness unfamiliar to diabetes literature, leading me to inquire, what would diabetes identity look like when using a sociopolitical lens. To answer this, I offer a theoretical model of diabetes identity. Within this article I contend with issues of variance in empowered thinking among diabetes online community users – drawing out themes related to illness, individuation, and culture.

5.2   Introduction

At the age of 19, I tattooed the word 'diabetic' on my arm as a way to challenge my fear of being labeled a disease. I'd had diabetes for nearly ten years before I met another person with it, feeling isolated and alone all the while. It also took me exactly that long to allow diabetes into my self-concept and identity. The internal negotiation was a trying process. I wrestled with the idea that having diabetes could give me something with regard to identity while also not wanting to afford it my positivity, because I simultaneously felt that diabetes had taken something away from me. And after writing about it in my college entrance essays as a challenge I had to overcome, I began to see it as a thing that was also external to me, as a platform. In a diabetes blog I started in 2012, I wrote the following:

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"I don't know who I would've ended up being, if it weren't for my diagnosis. But, I do know that right now, I wouldn't be sitting in this chair at the Diabetes Hands Foundation office after-hours, sharing with you... I may not have a passion, a drive, a mission. I might be fighting to find something to fight for. What I'm trying to say is that I used to take the fact that I knew my passion for granted. I'm trying to say I feel grateful to be where I am, to be going where I am going, and to have been where I've been."

This text lived on a static page called "*d-story (1.0): invisible billboards for change*" on that, now, retired blog, www.unexpectedblues.com. It was my about-me page. It was the space I used to let the world know that I write about diabetes because I was meant to. As if to say, having diabetes led me to some divine purpose. However, at the time of writing it, I don't think such was my intention. Rather, I was trying to convince myself that there was a *why* behind my diagnosis, overthrowing the one question I'd never be able to answer. In that same about-me page I wrote:

"Now, to be clear, I don't feel lucky because I WAS diagnosed, but because of my reaction to it. I feel lucky for the way I was taught to react to felt injustices – and in my 11-year-old mind, diabetes wasn't a disease; it was an injustice."

In present time, I identify as a diabetic woman, disabled, a mother, a scholar, and a partner. As a researcher, I study diabetes communities from multiple angles using literature from disability studies, communications, sociology, and health fields, some of which see my dual-position as an asset (e.g., participatory action research). My experience as a community member has served to illuminate, challenge, and in some case, affirm diabetes phenomena appearing across disciplines. The research questions, study design, and data analysis use my positionality

within the community as a tool of the research (Dwyer & Buckle, 2009; Richards, 2008). I use reflexive practices, like fieldnotes, to acknowledge tensions, subjectivities, and biases throughout the work (Emerson et al., 2011). I study diabetes and identity because my lived-experience tells me there is more to the story than what the literature on the subject has captured thus far. Identity in diabetes is not just a process that impacts a person's willingness to self-manage or the extent to which they believe in their capabilities. There is something else, something deeper, something I sought to identify and explore throughout this research study.

What follows in this paper is a qualitative dive into diabetes identity and why it matters. In this paper, I contend with the social landscape that understands diabetes to be a disease of gluttony and inactivity. Popularized and normalizing discourses in diabetes "call attention squarely to individual choice as the source of blame" resulting in the disease presence coming to be understood as a "physical manifestation of problematic character traits" (Bock, 2012, p. 157). Diabetes, then, has come to be associated as a marker for a spoiled identity, providing for systemic discrediting of all who are stamped with such a diagnosis (Goffman, 1963).

Perhaps built into the sense of injustice I felt over my diagnosis was an acquiescence to this popularized discourse of diabetes. I was left inquiring *why me* because at the time I believed that there were others who did deserve diabetes and I just wasn't one of them. To put it simply, the social landscape of diabetes conditioned me to believe that people were good if they did not have diabetes, and bad if they did. This logic gnaws at the possibility of establishing diabetes identity, and even more so at the potential for outsiders to acknowledge diabetes identity as something more profound than a tool for medication compliance.

5.2.1 The Social Landscape of Diabetes

Diabetes has metabolic, autoimmune, and socio-economic roots. Impacting roughly 80 million people in the United States, diabetes has been associated with obesity, physical inactivity, high blood pressure, smoking, and high cholesterol (Centers for Disease Control and Prevention, 2017). Diabetes care has been emphatically reliant on self-governance (for medical compliance) on the part of the patient (Rock, 2005). Furthermore, adults with diabetes have reported a belief that the stigma they face is constructed around the perception that it is up to them as individuals to fix the problem of diabetes (Liu et al., 2017, p. 29). Research in the early 2000s found that if individuals could more tightly manage their glucose levels, they would face fewer complications and be healthier in the long run (Peyrot, 2001). As a result of this research which placed the oneness of diabetes management onto the patient, standards of care changed and concepts of empowerment through self-management became trendy. *Activating* patients to adhere to lifestyle prescriptives enveloped the clinical landscape of diabetes, ushering in a new cognitive and mental burden unto those living with the disease. Rather than acquiescing to the inevitability of future complications, persons with diabetes began to ruminate on the possibility of complications *if and only* if they are not able to sustain tight enough control over their glucose levels. The shame, blame, and stigma around diabetes intensified, and the attribution of poor diabetes control latched to willful characters instead of biophysical factors. Thus, improving patients' self-management abilities and practices ever-more vigorously became the subject of clinical intervention through theories of empowerment, activation, and self-efficacy (Anderson, Funnell, Fitzgerald, & Marrero, 2000; Lorig et al., 2010; Lorig, Ritter, Villa, & Piette, 2008; E. Whitney et al., 2017).

While empowerment, activation, and self-efficacy are important, they do little to recognize and

create change in the social structures impacting diabetes health and health care access. Social inequalities, especially those who are stigmatized based on attribution to lifestyle factors, may be "so powerful that they affect people's blood glucose levels, irrespective of how much they eat, what they eat, or how physically fit they are" (Rock, 2005, p484). When considering this landscape of diabetes care and health perception combined with a popularized media representation of diabetes as a disease of gluttony and inactivity, it is no wonder people living with diabetes often reject the term, *diabetic*. What is more, at its most extreme, some avoid diagnosis to distance themselves from the label altogether.

 To summarize, folks with diabetes, myself included, are subjected to two forms of stigmatization. First, we are adjudicated at the point of diagnosis because diabetes is understood as a disease of gluttony reserved for those who "don't take care of themselves." Second, we are adjudicated for every micro-decision around food, exercise, and health behavior (e.g., blood sugar monitoring, injecting insulin, taking oral medication) because diabetes management is understood to be controllable by the individuals inflicted with it.

In the face of these two forms of stigmatization, persons with type-1 diabetes, an autoimmune variant of the disease, often manage stigma through derision and contempt. For example, in early 2013, a group of mothers of children with type-1 diabetes (D-moms) banded together to write and disseminate an online petition at change.org for a diabetes rebrand (Perez, 2013). The petition gathered over 16,150 virtual signatures. Within the petition language, primary D-mom leader, Jamie Perez argued that those with auto-immune diabetes were not to blame for their disease and thus should not be subjected to the stigma faced by those with metabolic (type-2) diabetes. Her solution to stigma reduction, which also resonated with thousands of others, has been explained in disability studies literature as *defensive othering*

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(Parsloe, 2015). *Defensive othering* occurs when members of a stigmatized group reinforce "the power of stigmatizing labels by arguing that the label is true for other members of their social category, but not for themselves" (Ezzell, 2009, p. 114). As a teenager with diabetes myself, this was the easiest way to evade the stigma I felt trapped under. However, over time, I was able to acquire more effective rhetorical tools to manage the stigma I encountered, though not everyone with diabetes has access to these.

Without more effective tools to manage stigma, persons with diabetes either reinforce stereotypes or internalize stereotypical representations of the disease, deep down believing inequitable social contexts are *normal*, *natural,* or *inevitable* and that the only thing that can improve their health is to change their behavior (Chaufan et al., 2013). While there are new tools to measure internal and external stigma, these have not been fully explored in the social context of diabetes (Beach et al., 2018; J L Browne, Ventura, Mosely, & Speight, 2017; Jessica L Browne, Ventura, Mosely, & Speight, 2016).

I argue that the social landscape of diabetes, constructed around a historical development of research, care, and burden-driven economics, revolves around the reproduction of normalizing discourses maintaining the formulation of diabetes as a *lifestyle disease*. These normalizing discourses have created a splintering effect within diabetes populations which serve to both construct and maintain "boundaries between those who are stigmatized" (Bock, 2012, p. 172). I further argue that to address this issue, close attention needs to be paid to discourses around the development and integration of diabetes identity from within diabetes communities.

5.2.2 <u>Considering the Study of Identity</u>

According to Disability studies scholar, Tobin Siebers, "identities are the theories that we use to fit into and travel through the social world" (Siebers, 2008, p.21). Identities are

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adjustable, malleable, and informative. They involve self-awareness and group consciousness –

some come with social action and responsibility. Identity is a mechanism through which

individuals associate themselves with "a set of narratives, ideas, myths, values, and types of

knowledge of varying reliability, usefulness, and verifiability" (Siebers, 2008, p. 15). Identities

create and solidify diverse social values and symbolic meaning-making systems. Siebers

contends however that, "*The presence of disability creates a different picture of identity – one*

less stable than identities associated with gender, race, sexuality, nation, and class – and

therefore presenting the opportunity to rethink how human identity works." (Siebers, 2008, p. 5).

He describes this instability as a social construction through which the other named identities

have become "pathologized by association with disability" (Siebers, 2008, p. 8). He argues that

for the field of Disability Studies and our understanding of disability identity to advance, we

must take into account both the positive and negative aspects of lived and embodied disability

experience. Siebers' book situates itself into a broader debate of identity politics, which have

been criticized heavily and has slowly fallen out of fashion in academia through time.

The term *identity politics* has been used incongruously throughout various literature

across numerous academic disciplines. Scholars have categorized identity politics through their

mechanisms of change, be it social class and classicism (e.g., neo-Marxists), cultural areas of life

in search of respect and recognition against hegemonic culture, or social movements to challenge

dominant norms and cultural codes (Bernstein, 2005). Scholars have argued for the examination

of identity politics across mechanisms of change using a *politics of difference,* arguing only

when difference is confronted can its presupposition as a natural part of the human experience be

dismantled (Carby, 2001). Use of identity politics by groups within and outside of academia

respects autonomy and builds affiliation (Kauffman, 2001).

The study of identity politics has been criticized for: 1) being unstable and in a state of constant flux; 2) being inauthentic because no single person's experience can be representative of whole group identity; 3) risking ideological normalization and exclusion through assumption that a group is monolithic; and 4) being too subjective since all researchers have their own subjective identities which impede understanding identity objectively (Moya, 2000). Nevertheless, the listed criticisms can and have been addressed. For example, by exploring the ways in which identification with minority and stigmatized groups can be "enabling, enlightening, and enriching structures of attachment and feeling" we can study identity and avoid criticism three (Moya, 2000, p. 8). Not only has the study of identity been criticized, so also has the claiming of identity.

The claiming of any particular minority identity label/status has been viewed by those in positions of power as a point of individual weakness (Siebers, 2008). It has been argued that only those who are needy and lacking in a natural sense of belonging seek identity for self-validation or self-worth. Put another way, the impulse to seek identity has been credited to pathology (Siebers, 2008). It is for this reason, among others, that *disability identity*, in particular, has been criticized. Along a similar vein is an argument, which augments the ideology of ability, suggesting that people who are suffering cannot experience the external world that exists beyond their pain. This argument brands those in pain as narcissists (Garland-Thompson, 2009). However, *disability identity* as a minority identity breaks down in such a way as to counter the claims of those in power (who likely feel threatened by the potential uprising of minority populations).

Theoretically, *disability identity* functions as a minority identity which contains complex embodied knowledge. Siebers makes use of Dworkin and Dworkin's theory of minority identity

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which states that minority identity is characterized by "identifiability, differential power, differential treatment, and group awareness," and adds that groups claiming minority identity are compelled in society and universally to pass a non-fraudulent ethical test (Siebers, 2008). That is, they must prove they are not a fringe group attempting to colonize, imperialize, or take advantage of other groups (Siebers, 2008). Disability identity is then defined by Siebers as "a politicized identity possessing the ability to offer social critiques" (Siebers, 2008, p. 22).

When considering disability identity, we again must consider positive, negative, and neutral valences, so that we can properly contend with the nuance and complexity of what it means to be disabled (Siebers, 2008, p. 5). Disability identity involves community and a sense of belonging; a collective setting forth of a political and social agenda through identity integration (Gill, 1997). However, I question how theories of disability identity as an elastic social category can be reworked to include the voices and experiences of groups of people who are afforded protections within disability rights legislation, but who do not claim disability identity as an identifier. I question what qualifies as politicized, and to whom do said social critiques need to be issued? Siebers goes on to say that "any group that forms a coalition to make arguments on its own behalf and on behalf of others in the public forum takes on a politicized identity" (p. 22). While this partially satisfies my first question, it strengthens the second. What constitutes a public forum, and to whom shall those arguments be directed within the said forum?

When it comes to chronic illness, claiming disability identity becomes an option because passing as non-disabled is possible. The choice to claim and disclose and contemplation around when to do so becomes a process of ever-fluctuating identity and vacillating self-concept (Valeras, 2010). Can purposeful disclosure be considered an argument performed? When an individual isn't forced to claim and make use of identity politics in pursuit of social change, what

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happens? If and when chronic illness is acquired, does the experience of a loss of self through the disablement process of their illness or disability change willingness to identify (Dinapoli & Murphy, 2002)? What are the boundaries of disability identity for those whose status as disabled is experienced as in daily flux?

5.2.3 Diabetes Identity

Diabetes, experienced and defined physiologically as a chronic illness, triggers a process of questioning identity and negotiating self-concept in relation to a popularized representation of diabetes that remains stigmatized through attribution of character-flaws. The study of identity in diabetes has been taken up by academic and health researchers using an array of methodologies. In line with Erik Erikson's formulation that identity development happens most rapidly during adolescence, most studies regarding diabetes identity focus in on youth (Commissariat, Kenowitz, Trast, Heptulla, & Gonzalez, 2016; Fonte et al., 2017; Luyckx et al., 2008; Sparud-Lundin, Öhrn, & Danielson, 2010; Tilden, Charman, Sharples, & Fosbury, 2005). It is known that youth identity in diabetes is mediated by the development and reconsideration of relationships with parents, friends, and self (Sparud-Lundin et al., 2010). Also, using an Identity Illness Questionnaire, a team of researchers found that youth who accepted diabetes and felt in some ways enriched by the condition had better health outcomes and behaviors (Oris et al., 2016). Overall, studies focused on youth identity in diabetes, tended to explore identity constructs and contexts insofar as they possibly impacted health outcomes and behaviors – marking an overlap with the few adult-focused studies which exist on this topic.

Adult identity in diabetes has most often been studied in the context of self-management. That is, identity is valued within this literature as its development supports or hinders a person's ability to perform self-care behaviors. For example, unwillingness to identify as *a diabetic* was

found in one study to be associated with expressed feelings of helplessness and an unwillingness to self-manage (Brouwer & Mosack, 2012). Conversely, another study suggests that those who accepted their type-2 diagnosis also identified with being ill and were thus less likely to follow self-management requirements (Amorim, Ramos, Brito, & Gazzinelli, 2014). Therefore, diabetes is complex in that for some, claiming identity produces disengagement, and for others, not claiming creates disengagement. I would argue that the way identity has been approached thus far in the literature, as a tool of medication and behavior compliance, pads rather than disrupts the ever-pervasive stereotypes. That is, if we only ask about identity in the context of its impact on compliance, we still subscribe to the idea that fixing the problem of diabetes lives within the individuals who have it. As a result, we must question if identity has been measured at all, or if what has been captured is more about patients being accepting of the need to engage with self-management practices.

Evermore, a problem with looking at identity in diabetes only as it relates to health behaviors is that it doesn't consider the social or historical factors shaping that identity or how identity constructions impact the social world and communities within which that identity interacts. So, while *identity in diabetes* has been considered across studies, *diabetes identity* has not. The present study advances the literature by theorizing how *diabetes identity* is constructed and what that construction seeks to do beyond the realm of the individual. As described in my personal process of coming into diabetes identity, both internal and external elements bore weight on my thought progression. I have had the privilege of being exposed to disability studies content that starkly challenged the way I thought about diabetes and disability. As I will unpack within this paper, accepting a diabetes identity does not necessarily include disability within it. Many people with diabetes simultaneously accept diabetes identity and reject disability identity,

along with any association with sickness. This paradox, of identifying as a specific type of sick, but not as generally sick may presents limits on what a theory of diabetes identity can do. To address this paradox at least in part, I have ventured to hear from people with diabetes who share widely and speak loudly about their lives with this condition. My historical knowledge of diabetes online communities (DOCs) allowed me to locate such individuals in online social media spaces, and thus embarked there.

One scoping review defined Diabetes Online Community (DOC) as, "a user-generated term that encompasses people affected by diabetes who engage in online activities to share experiences and support in siloed or networked platforms." (Litchman et al., 2019, p. 22). While DOC is undoubtedly a user-generated term, it is also a place in which discussions are being had about what it means to have diabetes. As a research site, it presented me with a stage upon which many people with diabetes were talking about their shifting diabetes identity.

5.3   Methods

This study is part of a larger dissertation aiming to unpack how the condition of diabetes is being politicized online through narratives and counter-narratives. In the parent study, I conducted a netnography (ethnography of an online group) in three diabetes online communities (DOCs) across Twitter, Instagram, and one Tumblr page (www.MyDiabetesSecret). As a part of that netnography, I conducted 20 semi-structured 60-minute interviews with social media users who utilize diabetes-related hashtags.

5.3.1   Setting, Sample, and Recruitment

I found interviewees' social media accounts by searching hashtags like #T1D, #T2D, #DiabetesCommunity, #DOC, #DSMA, #IWishPeopleKnewThatDiabetes, etc. After reviewing a hash-tagged photo or tweet, against the following criteria:

- post about representations of diabetes on their social media channels

- are a person with diabetes

- use story or personal experience to talk about those diabetes representations

I audited the profile of the author and took note of the following:

- frequency of diabetes-related posts

- audience/follower type and size

- type of diabetes

- ethnicity

- gender identity

- social media platform preference

- age

- level of personal sharing

As a recruitment strategy, my initial intention was to locate two users who exhibited dominant-aligned narratives (e.g., I lost weight and now I don't have diabetes), two users who exhibited counter-narratives (e.g., diabetes is a complex condition that requires constant work), and two who seemed more neutral. However, after digging into the auditing process, I found that most users used a combination of narrative types. As a result, my recruitment strategy focused more on ensuring a representative sample which included users varied in type of diabetes, age, race, and ethnicity.

5.3.2 **Ethical Considerations**

This project was approved by the University of Illinois at Chicago's IRB in April 2019. All participants recruited were subjected to a full-length consent process in which they were asked their preferences for privacy and confidentiality. Because all participants in this study

publicly share content about diabetes across social media platforms, they were offered the option to have their real names and social media handle disclosed in presentations and publications. This ethical consideration was included to serve as a form of community capacity building by giving credit to these individuals as authors (Roberts, 2015) and disrupting the oppressive power structures that deny credit to patient authors as a form of paternalistic forced protection (Roberts, 1981). All 20 participants recruited elected to use their real name and social media handle when quoted. Fourteen of them selected to review all quoted material used before submission for publication. Thus, this manuscript and the quotes used have been manually approved by fourteen participants. Each interviewee was provided a $20 gift card honorarium for their time.

5.3.3   Research Questions

Three research questions drove this study:

1) How does participation in diabetes online communities impact users' sense of identity?
2) What are the components of diabetes identity?

    a. If at all, how is diabetes identity formulated around social change?

3) If at all, how is the condition of diabetes politicized across social media platforms?

    a. How does it then influence diabetes identity?

5.3.4 Study Design

This qualitative study aimed to answer these research questions through a series of iterative in-depth interviews designed using grounded theory principles. Reflexive fieldnotes were utilized as a part of the study design to check author assumptions and biases.

5.3.5 Interviews

Each semi-structured interview lasted 60-minutes and covered topics relating to participation in diabetes online communities, lived experiences with diabetes, and diabetes

identity. The initial interview guide, along with questions developed throughout the interview

process in response to participants' stories, are provided in Table IX.

TABLE IX.
INTERVIEW GUIDE QUESTIONS

Original interview questions	(8) Why do you post content online about diabetes? (9) Overall, what is your goal for posting about diabetes? (2.1) PROBE: What do you hope to gain? (10) How would you describe your online self/persona? (3.1) PROBE: How do you think your followers see you? (11) Next, I'd like to ask you about a specific post you made, [shows or describe post] in which you [said/photographed] [describe post]. Can you tell me a little more about it, and what it was like to post that? (4.1) PROBE: What led you to decide to post that in particular? (4.2) PROBE: Who were you hoping would see the post? (4.3) PROBE: What were you hoping would come of the post? (4.4) PROBE: In what ways were you satisfied or not satisfied with the result of posting it? (12) To what extent is diabetes a part of who you are? (13) Is there a diabetes identity? (14) If you had the opportunity to go on the Ellen show to talk about diabetes, but you could only share one thing about diabetes, what would it be?
Added interview questions based on the iterative process	(1.1) Has your reason for posting changed at all? (1.2) If yes, how? (5.1) Who does diabetes require you to be? (5.2) How does diabetes require you to be? (5.3) What parts of you is diabetes *not*? (6.1) If not, do you want there to be? (6.2) Is there a type 2 identity? (15) Imagine one of your dear friends was just diagnosed with diabetes. What story would you tell your friend about your DOC? (8.1) PROBE: Why that story? What does it mean to you? (16) Are there any narratives, or stories that you often see on asocial media that really resonate with you? (17) Are there any narratives, or stories that you often see on social media that you don't agree with?

As detailed in Table IX, I used an iterative interview process (DiCicco-Bloom & Crabtree, 2006), in which I allowed questions to be shifted throughout the interviews as interviewees saturated certain questions and brought up new ones. For example, the fourth interviewee suggested question (5) be expanded upon, and so I added two probes to garner additional feedback. Additionally, throughout the interviews, I altered the question order. For example, because the first seven interviewees answered question (7) nearly exactly the same way, I moved the question up to the front to suss out whether or not the questions asked prior to it were priming interviewees to all respond in the same way. After three more interviewees answered similarly despite the order change, I relocated the question back to the end. As is common in in-depth interviewing, the interview guide remained flexible to accommodate participant responses and data processing (Seidman, 2006).

Throughout the interviewing process, I used a constant comparative technique. From interview to interview, after a participant had answered a question, I strategically disclosed how other participants had responded (e.g., you're not the only one to say that, or, other people said x), then ask, "how does this compare with your thoughts?" (Redman-MacLaren & Mills, 2015). This form of interviewing followed with grounded theory technique to triangulate data (Charmaz & Belgrave, 2012).

Data Collection, Processing, and Analysis

All interviews were conducted by telephone, audio recorded, and transcribed using Rev.com, a pay-per-minute human transcription service with a 99+% accuracy rate (Rev, 2019). Rev.com ensures that all files are securely stored and transmitted using TLS 1.2 encryption, the highest level of security available. All transcriptionists have signed strict confidentiality agreements. Rev was asked to delete the files once each transcription order was complete. A

signed non-disclosure agreement between Rev.com and the University of Illinois at Chicago Institutional Review Board was completed. A subset of audio files was compared to delivered transcripts to ensure accuracy.

After each transcription was received, the resulting text document was imported into MAXQDA (VERBI, 2016). Initial coding within MAXQDA occurred within 24-hours of the time each interview transcription was uploaded into the computer program. All data was subject to an iterative coding and recoding process borrowed from grounded theory procedures, paired with heuristic analysis (Charmaz & Belgrave, 2012). This way of axial reading of the data as it was recorded allowed me to continue asking if, how, and why a phenomenon was happening (Charmaz & Belgrave, 2012).

Lastly, in order to meet the standard of rigor in qualitative research (Morse et al., 2002) and to ensure to social validity of the findings shared within this article (Foster & Mash, 1999), I subjected my analysis to two-member checking processes. First, I sent the two identity constructs I developed to three interviewees for reflection and feedback. Second, I sent the first draft manuscript to 14 participants for approval, reflection, and feedback.

5.4   Results

Participants included individuals living with type 1 (N=15) and type 2 diabetes (N=5). Participant age ranged from 18-69 years old (*M*=39.4, *SD*=15.88). Table X shows participant characteristics by diabetes type, sex, location, and ethnicity.

TABLE X.
PARTICIPANT CHARACTERISTICS
(N = 20)

Variable	n	%
Diabetes Type		
Type 1	15	75%
Type 2	5	25%
Sex		
Female	10	50%
Male	9	45%
Decline to state	1	5%
Location		
US	19	95%
UK	1	5%
Ethnicity		
Caucasian	14	70%
Hispanic	2	10%
Black	4	20%

Table XI demonstrates examples of the coding and categorization procedures.

TABLE XI:
DEMONSTRATION OF ANALYTIC CODING AND CATEGORIZATION PROCEDURES

Interview Quote	Code	Sub-Category	Category	Core Category
I think there is a diabetes identity, a kind of sense of a D-nation among type-1s. I don't see that kind of identity among type-2s, and that's a complicated question. Some of it has to do with the questions of shame and self-blame. Some of it has to do with the degree to which I identify as a diabetic. I'm able to identify as a well-controlled diabetic. I think many people are not, and that keeps them from really being able to or wanting to identify as a diabetic because it requires identification with a condition of shame and failure.	Willingness to identity-based on sense of diabetes self-management	Type-specific diabetes identity	Mystification of difference	Identity conceived of as unified social category
But I will also argue that there is also an identity split, as it were, between... especially like an American... the American side of things where the healthcare system, insulin is so expensive that it kind of... what an American diabetic is going through and what a UK diabetic where the healthcare system's funded. So they don't have to worry about paying for insulin if that makes sense. They have different factors to consider. But overall [diabetes identity] is one big shared experience, I suppose.	Location-based differentiation	Identification based on social conditions creating hardship	Mystification of difference	Identity conceived of as unified social category

TABLE XI. (continued)

I don't know if there is a diabetes identity because all of us are different. Everything we go through is different. We may have peaks of similarities, but it's not enough to make it a universal thing. But, you know, no, we don't live in the same extent every day. But the minute we see it, when we see a CGM monitor on someone on TV, we see an insulin pump tubing or something, we're like, "Oh my God, oh my God, this is me." There's automatically that connection we have and I love that. I want that to stay. I want that to be more universal because it's what we need, and it's what helps us get this every day because we're not alone.	Experiential-based differentiation	Identification based on visible markers	Sense of sameness	Identity conceived of as unified social category
I would equate it a little bit to medical training or going to war. You're experiencing, in some cases for some people, traumatic experiences or diagnoses. But more than that, you're experiencing a life-altering every day, minute to minute experience that, unless you yourself have and do, you can't truly deeply relate to. And so when you have that relation, I think that immediately creates that bond.	Day-to-day shared experiences	Identification based on social conditions creating hardship	Sense of sameness	Identity conceived of as unified social category
I think if you put a bunch of diabetics in a room the same way if you put a bunch of depressed people or cancer patients or anything like that, I think they would have lived this similar lived experiences of dealing with insurance companies, dealing with doctor's offices, dealing with institutions like schools or a workplace. Maybe having a high or low episode that was particularly debilitating or scary.	Diabetes-related hardships	Identification based on social conditions creating hardship	Sense of sameness	Identity conceived of as unified social category

Participant conceptions of diabetes identity had overlapping elements, and the extent to which each person said diabetes was a part of them was complimentary across diabetes-type, gender, ethnic, and age boundaries. The following themes related to diabetes identity emerged: willingness to identify, takes of the un-sick, legends of the responsible, a tradition of change-making, diabetic culture, sense of sameness, mystification of difference, and diabetes as a unifying social category.

5.4.1 Willingness to Identify

Interviewees differed in their willingness to identify with diabetes. When asked to what extent diabetes was a part of them, most interviewees initially responded with an adage: *it is a part of me, but it isn't all of me*. Having participated in diabetes community groups on a personal level, I'd previously interpreted this adage as a partial acceptance and partial rejection of diabetes identity. I figured that saying, '*it isn't all of me*,' meant people didn't want to let something associated with negative character attributes to define them, so they personally rejected it as a full identity. To challenge my pre-conceptions and to probe the interviewees to dig deeper than common narrative scripts, I asked what part of them diabetes was *not*. And how interviewees prefaced or qualified the statement brought nuance to its interpretation. After reflection, the majority of interviewees concluded that there were not many parts of their lives that diabetes didn't touch. They struggled to find parts of them diabetes wasn't. After long periods of reflection, it became clear to me that interviewees were positioning themselves around a *dual-directional identity*. The first direction was to self (*it is a part of me*), and the second, to other (*but it isn't all of me*). Interviewees, in an attempt to not be reduced by able-bodied persons, demand recognition of their full personhood.

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Willingness to identity, however, wasn't categorically limited to questions about identity integration. One interviewee, Douglas Michael Massing (Twitter: @T2DRemission) questioned willingness to engage with diabetes communities and diabetes identity as associated with the level of one's diabetes control, contemplating that willingness to identify may occur in higher rates in people who have a sense of control over their self-management. He continued this line of questioning, drawing together willingness to identify into willingness to challenge the status quo, He said,

> In order to be willing to come forward with one's chronic condition, diabetes
> or any other...condition, one has to feel confident about being engaged in
> managing the condition. And managing the condition and being engaged with
> managing [a] condition sometimes means either directly challenging the
> orthodoxy of medical care or setting standards for it; deciding what one will
> put up with or not, what one will listen to or not; deciding whether the messages
> that come to one through the medical system are helpful or not. So yeah, I think
> that in order to identify with a condition, a certain degree of—I don't know—
> empowerment perhaps is necessary, however one finds that.

After this interview, I went back and recoded some previous interviews. Nearly all interviewees had considered something along these lines. They explained that when posting diabetes-related content, one of their goals was to be *real* – to show the ugly, scary, turbulent parts of diabetes so that their followers didn't manufacture unrealistic expectations for themselves or others with diabetes. Kylene Redmond (Instagram: @BlackDiabeticGirl) shared that when she posts about diabetes online, she tries not to lose sight of the realistic portrayals of diabetes. She said, "I always want anyone that ever follows me or likes a post or sends me a DM

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to know that, 'I'm just like you. I've been there. I'll be there, and we're all battling this together.'" Others described being real as showing that there is no such thing as perfection when it comes to diabetes management, or as showing all sides of the disease. Dex Geralds (Instagram: @DexGeralds) described being real as "putting it all out there" and shared a feeling of relief when sharing the whole story, the whole process of what it is like to live with diabetes. It should be noted here, however, that everyone I interviewed was '*out*' about their diabetes. A criterion to qualify for an interview was publicly engaging in conversations of diabetes and how the condition of diabetes is represented, so this study is limited in being able to affirm or deny Michael Massing's thoughts. It did, however, expand my thought process. I began asking, could it be that those still *in the diabetes closet* remained in hiding due to a sense of being out-of-control? And if that is the case, are they less likely to engage with communities/groups with members who seem to be in control? Does a *culture of control* with communities produce exclusion? If yes, what does it mean to be excluded based on being *out-of-control*? And is that exclusion constant or cyclical – do people with diabetes feel permanently excluded because they don't think they will ever be in control, or temporally excluded during periods of diabetes burnout?

From my own lived experience, I know that having variability in glucose levels feels terrible physically, emotionally, and socially. It can be debilitating at any moment. For example, recently, I ordered and consumed a diet soda at a restaurant. Two hours later, my blood sugar was over 500, and I felt dizzy, lethargic, and irritable. My husband had to take over with childcare because I wasn't able to give my son the attention he needed. I was in a complete fog. I must have been served regular soda, I thought. And in the 3-hours that followed, I felt *sick*. It reminded me why diabetes is protected as a disability under the Rehabilitation Act of 1973

(United States Department of Health and Education, 1978). After all the interviews were completed, I put the data through a recoding process to look for what *out-of-control* might have meant to interviewees. I found that, most frequently, interviewees distanced themselves from descriptors of being out-of-control (e.g., variability in glucose, disabled, sick, prolonged hypoglycemia, etc.). *Sickness* was almost exclusively rejected as an identifier.

5.4.2   Tales of the Un-Sick

To proactively protect themselves from pity arising from stereotypical formulations of people with chronic illness and disability, interviewees described processes of finding and publicizing silver linings related to the disease. One interviewee, Ginger Viera (Instagram: @GingerVieira), discussed this as an intentional, proactive process of between-the-lines narrative construction. She said,

> "I have three diagnosed conditions, technically. Celiac, fibromyalgia, and type-1 diabetes. And somebody could hear me say that and take away from that that I'm a sick, unfortunate case of someone bogged down by autoimmune disease, depending on how I said it and the look on my face. Or I could say it, and they could be like, 'Damn, girl. Look at you go.' Right? It is all about how you carry it."

To Ginger, proactively protecting oneself from pity is a part of the identity integration process. And Ginger wasn't alone. Without being prompted, Anita Nicole Brown (Instagram: @Anita_Nicole_Brown), jumped into describing what diabetes has done for her as a person, taking a positive disposition toward it overall. She said, "But because I have to know my body, I have to listen to my body. I have to be able to understand what I'm doing to it and how I'm doing the things that I am doing to it. Would I have been able to do that had I not gotten this disease? I

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really don't know if I would have." Here, Anita Nicole disassociates herself with an image of a diabetic as a sick person focusing on the negative aspects of the disease and turns toward gifts it has given her. She is exploring diabetes identity in a way that protects her mental health. If she can see diabetes as a gift, as a source of strength, maybe she will feel less sick. But what kind of internal and external pressure could potentially build up by asking oneself to see diabetes as a gift – especially within the context of actively pushing away from sickness as an identity?

One interviewee drew out this line of questioning. Michael Massing (Twitter: @T2DRemission) said that in his diabetes online community, he frequently sees people saying, "*I don't want to be seen as a sick person.*" He went on to consider, "*well why not*?" citing a popular novel in which a character is damned to hard labor because of an illness. He said that just like in the book, there is a "*neo-puritanism where ... extending beyond diabetes, that if you're sick, it's your fault. If I'm healthy, it's because I'm a good person.*" Despite frequently deployed empowered statements which challenge the status quo, there contrarily do seem to be aspects of diabetes identity that pull back and reinforce discourses of normalization. In an attempt to liberate oneself from associations with the diabetes stereotype, people with diabetes proactively reject the pity they feel is associated with sickness.

5.4.3 Legends of the Responsible

When asked who diabetes requires them to be, nearly all interviewees gave some iteration of responsible: *organized*, a *constant planner,* and *a person who thinks through all situations in advance*. Being responsible was also explained as an external social pressure that impacts diabetes identity. Abby Burch (Twitter: @orbingpunk) said,

> "There's kind of this identity of who you're expected to be as someone with
> diabetes, so you're expected to be this person who is checking their blood sugar

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regularly, or if you're not, then you're getting chastised by your doctor. And

you're expected to be this person who is eating the right things and not eating

sweets for fun, things like that. So I feel like the public has a perception of who

they think diabetes should be."

Being responsible with one's diabetes self-care through preparedness meets external demands,

and when performed publicly also works to change the media-perpetuated construction of

diabetes as a disease of people who don't care about themselves.

All interviewees were asked a high stakes question which required bargaining and

prioritization. The question asked, "If you were on the Ellen show to talk about diabetes, but you

only had 1 minute to speak, what would you say?" This question required interviewees to

prioritize what they would say about diabetes to a massive action-oriented audience. I imagined

several people would use the time to talk about the insulin crisis happening in the United States

or education around diagnosing. Rather, all but two interviewees used their only minute on Ellen

to talk about the *seriousness of diabetes*. For example, the youngest interviewee, Amber

Finneseth (Tumblr: https://liv-abetic.tumblr.com/), used her minute on Ellen to say,

"People don't know what sort of struggles you go through with it. It's very hard

because a lot of people go through things, but it's a very hard disease, as far as

I'm concerned. A lot of people don't seem to grasp that, they don't really take

it seriously."

When asked why they shared a *narrative of seriousness*, interviewees described a world

that misunderstands them – a world that thinks they are lazy unmotivated and blameworthy.

They described carrying the weight of a stereotype on their shoulders yet having to continue self-

care anyway. One interviewee brought forth an analogy from an early Disney movie, *Mulan*. She

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said, "*and every day for us mentally is like that scene where [Mulan] is learning to carry all the weight on and trying to climb the pole. The song is 'I'll make a man out of you' I think, but so yeah, we have to be strong all the time constantly to do the diabetes stuff AND show the world we can.*" Like this, eighteen participants said the most important thing they want outsiders to know is that diabetes is hard, that it requires 24-hour attention and planning. Across diabetes-types, ethnicity, sex, and age, dispelling the myth that diabetes is easy was the highest priority. Diabetes, in all its seriousness and complexity, changes a person. It changes their disposition, the pragmaticism through which they conceive of the world around them, and the way they approach aspects of life many without diabetes can move through with relative ease (e.g., food, exercise, sleep, social activity, etc.). A diabetes blogger, Scott Johnson (www.ScottsDiabetes.com), frequently shares at conferences that when he looks down at a meal, he doesn't see a plate of food, he sees a plate of math (S. Johnson, 2016). And his provocative statement was echoed in the interviews. As I read through transcripts and reflected on the interviewees' decision to use their most public moment to inform audiences that diabetes is a serious disease, I began to wonder, what purpose does that serve? If the goal is to elevate the social class within which diabetes currently exists, how could this happen through the narrative of seriousness? Why was the *narrative of seriousness* chosen by so many as the primary mechanism of change?

5.4.4 A Tradition of Change-Making

A process of personal and social transformation emerged across all interviews. As interviewees explored their diagnosis and their own story of living with diabetes, they attached value and meaning to their experience. Diabetes had to mean something; they explained not being able to understand it or why it happened in their bodies, but they all made sense of and meaning from it through *change*. Many describe using their experience to create change, to make

a difference. It is through meaning-making and reflection of circumstances that interviewees in effect *liberated* themselves and others from the stereotypes. Some called their diagnosis a test from God; others described it as their purpose in life – diabetes to them, was a calling. Some also described diabetes as a force, pushing them to listen to their bodies in a way they hadn't before. Thus, for those who aren't actively advocating or trying to make a difference, the process may be directed more inward.

For those with increasing exterior-facing motivations, change-making was more integrated into diabetes identity. For example, John (Twitter: @JoltDude) described their primary identity as change-maker. They said, "*I think who I am is somebody who wants to try to make a difference for others who are in the same boat as I am. And diabetes is not a one size fits all problem and has limited solutions at this time*." John rooted their change-maker identity within diabetes contexts citing an area which needs confronting, diabetes solutions. The most frequently cited area of change mentioned by interviewees was a shared experience of isolation amongst people with diabetes. Seventeen of the twenty interviewees described a hope that their diabetes-related posts helped other people feel less alone. Several invoked their own stories and experiences of isolation, saying they wanted to create a world where no one else would ever have to feel that way. And one, Abby Burch, described it as a form of liberation. She said it is about being able to let go of it as a hardship only you face and let the world in.

Diabetes Identity, then, is built on internal and external processes and imperatives, underlying more delicate and flimsy principles and mechanisms of social change. There is an effort for liberation built into it, a liberation from associations with a spoiled identity, from stigma, external blame, shame, and reductionist perceptions (Goffman, 1963).

While not every person with diabetes is making a public effort to change the popularized representation of diabetes, all of the interviewees selected for this study are. To most, posting about diabetes online changed over time from an exercise in self-healing, to one of social change. Claiming diabetes and redefining what diabetes looks like is an unfolding tradition across diabetes online communities. Redefining what diabetes looked like took different forms for different people in this study. For some, like Brad Slaight (Instagram: @DeeHeroSquad), posting about diabetes publicly helped the general public accept the new non-normal normal around diabetes. He said, "*The new normal is no-normal, and I think that's what I was getting at is that we're all individuals. We're all snowflakes. They may look alike, but they, if you really look at 'em closely, they're vastly different*." Brad's use of an ever-changing diabetes identity in oddity/abnormality invokes acceptance of a social construction of diabetes not reliant on stereotypical formations.

5.4.5   Diabetic Culture?

One interviewee, Anthony Paviour a UK-based Tumblr blogger, (Tumblr: https://whoneedsapancreasanyway.tumblr.com), said that if there was a *diabetes identity*, it revolved around the tiresome social conditions wrapped up in the whole experience. Then he said there is a playfulness within *diabetic culture*. Personally, I'd seen this term within social media circles but never been in a one-on-one conversation around it. I asked what that meant to him, and he offered examples. Anthony said, "*like reaching into your bag to get something and getting stabbed by the lancet that you left for six months and forgot about; or having a deep appreciation of juice boxes, for example*." These shared experiences, to Anthony, were representative of commonalities across borders, across physiological differences, across social conditions. To him, diabetes identity only existed as a product of diabetic culture. What would it

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mean for a *diabetes identity* to be built around a "diabetic culture" and the inclusions and exclusions that go along with that?

When asked, "is there a *diabetes identity*?" interviewees were split 50/50. Of the half who said no, most argued the case that individuals with diabetes are too different to be coalesced across boundaries, revealing a *mystification of difference*. Of the half who said yes, all argued that all people with diabetes share an understanding of experience – revealing an *illusion of sameness.* Of those who were on the fence, all cited access as a mediator of diabetes identity, suggesting an inequitableness involved in the process of *diabetes identity* integration.

5.4.5   Sense of Sameness

When describing their online connections, interviewees expressed closeness to others with diabetes that extended beyond space and place. One interviewee said, "It's hard to explain, they're strangers, but they understand parts of me more than my family and friends" – a sentiment which nearly all interviewees shared. In my own experience with diabetes online communities, the summative phrase often used to portray this is that online people with diabetes find others *"who get it."* Interviewees expressed a sense of relief as they outlined their coming to community moment when, for the first time, a stranger said, "*me too*." For a group of people who have to self-manage a disease personified as a 'needy toddler', whilst feeling an immense social pressure to affix their social behaviors to meet expectations, it is understandable the relief that could come with a new sense of 'not-alone'.

Many who expressed this sentiment shared stories of connecting with other people with diabetes as a beacon of light. Mike Natter (Instagram: @Mike.Natter), for example, said that "The family component of [diabetes identity], that kind of instant connection with someone who also shares it is very real and very deep." He went on to compare the deep shared feeling to

going to war. He said, "You're experiencing a life-altering condition every day, minute to minute experience that, unless you yourself have and do, you can't truly deeply relate to. And so when you have that relation, I think that immediately creates that bond." Here, Mike and others point to a transformation built on an illusion of sameness. That is, people with diabetes are able to focus deeply on a single point of connection, and immediately bond with others with diabetes.

I went back through the data, highlighting points at which interviewees talked about meeting their online diabetes friends in real life (face-to-face). Eleven of the twenty interviewees organically brought this up during the hour-long interview. All of them drew a deep breath before elaborating on those connections. They took pause, and most fumbled over their words. Kylene Redmond (Instagram: @BlackDiabeticGirl), for example, said of meeting her online friends in real life,

> "It was amazing [long pause]. And it was kind of different, [audible hmm] someone walking up to you, like, 'I know you, you're the black diabetic girl', and you're like, 'Oh, hey!' You know like, 'What's your Instagram name?' [laughter]… So, it does, the community definitely brings you lifelong friends, because you can have pretty good friends and family to support you, but they don't know what that high and that low really feels like, they don't understand when your blood sugar goes high from little things and what you need to do to care for it."

Reactions like Kylene's lead me to wonder, was there something *ineffable* about these encounters? Is this bond something that can be felt, but cannot be explained? If yes, can it not be explained because there is an illusory process at work which the mind cannot wrap around? Do people with diabetes let their guard down, even in the face of difference, and open up upon meeting another person who *gets it*?

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Anita Nicole Brown expressed that a unifying factor in diabetes is the process of transformation. She describes a collective experience of transformation in her diabetes online community, "It can be the most hideous disease in the world, but we have to find, as a group, and as a community, I know we can find a way to find the beauty in it no matter what." There is an unconditional search for silver-linings even when the silver-lining is recognition that a place exists where you can let it all hang out and say diabetes sucks to those who understand.

Thus, the illusion of sameness is wrapped around an internal drive to feel less isolation, to be liberated from the mental burden of experiencing such a serious disease alone.

5.4.6   Mystification of Difference

Together with the sense of sameness, interviewees showed an overwhelming tendency to construct separation through difference. In their personal connections, they were able to bypass differences and connect through a sense of sameness; however, when considering a larger population, interviewees highlighted distinctions. They did this even when asked to imagine bonding factors that might draw cohesion to the group. Interviewees described an array of differences between people which would make unifying them under one social category impossible.

Differences explained included: diabetes-type, physicality and physiology, race, cultural backgrounds, personality, disposition, attitude, socioeconomic differences, political differences, and in the social acceptability of the person irrespective of personal attributes. People frequently cited a common diabetes colloquialism, "your diabetes may vary" put forth by a diabetes blogger, Bennet Dunlap, in the early days of diabetes blogging (Dunlap, 2013). Interviewees frequently incited this to describe physiological and economic differences between people that

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work to *diffuse* a diabetes identity. For example, when asked if there was a *diabetes identity*, Anita Nicole Brown (Instagram: @Anita_Nicole_Brown), said:

> I don't know, because every person with this disease is different, so there's not a generalized diabetes identity, because my identity is mine. I can't say my identity, and what I go through as a type-1 diabetic, someone else is going to be like, "Oh my God, Anita, YES." No. I can't say that because I am me and all my awakenings and how I live with this and with diabetes, I can't say anyone else's going to live the exact same route, which is another reason why I want us to recognize that because everything I go through every day with this disease is entirely different from what someone over in New York or Honduras is going to go through. Even though it is the same disease, we aren't the same with it. So I don't know if there is a diabetes identity because all of us are different. Everything we go through is different. We may have peaks of similarities, but it's not enough to make it a universal thing. So I don't know if there's a diabetes identity.

Here, Anita Nicole reveals an understanding of identity as an individual, rather than collective, construct. Because her diabetes and experience with it aren't the same as anyone else, she sees it as uniquely hers. Other interviewees took a more globalized look at diabetes identity, identifying micro-groups within the broader social category. Corinna Cornejo (Twitter: @Type2Musings) identified the four archetypes or personas when considering identity: **the diabetes hero** who says "I'm going to run marathons, be a triathlete, climb mountains, despite diabetes"; **the tiger parent** "whose child has diabetes and they're forever fighting for their child and their child's ability to get access to the care they need and be able to do things like participate in sports and

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live a full life"; **the savior** who says "I want to dedicate my life to being a medical professional or researcher or work in diabetes so I can make life with diabetes easier, better for other people with diabetes" and **the 'poor me' person** "who's really been either brought into or been affected by the stigma that surrounds or can surround diabetes and feels like there's little or no hope of having a full life or maintaining their level of health". Ginger Viera (Twitter: @GingerVieira) categorized along similar lines, arguing that identity sub-groups vary based more on lifestyle interests. For example, there are low-carber groups, vegan groups, exercise groups, coach groups, etc. which all have their own sets of rules and norms that show splintering within the social category. Both Corinna and Ginger here are reflecting on subgroups within their DOCs who seem to exhibit specific sub-identities. Corinna's reflect narratives that pertain to attitude and a pursuit of living a full life for self or other, and Ginger's reflect narratives that pertain to specific interests related to healthy lifestyles. Taken together, they demonstrate how non-monolithic and complex people in their DOCs are perceived to be.

Interviewees who argued against a unified diabetes identity on the base of individual difference were also those who shared stories of an indescribable bond with others like them. While these may seem to contradict, they actually are compatible. Both theoretically conceive of diabetes identity as a social category. Both weigh the reality of membership, taking into account divisive inter- and intra-personal differences between people. The illusion of sameness and the mystification of difference work together to acknowledge the potential unifying factors surrounding the experience of diabetes. Whether you call it *diabetic culture*, *diabetes identity*, or a *diabetes community*, there is a general recognition of a unifying social category.

5.4.7 <u>Diabetes Identity as a Unifying Social Category</u>

Kate Cornell (Twitter: @SweetenedKate), answered the question of a diabetes identity by highlighting differences. Then, she came around to consider the difference between diabetes identity as it is felt from the inside versus the outside. She said,

> "I'm thinking about all the people that I know in the online community, and we are such a diverse, awesome group of people, but yet the people who don't have diabetes or are not connected in some way and don't really understand it, there is definitely a persona. There's a stigma. There's an assumption made about people with diabetes and who they are and what they do or don't do. I don't think so. From the inside, it doesn't feel like it. It doesn't feel like there's ... other than perseverance, you know, and so on, I don't believe there is."

Kate describes a recognition of differences alongside an externally-maintained stigmatizing categorization of diabetes. The unifying factor for her was perseverance through the adversity of ascribed identity with negative associations. For others, the named unifying factors closely aligned with social conditions like being forced to navigate a health system and being financially disadvantaged because of the cost of medications and supplies. These unifying factors were discussed as oppressive elements requiring people with diabetes to be resilient and to persevere. Diabetes was recognized as a social category impacting populations so diverse they can only be unified through the experience of social marginalization. Figure 12 shows a visual theoretical construct of cohesion and access in diabetes identity.

Figure 12. Theoretical construct of cohesion and access in diabetes identity
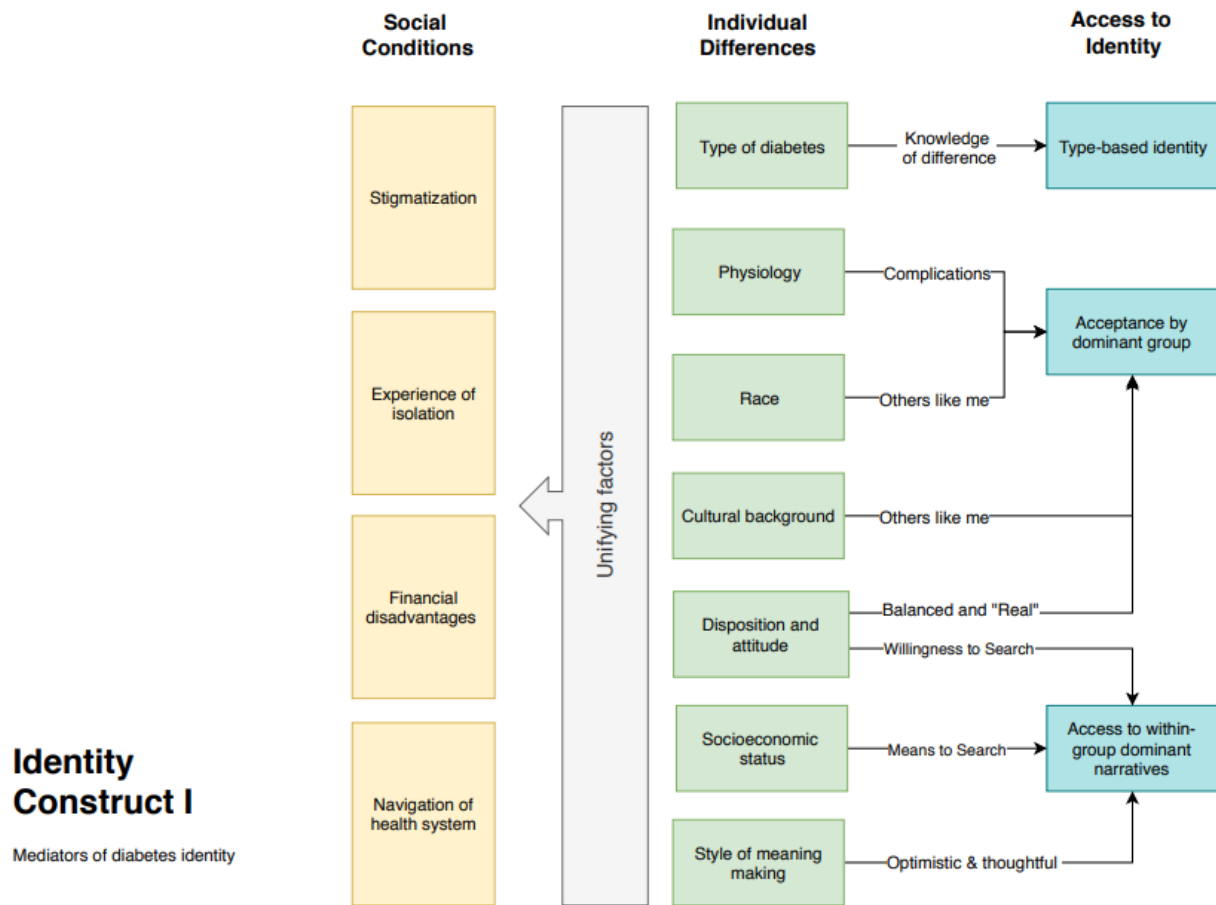
And just like other social categories, resources available to those within the group are limited (e.g., financial, free time to engage, means to search). Resources to connect feed elements of inclusion and exclusion. Interviewees who mentioned this, described it as an issue of access. Diabetes identity has a hive mind (popular opinion attached to action), according to three interviewees. The three described stories of interactions within DOCS in which they spoke up

against the popular opinion, only to be left feeling excluded or dismissed. For example, one interviewee shared a story of feeling ostracized for pointing out that when pharmaceutical companies fund community events, the community is subdued into a state of inaction. The interviewee shared that because the community leans so heavily on "deep pharma dollars, we can never do anything real." It is possible that the hive mind of the group thought the interviewee's responses threatened or put a negative spin on their attempts to do something good in and for the community.

A person with diabetes may not have access to the narrative coming from the hive mind due to a lack of socio-economic or political resources, or they may be rejected by the hive because they do not conform to the hive mind narratives. That is, a person must have the means and willingness to search for others like them to tap into dominant diabetes identity, and in so doing take a balanced and *real* approach to diabetes while remaining relatively optimistic and thoughtful, in order to find and be accepted by the group. Two interviewees with type-2 also described a splintering within diabetes identity that worked to exclude people with type-2 altogether.

The power of diabetes identity as a unified social group despite the splintering with it, to diabetes advocate Corinna Cornejo (Twitter: @Type2Musings), is to create change for all people with diabetes. Corinna said,

> I think that there's this whole impetus and movement to humanize healthcare
> and everything from patient engagement to patient representation to really
> trying to change the way healthcare is practiced. It's not the traditional 'I'm
> the doctor, I know everything. I'm going to tell you, and you're going to take
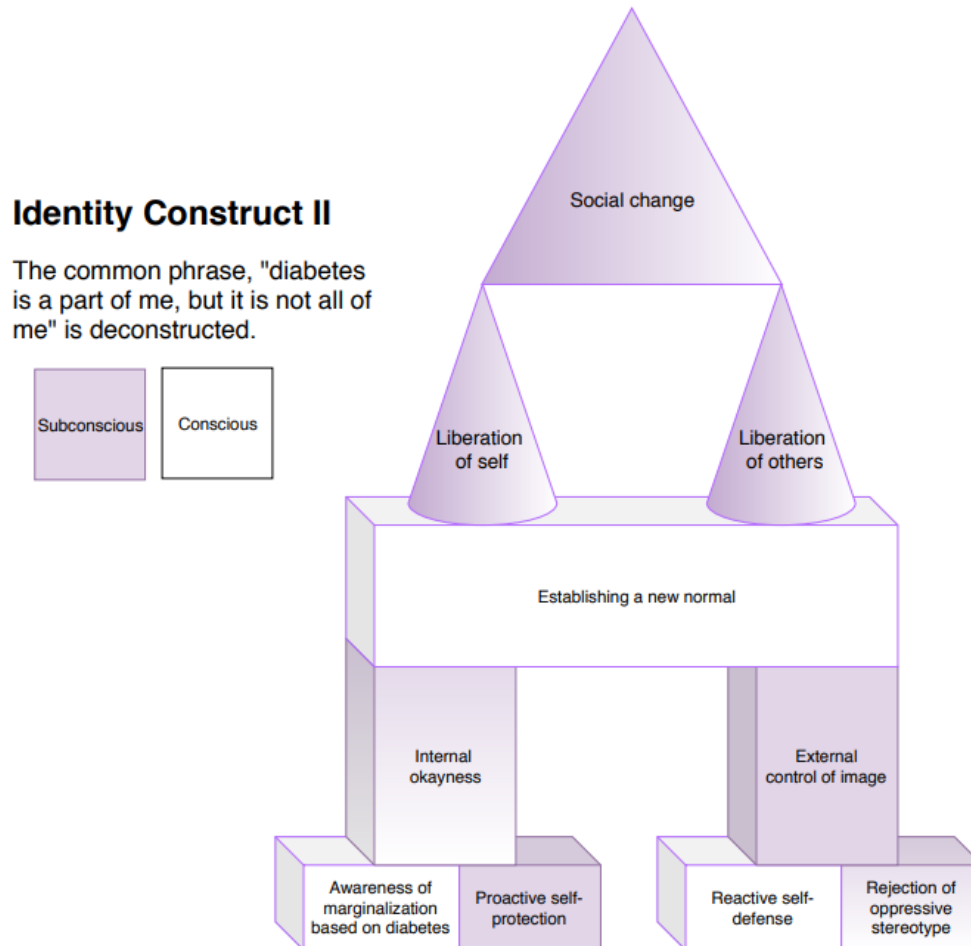
it,' or, 'I'm going to give you the miracle pill to make you better.' To more of

sort of an ongoing, collaborative, hopefully, collaborative process.

And Corinna wasn't alone. Several other interviewees said a part of their motivation for posting about diabetes was to raise awareness about and elevate the realities of diabetes, hoping that non-diabetic audiences would see it and change their mind about what it must mean to live with it. Anita Nicole Brown (Instagram: @Anita_Nicole_Brown) pushed this message further when she said she would share the following on the Ellen Show, "I would say we are a force that needs to be recognized. You guys have no idea what we're capable of, but it's about time you learned."

Synthesizing all of the themes, the results reveal a second construct of diabetes identity as a mechanism of social change. Figure 13 demonstrates a theoretical model which deconstructs the adage "diabetes is a part of me, but it is not all of me" using elements of diabetes identity identified throughout this paper.

Figure 13. Theoretical construct of diabetes identity

Identity Construct II

The common phrase, "diabetes is a part of me, but it is not all of me" is deconstructed.

Subconscious   Conscious

Social change

Liberation of self   Liberation of others

Establishing a new normal

Internal okayness   External control of image

Awareness of marginalization based on diabetes   Proactive self-protection   Reactive self-defense   Rejection of oppressive stereotype

5.5   <u>**Discussion**</u>

My aim for this study was not only to problematize the conception of identity in diabetes as an individualized, apolitical, ascribed health-based category but also to explore the unfolding drama of identity experienced by DOC users. While *identity in diabetes* has been discussed in the

literature and explored through a variety of qualitative and quantitative methods, *diabetes identity* as rooted in politicized aspirations, as more social than personal, as extending beyond the impact on health has not. In this study, I have sought to do that, to unpack the social meaning of *diabetes identity* and to formulate a theoretical model of diabetes identity through a sociopolitical lens.

According to disability studies scholar, Brenda Jo Brueggamann, everything exists in *Betweenity*, a state of extreme-less being, of hyphenated existence (Brueggemann, 2009). It is where you both belong and reject to live, who you are, and who you refuse to be. Betweenity is a theory of self, social, and linguistic exploration, an active denial of illusory binaries and trinaries and stuck-ness. It is in the liminal space, in the Betweenity, that *identity* resides. Away from linguistic limitations and metaphorical dividing borders, is where we find the room, time, and deliverance to "create a *new geometry*," a new space for exploration, a new frontier to traverse.

By formulating diabetes identity as a dual-directional one which is embedded not in physical space, but rather in experiential place, its roots and mechanisms built around social change become evident. Within seeking change, those with diabetes play a cost-benefit game of identification involving the processes of blame-negotiation and stigma management. Identification with a diabetes identity has been argued to heavily rely on where the group or person lands in their perception of blame for the stigmatizing attribute (Crocker & Major, 1989). One interviewee who served as a member checker after all interviews were completed described her disconnect with the first Identity Construct. She said, "*The building block of marginalization is definitely subjective. I personally don't feel 'marginalized' just that I have a condition that not everyone in the world does. If the whole model is built on that construct, it won't apply to me.*" She didn't feel marginalized on the basis of diabetes while recognizing that others do. She

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described herself as lucky for having good health insurance and social support around the experience of her illness, thus saw the model as not befitting her experience. However, her experience of online community support and advocacy could certainly be swaying her sense of identity. The linkage of one's lived experiences to institutionalized discrimination has been described as a "part of the iterative process of identity-building and group affiliation" (Evans, 2017, p. 3). Choosing to associate with the factors of an illness that are marginalized is a process or negotiation and re-negotiation that occurs gradually and cyclically.

It has become apparent through these interviews that those with access to dominant narratives around diabetes identity may experience and politicize diabetes differently than those who do not. In considering this, future research ought to address those with diabetes who have never met another person with the disease (or has met someone with it, but only superficially). Because diabetes is so prevalent, it seems impossible that a person with diabetes could go a decent length of time having not met someone else who has it. Yet, this is a common shared experience for people post-diagnosis. Despite our ever-connected world and an internal drive to move away from a sense of isolation, people go years, even decades feeling alone. How would the theoretical constructs developed within this study be perceived by those without connections to others like them?

The findings of this study also point to the concept of control, which is a problematic concept to deconstruct socially because there is an experienced materialization within the body which bio-physically reinforces the objective to maintain that control and normalcy. With variable and fluctuating blood sugars come mood changes, body aches, headaches, and physical complications such as neuropathy and vision loss. That is, the physical, emotional, and mental ebb and flow of one's physical diabetes levels cannot be neatly detached from the social concept

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of control. Control, lack of control, and their respective fluctuations can be felt within the body in immediate time. Thus, *diabetes identity* interacts with both the materialized biophysical feeling of lack of control and lack of control over social stigma perceived to revolve around diabetes as attributable to undesirable character traits such as laziness, ignorance, and deficiency. The concepts and constructs explored in this article challenge the popularized representation of diabetes by considering diabetes identity as a mechanism of social change. Should other researchers take up this formulation of diabetes identity in their studies, what we know about what it means to live with diabetes today might drastically shift.

5.5.1 Study Limitations

There were a few limitations for this study. First, all qualitative coding was performed by me and me alone. A second researcher helping to code the data may have strengthened the trustworthiness of the interpretations (Morse et al., 2002). With that said, the rigor with which I used member checking procedures compensates for some of that (Birt et al., 2016). A secondary limitation for this study is that I only recruited individuals who are arguable well connected, presenting a potential skew in the results. Their access and contribution to DOCs likely influences their positions and experiences. Future research ought to replicate the concepts I explored here with populations less connected to compare diabetes identity in a general population. Lastly, I was not able, within the scope of this work, to more fully explore the potential sub-identities perceived to exist by some interviewees (e.g., Corinna Cornejo and Ginger Vieira). Based on the brief descriptions provided by interviewees, these sub-identities/personas are likely based on internal motivation, online behaviors, access, diabetes behaviors, social support, and a drive for achieving optimal health. There is much to unpack

regarding the structure and motivation behind sub-identities, and future researchers would do well do examine them closely.

5.6   Conclusion

The findings I described within this paper point to an overarching theme of balance through hardship. Diabetes requires that people be responsible when they hope for freedom, and attentive when they hope for rest. However, in contrast to literature that has come before, it seems folks are using these frictions to do something external for the greater good, then they are using to change their self-management behaviors. As Disability Studies Scholar Tobin Siebers described, when collectively in the face of identifiability and pejorative treatment, "Individuals begin to constitute themselves as a minority identity, moving from the form of consciousness called internal colonization to one characterized by a new group awareness." The findings I presented here do suggest the formation of a group awareness – of critical consciousness. As such, from here, we must begin to explore the structure of any resulting social change. Is it effective? Does it play out as it is intended to? Where is the locus of change, and why was that locus selected? What can we do to assist communities in their efforts to effect change? As researchers, it is our responsibility now to understand diabetes identity as complexly embodied, and, equally important, as a mechanism of social change.

6. DISCUSSION

6.1   Introduction

Within this discussion chapter, I aim to discuss: 1) emergent cultural themes which did not fit into the three manuscripts produced for this dissertation; 2) how the selected methodologies and methods played out collectively for this overall dissertation; 3) each research question posed in the introduction chapter; 4) the sociocultural implications of the work. This chapter then offers recommendations for further research. Finally, a conclusion to the overall dissertation is provided.

6.2   Emergent Themes

Four thematic categories emerged from the data which didn't directly answer a research question, but that contributed to the cultural context of the groups. By highlighting these high-level thematic categories, elements of the culture which are not as intently focused on *change* can be acknowledged as well. The thematic categories I chose for representation here show emergent cross-social media platform norms, beliefs, and inconsistencies. The first three emergent themes which revolve around enculturation are welcome to the club, mourning loss of self, and aversion to limitations and disability. Lastly, the fourth demonstrates an inconsistency or paradox of understanding.

6.2.1   Enculturation

Across DOCs examined, there was an evident process of enculturation in which some users new to these groups became accustomed to the norms and rituals of the groups. In some cases, they were directly welcomed, and in other cases, they offered a comment reflecting a discovery of the group. In either situation, for some, there began a deep dive. With that said,

tracking single-user's movements and networks were not within the scope of this study. Thus, I explore these interactions phenomenologically.

'Welcome to the Club'

Across all platforms, users sharing stories of a recent diagnosis were *welcomed to the club*. They were offered condolences, but also messages of hope and resources for seeking support. Proverbs offered often read, "*I'm not glad you had to find us, but I'm glad you did,*" or "*I know you feel like you've lost a lot, but know you've also gained a tribe.*" In many cases, veteran DOC users prefaced their welcome with "*It's a club no one wants to be in,*" which reflects the culture's ontology. They expressed a belief that while there are gains to be capitalized upon through the journey with diabetes, such as community, that overall, at the end of the day, *diabetes still sucks*[7]. This welcome was laced with a kind of dark sarcasm that at times, seemed to keep users afloat. Humour was identified as a cultural element in a DOC netnography published prior to this project (Tenderich et al., 2018). However, humor was discussed there in the context of coping at the level of the individual users. At the group level, I found that humor was deployed to diffuse intense threads and conversations, to ritualize laughter as medicine, and to establish boundaries of inclusion and exclusion. So, while a culture built around humor likely does function as a coping strategy for the individuals who engage in humorous content, it is also fortified the collective *sense of community*. Humour, together with commiseration, support narratives of understanding which then either grant or deny access to the group and the collective wisdom within them.

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[7]. There is one user on Twitter, who relentlessly argues that *diabetes is easy*. He believes that when so many people with diabetes go online and talk about how hard it is, they are reinforcing notions that people with diabetes are weak and incapable. He has been blocked by many of the leaders in Diabetes Twitter, effectively erasing his perspective from the wider narrative

Mourning Loss of Self

Aside from messages welcoming newcomers, there was also a collective evolution in consciousness occurring through *mourning loss of self*. Space was created to grieve regardless of the time-distance between diagnosis and expression of grief. Because diabetes can be diagnosed in those too young to remember life before, this feeling does not extend to everyone. However, there was nevertheless a similar ongoing process of *mourning the loss of an imagined self* that transcended variances in diagnosis time-distance. Three particularly salient quotes from MyDiabetesSecret reflect the complexities of this evolving consciousness,

> "My mom was diagnosed with type one diabetes about thirteen years after me. I was diagnosed at age one, and have lived with it all my life. I don't know anything different, but when she came home and told me she was just like me now, I could see the sadness in her eyes. I could see the fear take over as she had to learn what it was like to be 'sick.' I never had a normal life, to begin with, but I think I felt what it was like to lose one through her."

> Every time I leave for a school dance or decide to go out with friends, my mom feels the need to tell me, "don't take drugs and don't drink alcohol or you'll die." And I'm sick of it. I know I'm never going to get the chance to let loose and be a normal young adult-like all of my friends, and I've kind of come to peace with that, but I'm so sick of her reminding me over and over again, all of the time that I'll never be 'normal.'

> Drinks and sushi with the girls from work. Apps are getting passed around but where others are keeping a mental tab of what their share of the ticket is I'm keeping track of Carb counts. I miss being normal.

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Through stories, users explored and tested expressions of grief. They expressed sadness and frustration with a *freer self* they can no longer access – a self they perceive as normal, and also with the *potential self* they could have been if diabetes was never in the picture. This profound emotional exploration shapes the culture of support, through which within-group vulnerability is a prerequisite for inclusion. However, that vulnerability has a semi-concealed cap. When it comes to narratives of diabetes being *limiting*, users change their tune.

Aversion to Limitations and Claiming Disability Status

A clash stirred across platforms in conversations about limitations due to diabetes. There was a large camp of users who outright reject the idea that diabetes is limiting – that it prevents a person from doing something they want to do. Within this camp were mega-athletes, protective parents, and adventurous individuals, to name a few. This list is in no way exhaustive, and some individuals within the groups listed would not subscribe to a rejectionist approach. Posts that reflected the rejectionist approach to limitations were often meant to be inspirational. Those inspiration-based stories make up the current dominant narrative. With that said, that dominant narrative seemed to be fading out and starting to take a back seat to a revving internal counter-narrative.

A heavy push was being made across platforms to bring a sense of *okayness* to the conversation about limitations due to diabetes. The way people in DOCs used the #IHearYou campaign is evidence of this. While the campaign was not designed to ask people to be vulnerable about their limitations, users took the campaign as an opportunity to talk about the parts of diabetes they tend to hide. They went deeper to show others it is okay to be in a hard place and to acknowledge those who might not be sharing about diabetes online because they think they need to 'have it all together' to do that.

As discussed in Chapter V, micro-conversations about diabetes complications also impacted the wider conversation about limitations. DOC users seemed to be slowly moving toward looking at complications with a more social lens. With the insulin crisis in the United States, more individuals with diabetes are dying due to lack of access to insulin. Some users in DOCs were drawing out these deaths into discussions of complications. In other words, they were broadening the concept of complications in diabetes to address the system as a root cause involved in diabetes-related complications. The same reframing phenomenon is happening around claiming disability status.

While the dominant within-group narrative was that "*diabetes doesn't limit me, I am not disabled*," the internal counter-narrative was just as strong. For the former, this phrase was invoked with two primary rationales: 1) I don't feel disabled, and 2) it wouldn't be *right* for me to claim disability status when other people are *actually* disabled. The counter-narrative is invoked with three primary rationales: 1) I may not feel disabled today, but I want the protections for the days where I do; 2) being disabled is not a bad thing; 3) activists before me fought for the protections I'm afforded via the Americans with Disabilities Act Rehabilitation Act, so I claim disability status to honor them. The third counter-narrative was not as common as the first two but tended to elicit more in-depth conversations and more users expressing gratitude for having a new way to look at the overall issue. In this way, some PWD defended their position within a protected class, while others expressed relief at the connection and recognition. The following quote exemplifies this:

> A few days ago, someone called my diabetes a disability, and, honestly? It felt
> so relieving to see someone recognize that this isn't easy. I'm fed a constant
> stream of "diabetics are unstoppable and can do whatever they want!" And

having an acknowledgment that it's not all smooth sailing, that it is hard work

just to keep going, just felt good, because I never get that recognition.

From the outside, internal counters expressed a feeling of exclusion because the dominant

narrative doesn't speak their truth. For example:

There are so many 'inspirational' articles about diabetes … and they just make

me feel depressed. I'm not active, or ambitious, or athletic. I'm not young.

I'm disabled and tired.

Taken together, the conversations about complications and people with complications as

representative of a sub-group within the wider diabetes population was slowly shifting toward a

more elevated critical consciousness.

6.2.2   **The Paradox of Understanding**

One interviewee said when reflecting on her community, "it is like no one can do right by

us." She was talking about how her community is quick to jump into attack mode when someone

in the media "gets diabetes wrong." She described crafting her online persona around this,

attempting to always walk a middle path in advocating for more accurate representations of

diabetes. She said she doesn't want to come off as angry or to attack, but rather constructively

correct outsiders who get diabetes wrong. However, as this issue continued to come up in

subsequent interviews, I began writing in my fieldnotes "Can an outsider get diabetes right? Find

example." After going back to the data and searching for an example of this, I found several user

stories of interactions with healthcare providers who 'got it.' However, there was little to no

stories about this with non-diabetic family members and friends. Then, after a tantalizing search,

I came across a young woman, Amber Finneseth's diabetes Tumblr page, which offered some

insight. The post she wrote grabbed my attention because it highlighted a paradox of understanding that I hadn't been able to put my finger on. She wrote:

> The inner struggle of having diabetes: you get mad at people when they tell you that you can't eat something, and you get mad at someone when that's what they offer you. It's that they're making assumptions about you, and that's why we can get mad about two opposing things.

Amber's described the paradox and then explains the logic of both. When I asked about this post during her interview, she said that she talks with her friends with diabetes about this often. She said the problem is about choice. Outsiders take the little bit of information they have about this complex disease and use it to make decisions for you. And other interviewees, as well as a glut of the data collected, conveyed an overarching argument that *you can't understand diabetes if you don't have it*. You can't get it unless you live with it. And the profound paradox here emerges when looking at this argument next to the primary goal for social change emulated through social media around diabetes. People with diabetes want for diabetes to be understood by the masses yet believe that people without diabetes can simply not understand. This paradox is deserving of a more concentrated examination in the context of social movements. Further research ought to lean in and unpack this paradox of understanding as a social phenomenon.

6.3 Methodological Discussion

I made an argument at the outset of this dissertation regarding a full separation of methods selected. I fashioned two studies to maintain standards of rigor for each. However, there is something to be said for conducting these two studies together under one broader dissertation. When considering this, I questioned my ability to successfully and thoroughly accomplish both, though I believe after reflection that I was able to do so well. I was faced with the challenge of

harmonizing two methodologies, which diverge around ethics, approach, and style. And because

of my status as an insider researcher, I had to question my lens continually, balancing *etic* and

emic analyses and interpretations, which take on a different meaning to the two primary

frameworks used. Netnographic and PAR principles do not meet at every point, but they are

compatible.

A foundational element that draws this set of methodologies together is their humanistic

focus on research as a potential pathway toward liberation (Kozinets, 2019; Seifert, 2012). For

netnography, this comes through the use of a variant of the method called humanistic

netnography, which this dissertation utilized. In humanistic netnography, the researcher works

toward social and self-transformation (Kozinets, 2015). For PAR, liberation comes through as a

central philosophical tenant. A pillar of its philosophy rests upon Brazilian philosopher Paulo

Freire's construct of liberation through critical consciousness (Freire, 1974). Critical

consciousness involves learning how to see social injustices and how to act against oppressive

forces of reality. By selecting PAR and the framework behind it, I intentionally embarked on a

journey of liberation. I sought not to do research for the sake of research, but for the sake of

change, not for myself alone but for the DOC. Both humanistic netnography and PAR are geared

toward that aim, and blending studies together enhanced the potency of each.

There are other radical elements to netnography and PAR that epistemologically bind

them. Netnography radically emphasizes the researcher as a tool of the research, highlighting

that "the researcher's own reflective understandings are often the best instrument through which

to gain cultural understanding" (Kozinets, 2017, p. 374). In netnography, the data and the

researcher, then, have been described as co-constitutive, essentially giving rise to one another

(Kozinets, Scaraboto, & Parmentier, 2018). This radical concept echoes ancient concepts of

reality that have been devalued in science and academia. In Hua-Yen Buddhism, there is a metaphoric conception of reality as a jeweled net which prompts practitioners to dissolve feelings and experiences of separateness with others and the world around them (Cook, 1977). The jeweled net is described as an infinite net within which at each apex is a multifaced reflective jewel. In each jewel exists every other jewel inside the entire infinite net. It is said that the jewels have co-dependent origination. When meditated on, the jewel net metaphor should help a practitioner dissolve the illusion of separateness between self and other. While the netnographic method does not stretch as far as a dissolution of the self, it does require intensive *recognition of the self* whether the researcher identifies as a member of the group of study or not. With PAR, there is a semi-dissolution of the self; however, it comes in the form of ownership and control over the research process. PAR radically involves participants within the study and inquiry design process, principally allowing the research to address the issue they prioritize (Torre, Fine, Stoudt, & Fox, 2012). The radical empiricist techniques of participation by the self and/or by members within the group in question as taken up by netnography and PAR are still *radical* in academic and scientific realms that favor blunt objectivity (which requires a rejection of the self as an instrument of the work). These complimentary radical perspectives offered me the opportunity to see myself, and this large piece of scholarship as co-dependent co-constitutive entities capable of creating knowledge for change and facilitating social-change in real-time.

The differences between PAR and netnography, however, generate more power for this dissertation than do their similarities. Each offers an aspect of the story that the other would miss. PAR allowed me to inquire about the most important thing to leaders regarding group dynamics and how to go about addressing it. While the participatory elements of netnography might be able to elicit a semi-crowd-sourced prioritization of issues, it alone has not yet gone so

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far as to produce a community-generated action in-real-time for the groups in question.

Netnography, on the other hand, allowed me to dig deep into the group unfolding dynamics in

their naturalistic settings using a set of specific empirical techniques and stratagem.

Netnography, unlike PAR, can produce an atmospheric picture of the contextual culture of an

online group in relation to the wider human experience, drawing out sometimes hidden beliefs

within external-facing rituals and practices. Having one dissertation contain a study built from

the methodologies of each creates a poignant holistic painting of the culture while showcasing a

powerful micro-example of the brush strokes creating it.

6.3.1   Limitations

Though I have forthright made a convincing argument regarding the strength of

combining the methods used in this dissertation, doing so can also be viewed as a limitation.

Because I chose to hold an action group *and* write a netnography, it is possible that my

bandwidth for each was limited. Had I focused exclusively on one or the other, my analysis may

have been more in-depth. The product may have been stronger. In further defense of my

methodological choices, I argue that when researching discourses of representation in

marginalized groups, it is paramount to include an element of action and community

participation beyond traditional interviewing and netnographic techniques. When there is a

history of oppression and the academy has played a part in that oppression as it has for the

condition of diabetes, giving back is ethically imperative. Books have been written by Disability

Rights leaders and scholars regarding this issue (Charlton, 2000). Some consider research that

challenges the status quo as having a decolonizing effect (Doxtater, 2003), breaking down

historical boundaries of exclusion from academic and scientific process and the creation of

knowledge. I, too, argue that.

Another limitation of this research is typical in qualitative doctoral dissertations. All data was coded solely by me. While the use of fieldnotes was beneficial in helping me catch the influence of my preconceived notions, there are undoubtedly some aspects of the analysis that I overlooked or misread. I implemented rigorous standards of qualitative research to increase trustworthiness (e.g., extensive member-checking, keeping a detailed fieldnotes journal, and triangulating sources of data and story), but the possibility of potential error cannot be entirely dismissed (Krefting, 1991; Morse et al., 2002; Sandelowski, 1986).

Lastly, this dissertation covered a lot of philosophical ground and in some instances, stayed relatively on the surface. For example, in the introduction, I provided definitions of terms that have been used throughout this work. However, each of those terms has a deep interdisciplinary history that I was only able to graze. Because the concepts were so far-reaching, I may not have been able to do justice to the histories and complexities of each. In this way, the scope of this project, while in itself far-reaching, was also a limiting factor.

6.4   Answering the Research Questions

Three primary research questions guided my project. In the following section, I break down each question, describing which studies addressed them and what the overarching result was in relation to the expectations set out in the introduction. Overall, I answered the research questions meaningfully throughout this work and collectively contributed to the body of knowledge currently available regarding the condition of diabetes.

6.4.1   Research Question 1

If at all, how is the condition of diabetes politicized across social media platforms?

Research question 1 was taken up almost exclusively in study 2, the netnography. In the introduction chapter, I set forth expectations I came into the study with. I expected that the

condition of diabetes *was* being politicized through the use of within-group dominant narratives (internal) and beyond group counter-narratives (external). This assumption was based on years of personal experience with and exposure to diabetes online communities. I expected that five aspects of the condition of diabetes would emerge as the topics politicized most frequently: 1) cost of insulin and diabetes supplies; 2) seriousness of diabetes; 3) relentlessness of diabetes; 4) diabetes comes in all shapes and sizes; 5) diabetes rules are bendable.

While all of these topics did show up in the data, they did not necessarily emerge as I expected them too.

The issue with the cost of insulin and supplies as a method of politicization was more direct than I anticipated. People with diabetes are formally organized both online and off around this issue, gathering virtually through the hashtag, #Insulin4All. Users across platforms are writing this hashtag into their usernames and bios, suggesting they want to be directly identified with the movement. In droves, these individuals are self-identifying as activists rather than advocates. Upon reflecting on this issue, I tweeted a poll asking diabetes Twitter users which term they preferred and the reasoning behind it[8]. Several people who responded said that they are both, arguing that each serves a different but equally valuable purpose. Melissa Balland Lee (Twitter: @SweetlyVoiced) shared a tweet that spawned the conversation around this. She wrote:

> Call me sentimental, but to advocate means "to give voice to" and voice is just
> part of who I am. I feel like when I "advocate," I speak for the people who
> aren't privileged to stand in the moment where I'm standing. Activism is about
> action. Important, too. But different.

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[8] A link to the poll can be found here: https://twitter.com/Heather_RoseW/status/1156580222227099648

Several others echoed this distinction, separating *speaking for the cause* from directly *acting for change*. One user with a heavy hand in the #Insulin4All movement described being an activist as a necessity, calling on others to join that direct action. Because I collected data for this dissertation in the rev-up to a United States presidential election, the conversation across diabetes online communities with regards to insulin costs may have been more directly oriented toward creating immediate change. Groups of online activists were in the process of organizing and attending in-real-life events on the Hill and beyond to urge candidates to address the insulin crisis in presidential debates. And in the first democratic debate on July 30, 2019, two candidates (Bernie Sanders and Amy Klobuchar) did mention the cost of insulin as an issue worth addressing, a testament to the enormity and seriousness of the national problem and the profound work of activists fighting for space on the political agenda. Thus, the insulin crisis provided an example of how people with diabetes are directly politicizing the condition of diabetes to enact social change for all with diabetes. As my results demonstrate, there seems to be a process of oscillation around making social change in diabetes online communities dependent upon social context. Such oscillation is alluded to in scholarship around visibility politics, which theoretically and empirically argues that degrees of visibility occur around events (Casper & Moore, 2009). A study of LGBT[9] Parents' social media usage invoked visibility politics to describe shifting between self-disclosures around cultural-media events like Supreme Court hearings regarding same-sex marriage (Blackwell et al., 2016). Researchers found that around events in which the general public pays attention to LGBT rights, LGBT parents disclose more outrightly to benefit the collective social movement (Blackwell et al., 2016). In other words, as is

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[9] This acronym was quoted from the article. It does not include Queer within it, though the authors did not describe why it was not included.

supported by my findings here, there is a galvanizing effect within marginalized groups when issues regarding them gain the attention of the general public.

Within the context of diabetes, this galvanized oscillation requires a deeper reading and a more meaningful gaze into the psychology of diabetes to understand how the seriousness and relentlessness of the disease are used to politicize of the condition of diabetes across these groups. The distinction made by some of the twitter users between advocacy and activism does serve to illuminate it, though. If advocacy is conceived of as a softer form of creating change, it makes sense that users would advocate through their stories. To them, just talking about how hard diabetes is to live with politicizes it by countering the mainstream conception of diabetes as a lifestyle disease that can be reversed with a simple regimen of medicines, diet, and exercise. This softer form of creating change has been described as *incidental advocacy* – a form of making change that is almost accidental (Blackwell et al., 2016). I push back against this formulation of advocacy as incidental, however, for it takes the intention away from social media authors without reconnaissance. My findings, conversely suggest that people with diabetes in DOCs speak their stories to create change even when doing so feels like shouting into the wind. They play a cost-benefit game in their minds that results in sharing deeply personal physical and mental health information even if only one person ever sees it. This advocacy is not incidental or accidental, but rather, I argue, *relational*. That is, it seeks to create change and movement within individuals, within behavior, and within feelings. It also seeks to create change within the self, which as I've shown here serves the collective through demonstrating vulnerability and a process of inner-change. This relational advocacy ought not to be dismissed as doing such may carry a colonizing effect – reproducing the power structures involved in the research process I've tried to dismantle throughout this work (Hesse-Bieber, Leavy, & Yiaser, 2004).

My assumption that people with diabetes used messages about diabetes coming in all shapes and sizes turned out to be discussed much less frequently than I thought. Even amongst the type 2 social media users whom I expected would be using this counter-narrative frequently, it was only moderately used. As I reflected on this, I realized I assumed I would have captured equal amounts of data from people with type 1 as type 2 in my data collection process. However, this assumption was ill-thought-out. Research of these groups suggests that type 2 representation in DOCs is severely lacking (Hilliard et al., 2015; Litchman et al., 2019; Tenderich et al., 2018), and Peer Collaborators discussed this at length during the action workgroup sessions. It could be that people with diabetes who dominate DOCs are not yet ready for this narrative, or it could be that they do not find it useful. It is with caution that I propose one last possibility that such a narrative may be perceived as false within tighter-knit type 1 groups who actively use stigma management strategies like *defensive othering*.

Similarly, the last expectation I set forth in the introduction hardly came up at all – that diabetes rules are bendable. While messages about diabetes rules being flexible rather than rigid may frequently occur in diabetes online communities, they are not invoked in messages that talk about the condition of diabetes itself. This implies, then, people are not using the experience of diabetes rules being malleable to politicize the condition of diabetes.

6.4.2   Research Question 2

What discourses of representation are used across varying online diabetes groups?

Research question 2 was primarily answered through the netnography, though the generative appreciative inquiry did add nuance. Four narratives modes which indicate directionality emerged throughout these studies. Those modes are external dominant-narratives, external counter-narratives, internal dominant-narratives, and internal counter-narratives. IN

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chapter IV, I offered a table titled, *Perceived Frequency of Narratives in Diabetes Online Communities (range = 1-5); (N= 125),* which showed a breakdown of the member-checked narratives that emerged for perceived frequency and directionality. The four narratives that folks reported seeing most frequently within DOCS were: 1) *All people with diabetes deserve access to affordable insulin* (M = 3.98, external-counter), 2) *Diabetes sucks* (M = 3.77, internal-dominant), 3) *You are not alone* (M = 3.66, internal-dominant) and 4) *Living with diabetes is really hard* (M = 3.60, external-counter). The narrative that folks reported seeing the least frequently in DOCS was an internal counter-narrative that read, *type of diabetes does not define one's level of engagement in self-management* (M=1.92).

The four most frequently encountered narratives, then, were either external counter-narratives, meaning they speak directly against mainstream representations of diabetes, or internal dominant, meaning they present within-group narratives to guide the group toward change in collective sense-of-self. The generative appreciative inquiry study strongly reinforced this idea as leaders of the group pinpointed support, sharing vulnerability, and a reduction in the sense of member isolation as elements of the groups' unconditional positive core. The narrative users reported encountering the least was the only internal counter-narrative presented to them. Considering the theme of troubles in paradise explored in Chapter IV, this is not surprising, though it does bare implications. In my reading of the data, a significant number of posts talked about how the general public and people with type 1 think that people with type 2 bore less of a burden in terms of self-management. The self-report survey suggests not that such content doesn't exist, but that it isn't being seen by the users who took the survey. The most frequently encountered narrative was the only one which discussed the insulin crisis and given the sociopolitical climate at the time of data collection, this frequency is fitting.

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When considering the interactions between users invoking dominant-narratives and counter-narratives, the most likely conversations happened around internal counter-narratives, in which users spoke directly to others within the group and offered an alternative perspective. Some studies have looked at this process as a form of self-policing in which group members guide and steer away posts that give misinformation or promote snake-oil-like solutions (Eysenbach, 2008; Greene, Choudhry, Kilabuk, & Shrank, 2011; Litchman, 2014). However, that process of collective *self-moderating* doesn't thoroughly explain the evolution in user consciousness taking place. One Australia-based diabetes blogger and social media influencer, Renza (Twitter: @RenzaS), has been a voice of change across DOCs, whose internal-counter-narratives have been reverberating powerfully. Renza has been preponderant in a movement aggregated under #LanguageMatters, in which the language of diabetes is shifting from a medicalized model to a more social one. Overtime, Renza's radical perspective on how language matters have become more mainstream, demonstrating both her influence and the userbase's willingness to adapt and shift their thinking around issues of identity, language, and efforts toward change.

Notwithstanding what has just been said, is the evolution in thinking around type-related differences, as I previously mentioned. Stigma is a fickle thing that those with chronic illness (generally not apparent) often manage through stratagem like *defensive othering* - rejecting association with the stigmatized group (Ezzell, 2009; Joachim & Acorn, 2000; Parsloe, 2015). Those using this strategy reject the stereotype, but only for themselves. They create distance between themselves and the stereotype casting those within it as abject Other. When deployed in the case of diabetes, these stratagem function to reinforce mainstream representations of diabetes as the disease for people who are unwilling to take care of themselves. My findings suggest that

though some users have come to see this, they are few and far between and are often not heard[10].

This slow uptake in self-awareness may stem from a number of things. For example, it could be because seeing one's own form of education and awareness-raising as potentially harmful requires humility and a great deal of critical consciousness. As I've argued within this dissertation, the development of critical consciousness within diabetes populations seems to be rather slow. Perhaps even more slow, is the development of empowered consciousness. According to disability activist, Jim Charlton, empowered consciousness requires a conscious interest and active outlook toward change and is essential for political activists (Charlton, 2000). In his book *About Us Without Us: Disability Oppression and Empowerment*, he argues that in order to dismantle hegemonic oppressive social structures and ideologies maintaining the status quo, actors must systematically attack its foundations within the realms of politics, economics, and culture. Charlton argues that systematizing collective action is *imperative* to creating change. Using Charlton's logic, people with diabetes who use online platforms to make change will likely not succeed. Their connective efforts are not synchronized or planned out (with the exception of insulin price protesting). They're efforts do not fit within a logic of collective action (Mccluskey, 2014). However, there is yet something to be said for a slower-paced individualized approach to making change when it takes place in virtual spaces.

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[10] It should be noted that there are sub-groups that fervently advocate for type-1 users to stop defensively Othering those with type-2 diabetes on the basis that it reduces the power of the wider group and creates walls of exclusion. However, this view is perceived to come into direct conflict with a strong narrative functioning as a coping mechanism for those living with type-1. MyDiabetesSecret conversations regarding the treatment of people with type-2 diabetes are revealing of this. The raw emotion comes blaring out as users are likely emboldened by the anonymity of the platform.

Imagine walking or rolling through a materialized digital space, in which diabetes-related tweets are physical signs posted everywhere. Some of those signs are the size of billboards; some are single sheets of paper signposted to a tree. Now imagine that all of the signs say a version of the same thing. As you walk or roll through this materialized space, you start to think about diabetes, and perhaps question what you thought you knew about it. These signs, regardless of size, represent the action-frames of the individuals with diabetes who are sharing their experiences online. Their story-telling as relational advocacy is connected in content and the hope of a better future – in change. And in fact, more recent literature points to the efficacy of such connective action similar to what I found within these two studies. For example, in a study of a social movement aggregated through #BoycottAutismSpeaks, Parsloe and Holton found that autistic twitter users amplified the movement by reinforcing arguments with their own stories (Parsloe & Holton, 2017). These stories, which often played out through sarcasm, were described as a form of *communicative labor* (Parsloe & Holton, 2017), from which I can then draw a level of comparison to Charlton's imperative that efforts must be systematized. If sharing one's story is assumed to be a form of communicative labor, then the laborer must be working toward something specific for a specific group of people. So, I argue that the connective power illuminated throughout my findings does indeed meet Charlton's imperative.

6.4.3 Research Question 3

What do users expect will come of broadcasting various narratives, be they counter or dominant?

This last research question was answered by the interviews which took place as one method of the netnography. The purpose of this question was to get to where users were directing change. Did they post for change on a personal level, on a community level, both, or

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somewhere in between? To get at answering it, 20 users were directly asked why they post and what they hope to gain from doing so. Overwhelmingly, interviewees described an evolution in how they use social media. They described starting out hoping to help themselves – to use the internet as a space of catharsis where they could journal about diabetes and "*get it out there*," as one interviewee said. However, all interviewees said that now they primarily post about diabetes on social media because they: 1) don't want others with diabetes to go through the same struggle they did, and they 2) want the world to know that diabetes isn't what they think it is. Even the social media users interviewed who were relatively new to their diabetes online community said this. It suggests that there is something transformative happening through the process of sharing personal information about diabetes in the public, yet potentially anonymous, spaces of social media. The responses to this question did not surprise me, actually reinforcing my preconceived ideas about this from my own experience.

I started my first diabetes blog started when I was 17-years old and now get queasy when I go back and read it. I see a sad, scared, angry girl wishing for a different life, venting about the unfairness of my diagnosis. I see a young, less wise, version of myself trying to free myself of that anger by journaling publicly. Over the first five years of my engagement with other diabetes bloggers, however, my tune changed. I wasn't writing about the unfairness; I was writing stories of hope. I wanted others with diabetes to find a way to free themselves from the anger like I felt like I had. I shared my story in hopes that others would read it, and take something away from it. And now, another five years later, I write stories about concepts and evolutions in thinking around diabetes primarily. As I formed the interview questions, I expected others would have a similar story. Most did, but not all.

Three of the 20 interviewees described coming into their community for the purpose of change right from the get-go. The first interviewee who said this felt jilted by her interactions in-real-life and wanted to use her anger toward those situations *for good*. She started writing and drawing memes on Tumblr that played on diabetes humor. She said that looking back, she sees how it did help her personally, but that when she started her account, it was to change how people feel about the anger-inducing situations she was finding herself in because of diabetes. The two other interviewees who came to the community to create change from the start described searching for support online and not seeing 'anyone who *looked like them*.' They are both women of color, and the diabetes online community they had access to was predominantly white. So, they started Instagram accounts to be that person so that their community was more representative and inclusive. One advocate who has made a significant contribution to diabetes Twitter, Cherise Shockley (Twitter: @SweeterCherise/@DiabetesSocMed) also started an amalgam Instagram account called Women of Color Diabetes which is described as "*A visual collection of stories of Women of Color Living with Diabetes (#WOCDiabetes) from around the world. #diabetes*". Cherise, advocating daily across social media for DOCs to be more inclusive and diverse, created this account to elevate other women of color (WOC) in DOCs.

The action designed and implemented by Peer Collaborators from the appreciative inquiry study underscores the importance of *inclusion* to leaders across DOCs. The vision statement they wrote, in fact, revolved around it. To reiterate, their vision statement read:

> "*Our vision is to create a more unified community of people with diabetes that embraces and relies upon empathy, respect, and appreciation for similarities and differences of our unique diabetes experiences; aspiring for improved individual and collective outcomes.*"

Inclusion to them would require radical within-group change. And they acted toward that vision by creating a social media campaign called "IHearYou." Beyond the expectations of the Peer Collaborators, the campaign took hold, and users used it as an opportunity to share their truth and declare to fellow users, "I am a safe person with whom you can share." Within the first 24-hours of the campaign, users were asking if they could add the campaign hashtag to their profiles so that others in their DOC would know they can go to them when they need a listening ear. Thus, even though some users feel like their posts equate to shouting into the wind, they continue to post, hoping that by sharing their stories, their DOC will become a more welcoming place for those people have been or felt excluded.

6.4.4   A Last Expectation to Consider

The last expectation I set forth in the introduction chapter of this dissertation was that I would find unifying or binding elements across diabetes online communities based around shared lived experience. When I was searching for clearly identified unifying elements in online posts about the condition of diabetes and found only a few, I began asking about them in the interviews in the context of identity. I asked interviewees what, if anything, connected all people with diabetes. Some, though not all, identified social conditions as binding rudiments, such as having to navigate a healthcare/insurance system or pay for insulin. More often than not, however, interviewees identified personal experiences like seeing a used test-strip on the ground and thinking, "*Ah, someone like me was here*." This distinction is incredibly important when considering the social implications of the overall findings of the study. That is, even amongst this group of users decidedly *awake to the social injustices* of mainstream representation of diabetes, diabetes is seen as an individually-experienced phenomenon. This underlying view falls in line

with the way diabetes has been depoliticized in mainstream media and health research, even though change around them are actively called for.

6.5   Sociopolitical and Cultural Implications

This dissertation as a whole contains three separate publish-ready manuscripts based on two studies that collectively contribute a sociopolitical perspective of the condition of diabetes as a politicized one. Within the three manuscripts are three discussions covering topic-specific sociopolitical and cultural implications of the work. Here, those implications have been reiterated chapter by chapter. As a whole, the findings from this study have far-reaching implications that extend from policy and healthcare to research being done about them. By problematizing the way current literature focuses almost exclusively on individuals as well as the overreliance on measuring health outcomes in studies of diabetes, I have called into question the saliency of current literature to explain what it means to live with diabetes today. I have argued that the condition of diabetes has been effectively depoliticized as a result of methodological individualism (Arrow, 1994) and historical study findings pinpointing the intended target of change in diabetes care as the individual with diabetes (Peyrot, 2001). Rather than seeking to understand how people with diabetes use online communities to cope with their condition as current research has exclusively done, I sought to understand how they are used to create change and build critical consciousness.

6.5.1   Implications of Study 1: Generative Appreciative Inquiry

When asked to discuss the best of what is with regards to their respective diabetes online communities, Peer Collaborators highlighted 24/7 support, vulnerability, and realness. By placing value in those things, Peer Collaborators suggest that DOCs are filling a gap in care. Outside of DOCs, as with their doctors, family, friends, and other care providers, it may be that

people with diabetes feel unsupported, unable to be vulnerable, and unable to be real. If this is the case, it indicates a major issue underlying the condition of diabetes socially and culturally. Disability studies scholars have theorized that a far-reaching ideology of ability has created a culture that favors bodies that function species-typically (Siebers, 2008).

Moreover, that swooping cultural ideologies like these deeply engrain within those with passable disabilities as internalized ableism (Campbell, 2008). Peer Collaborators, arguably more awake to the social injustices around diabetes, even explained feeling like they needed DOCs so they could just 'be real' about diabetes and their lived experience with it without pretending to be '*normal*.'

Their collective vision statement honed-in on inclusivity and celebration of difference as the two main arcs of change, which also served to demonstrate a prioritization of issues. That their vision statement calls for inclusivity through diversity and celebration of difference simultaneously recognizes that DOCs are not always inclusive, and don't always celebrate differences between people and the way they manage their condition. Their vision is an expression of a desire for a community more representative of the broader American population. The social implications of the lack of diversity and desire to create more a more inclusive online environment mimic the trajectories of other social movements. Several social media movements in the last few years have been criticized using the moniker *too white* often through hashtags like *#DiabetesTooWhite* or *#DisabilityTooWhite.* Disability studies, a field built around bringing social justice through critical analysis, has been argued to have whitewashed disability history (Bell, 2017). This trend, though not surprising, echoes a much wider systemic societal issue of social exclusion from innovation. Peer Collaborators argue through their vision statement that in order for their DOCs to be the best they can be, more diverse representation is needed.

As a social element of diabetes health, engagement in online communities likely lends itself to positive changes in overall health and mental health. Diabetes online communities were described by Peer Collaborators as supportive environments, where a person with diabetes can be real and show sides of diabetes that are difficult to share with non-diabetic friends and family. Peer Collaborators described their experiences with diabetes online communities as sources of peer support shown to decrease diabetes distress (Barrera et al., 2002), increase sense of diabetes empowerment (Litchman, Edelman, et al., 2018), increase patient activation (Kokkodis & Lappas, 2016), and in some cases improve A1C (Litchman, 2014), all of which are supported by studies measuring changes in those areas. The design of the listening campaign also appealed to the idea that being heard is a factor of mental health and diabetes-well-being.

If the listening campaign helped community members feel heard, it might have also positively impacted their mental health and overall diabetes well-being, though discussing that is not pertinent to this study. When considering the advancement of research on the health implications of participating in diabetes online communities, it is thus imperative that researchers inquire about how *heard* patients feel in these spaces. Even if they are only reading the stories of others and not directly contributing, do they see themselves in those stories? Are those stories representative of their own experiences to the extent that they produce in the reader a sense of belonging? And how can patients be navigated toward users in diabetes online communities who share stories like theirs?

When considering these questions, this study demonstrated that community assets and strengths be can leveraged to create social change in community-identified areas of need by involving community members in the research process.

6.5.2   <u>Implications of Study 2: The Netnography</u>

In the current social landscape of diabetes, academic, mass-media, diabetes is only being heard in ways determined valuable from the top down. As researchers, clinicians, and scientists, it is imperative that we ask why people with diabetes are calling for a rebranding of diabetes? Is it to personally escape the character-attributed stereotype condemning them to a life of adjudication? This study suggested that yes, that is one reason. However, this study also indicates they are doing so in pursuit of a grander goal, to be collectively heard and understood. Many are using the only medium they have, social media, to air grievances and make corrections one post at a time. That is, they are connectively calling into question structural apparatuses of listening regarding the condition of diabetes. People with diabetes are calling for this because though the experience living a politicized life, they are systematically treated in health and the social as depoliticized individuals in need of internal change.

It has been an aim of this research to problematize the conception of identity in diabetes as an individualized, apolitical, ascribed health-based category, but also to explore the unfolding drama of identity experienced by its members. Through 20 in-depth interviews and an hour-long twitter chat focus group, this study found that the most common phrase (i.e. diabetes is a part of me, but not all of me) explaining diabetes identity positions it as dual-directional. Also, by formulating diabetes identity as a dual-directional one which is not embedded in physical space, but rather in experiential place, its roots and mechanisms built around social change become evident. Within seeking change, those with diabetes play a cost-benefit game of identification involving the processes of blame-negotiation and stigma management. Here, we see a horizontal movement of power happening through the negotiation of identity within diabetes, though no

studies have captured this. Furthermore, studies have not captured this not because it did not exist, but because it has not been the subject of critical inquiry.

Findings from the overall netnography cast doubt on patterns and constructs of change thus far examined in studies considering the condition of diabetes. They push for further research using methods with criticality built into them. This research requires researchers and clinicians involved in research to ask, for whom is current research in diabetes being done? If it is for people with diabetes, how do they weigh in on the social relevance of the study? How are their collective wisdoms, assets, strengths, and desires being naturalistically leveraged to ensure the study critically considers the condition of diabetes as a social element impacting individual health? Lastly, this study heavily pushes for stakeholders across disciplines and groups to conceive of diabetes as a politicized condition, worthy of placement within the polity. It demands these stakeholders question their reductionist associations of diabetes with simplicity, and take in the profound complexities rooted in it.

6.5.3   <u>Implications for Change: Collective Consciousness</u>

My overall findings suggest that within DOCs, there is a social change funnel. This social change funnel takes the following course: issue awareness, moderate non-conformity, vulnerability, evolution in narrative frames, empowered consciousness. Issue awareness requires folks have the resources to know what the issues are, the means to access to dominant within-group narratives and be accepted by the wider group. Moderate non-conformity requires politeness when talking about diabetes issues or calling out misrepresentations and offering alternative ways of looking at things. Vulnerability is to be used when drawing one's narrative into discussions of diabetes issues so that the reality that diabetes is difficult can come to light while also highlighting the strength of those who live with it. Evolution in narrative frames

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requires story-sharers include stories about their journey of self-reflection and inner-change, showing lessons learned and how to get there. Lastly, is empowered consciousness which requires seeing beyond the present and the self, and backing diabetes as a unified social category and the collective movement ahead. Within this social change, funnel are several theoretical entry points for future study. Throughout this dissertation, I have identified steps toward social change as they are performed in DOCs, but not theoretically explored how efficacious they are when compared to other health-related social change efforts.

One scholar, Vincent Miller, casts doubt on the efficacy of all social media activism, arguing that conversation and digital activism is more about social inclusion and recognition than it is about expressing political statements (Miller, 2017). Miller argues that these conversations that appear to be political promote a "passive, convivial political subject as opposed to an active, oppositional or transformation one" (Miller, 2017, p. 253). Under Miller's argument, digital activism is illusory because its motivation is rooted in connection rather than provoking reflection. Some of Miller's argument applies to the social change funnel I identified through this study (i.e., the normalization of advocacy which requires kindness through advocacy efforts). However, the empirical findings from these studies also call his theory into question. Miller's argument relies on a priori assumptions that seeking connection undermines rather than fortifies the process of social transformation. Peer Collaborators used a process of re-connection through *listening* to enact community-level change. That is, they sought to transform the community by increasing connections and networks. Similarly, people with diabetes use social media share their stories to transform the public perception of what it means to have diabetes. I argue, against Miller's argument, that the social change funnel within DOCS is mediated rather than subdued by connection. Connection, in DOCs, drives change.

6.6   Recommendations for Future Research

Elements of the studies conducted within this dissertation draw out several areas of need for analysis in regard to the condition of diabetes. Findings from this study indicate that further research is needed that

- *is participatory*. These findings indicate that communities of people with diabetes can be leveraged to produce research that is more socially relevant, and that is more deeply connected to the lived experiences of people with diabetes.

- *is rooted in listening*. These findings indicate a strong need for research to return to the drawing board, to (perhaps for the first time) attempt to *hear* those living with diabetes and to *see* diabetes as worthy of entrance to the political world.

- *inquires about disconnected people with diabetes.* Findings suggest that individuals with access to dominant internal narratives around diabetes identity may experience and politicize diabetes differently than those who do not. In considering this, future research ought to address those with diabetes who have never met another person with the disease.

- *considers the culture of in-person diabetes groups.* These findings may not extend to groups of people with diabetes who meet in real life. When they talk about diabetes, is there an element of politicization? If yes, how does that politicization compare to online groups? If not, what dynamic do those conversations take?

- *applies constructs of identity to PWD in offline settings.* The theoretical underpinnings of this research stem from interviews with PWD who are deeply connected to others like them. Future research ought to use a similar framework to the one used here to inquire about how identity may be constructed differently in a less connected sub-group.

- *compare how politicization differs across diabetes types.* This study posits that there are multiple threads across platforms in which the diabetes type-divide influences discourses of representation. However, analyzing the differences directly between them in each population was not within the scope of this research. Further research ought to directly compare how users who outrightly identify with one type or the other differ in their messages of politicization.

- *measure the impact of users' politicization efforts on policy and academia.* This dissertation established that politicization was happening and identified some of the ways it has been playing on across three diabetes online communities. However, it did not attempt to measure the social impact of these politicized efforts. Are they actually creating change? To do this, a researcher could examine virtual news articles and stories covering diabetes-related issues and see if any changes coincide with the politicized messages pushed through diabetes online communities.

6.7 <u>Conclusion</u>

Through this dissertation, I sought to explore how the condition of diabetes is being politicized by adults with diabetes online. I was able to accomplish this by creating a two-study dissertation that produced a sociopolitical and cultural deconstruction of three diabetes online communities, a theoretical exploration of diabetes identity as a mechanism of social change, and a generative appreciative inquiry workgroup that designed and disseminated a highly effective social media campaign to address inclusion within those communities. Overall, this study contributes to the diabetes literature, a picture of the condition of diabetes that has been overlooked, one that enters it into the realm of polity.

APPENDIX A.   PEER COLLABORATOR EXIT SURVEY

Peer Collaborator Exit Interview

Q1 Thank you for taking the time to complete this exit interview.

This survey should take about 10-15 minutes to complete.

Once you have completed it, please email me at hgabel3@uic.edu so I can send you the

compensation you are owed.

Q2 Have you ever participated in a work-group with the intentions of creating an action before?

○ Yes (1)

○ No (2)

Display This Question:
If Have you ever participated in a work-group with the intentions of creating an action before? = Yes

Q3 How many workgroups have you been a part of in the past?

○ 1 (4)

○ 2 (5)

○ 3 or more (6)

Q4 How similar was this experience to the other work groups you've been a part of?

○ Very Similar (1)

○ Somewhat Similar (2)

○ Somewhat Different (3)

○ Very Different (4)

Q5 How satisfying was this compared to the past group(s)?

○ much more satisfying (1)

○ somewhat more satisfying (2)

○ the same (3)

○ somewhat less satisfying (4)

○ much less satisfying (5)

Q6 What was your biggest take-away from this peer collaborator work-group experience?

_____
_____
_____
_____
_____

Q7 **Appreciative Inquiry.** This was my first experience in a workgroup that used appreciative inquiry.

○ Yes (1)

○ No (2)

○ Unsure (3)

Q8

On a scale from 1-10, please rate how effectively the appreciative inquiry approach

accomplished the following:

(1 = not at all effective, 10 = completely effective)

facilitated active discussion : _____ (1)
informed our collective vision statement : _____ (2)
allowed the group to move toward actionable plans : _____ (3)
helped me feel like a co-owner of the resulting action : _____ (4)
Total : _____

Q9 **Facilitation of the group process.** On a scale from 1-10, please rate how true each of the

following statements is to your experience. (1 = not at all true, 10 = completely true)

I was often directly asked to give my thoughts and opinions : _____ (1)
The flow of the meetings made sense : _____ (2)
The group process was managed properly : _____ (3)
I was told what to expect for each meeting ahead of time : _____ (4)
Total : _____

Q10 Facilitation of group dynamics.

Q11
I was often directly asked to give my thoughts/opinions

○ Strongly disagree (1)

○ Somewhat disagree (2)

○ Somewhat agree (3)

○ Strongly agree (4)

Q12
The group dynamics were managed properly.

○ Strongly disagree (1)

○ Somewhat disagree (2)

○ Somewhat agree (3)

○ Strongly agree (4)

Q13 **Group Composition.**

On a scale from 1-10, please rate how true each of the following statements is to your

experience.

(1 = not at all true, 10 = completely true)

There was a diversity of opinions : _____ (1)
There was a wealth of knowledge : _____ (2)
I was able to learn from fellow group members : _____ (3)
I heard perspectives I hadn't heard before : _____ (4)
Total : _____

Q14 Group Dynamics (i.e., the interactions between group members).

Q15

The group dynamics allowed for discussion that was **active.**

○ Strongly disagree (1)

○ Somewhat disagree (2)

○ Somewhat agree (3)

○ Strongly agree (4)

Q16
The group dynamics allowed for discussion that was **supportive.**

○ Strongly disagree (1)

○ Somewhat disagree (2)

○ Somewhat agree (3)

○ Strongly agree (4)

Q17
The group dynamics allowed for discussion that was **collaborative.**

○ Strongly disagree (1)

○ Somewhat disagree (2)

○ Somewhat agree (3)

○ Strongly agree (4)

Q18
The group dynamics allowed for discussion that was **inclusive.**

○ Strongly disagree (1)

○ Somewhat disagree (2)

○ Somewhat agree (3)

○ Strongly agree (4)

Q19 **Personal Experiences**. On a scale from 1-10, please rate how true each of the following

statements is for you. (1 = not at all, 10 = completely)

In my experiences as a peer collaborator in this workgroup I felt…

safe sharing my opinions : _____ (1)
safe sharing my experiences : _____ (2)
heard in the group : _____ (3)
heard by the group : _____   (4)
welcome in the group : _____ (5)
valued in the group : _____   (6)
Total : _____

Q20 I was able to meaningfully contribute to group discussions.

○ Yes (1)

○ Not Sure (2)

○ No (3)

Q21 Identify three ways you felt you were able to meaningfully contribute to the group

discussions

_____

Q22 Identify three ways you wish you could have more meaningfully contributed

_____

Q23 **Expectations for the Deliverable.**

On a scale from 1-10, please rate how true each of the following statements is for you.

(1 = not at all, 10 = completely)

I had a clear understanding of what the group was supposed to accomplish as a whole : _____
(1)
The action we designed corresponds with the expectations I had of what this group would be :
_____ (2)
I have a clear understanding of what I am supposed to do for the "I Hear You" campaign :
_____ (3)
I believe I can meet the action commitment I wrote in meeting 4 : _____ (4)
The action I helped co-design represents values I uphold : _____ (5)
The action I helped co-design represents values upheld by the community : _____ (6)
The action we developed will help move DOCs closer to the vision statement we co-created :
_____ (7)
Total : _____

Q24 I see myself in the listening campaign we designed.

○ Strongly disagree (1)

○ Somewhat disagree (2)

○ Somewhat agree (3)

○ Strongly agree (4)

Q25 I see the community in the listening campaign we designed.

○ Strongly agree (1)

○ Somewhat agree (2)

○ Somewhat disagree (3)

○ Strongly disagree (4)

Display This Question:
  If I see myself in the listening campaign we designed. = Somewhat agree
  And I see myself in the listening campaign we designed. = Strongly agree

Q26 Please explain why you see yourself in the listening campaign

_____

Display This Question:
  If I see myself in the listening campaign we designed. = Somewhat disagree
  And I see myself in the listening campaign we designed. = Strongly disagree

Q27 Please explain what could be done to increase how much you see yourself in the listening

campaign.

_____

Q28 Insights from the research.

On a scale from 1-5, please rate how often you see social media posts sharing messages related to the following quotes.

1 = never;
2 = rarely;
3 = sometimes;
4 = very often;
5 = always.

_____ "Diabetes is a very serious disease" (1)
_____ "Having diabetes doesn't mean I am a sick person" (2)
_____ "All people with diabetes deserve access to affordable insulin" (3)
___ ____ "People don't understand diabetes, but they need to" (4)
_____ "Diabetes does not discriminate"   (5)
_____ "The emotional toll of diabetes is immense"(6)
_____ "It is a myth that people with diabetes "don't take care of themselves""   (7)
_____ "Diabetes has shaped me into a better person"(8)
_____ "Diabetes makes me stronger" (9)
_____ "Diabetes does not limit me" (10)
_____ "Living with diabetes is really hard" (11)
_____ "Living with diabetes is possible if you put in the work" (12)
_____ "You are not alone" (13)
_____ "Me too" (14)
_____ "Diabetes does not control me, I control it" (15)
_____ "Diabetes sucks" (16)
__ _____ "I have diabetes, but it does not have me" (17)
_____ "You can't understand what it is like to have diabetes if you don't live with it" (18)
_____ "Diabetes comes in all shapes and sizes" (19)
_____ "Type 1 and type 2 should have different names" (20)
_____ "People with type 1 didn't cause their diabetes" (21)
_____ "Type of diabetes does not define one's level of engagement in self-management" (22)
_____

_____ **APPENDIX A.   PEER COLLABORATOR EXIT SURVEY (continued)**

Q29 **Our Vision Statement:**

"Create a more unified community of people with diabetes that embraces and relies upon

empathy, respect, and appreciation for similarities and differences of our unique diabetes

experiences; aspiring for improved individual and collective outcomes."

Q30

On a scale from 1-10, please rate how closely each core value is reflected in the "I Hear You" campaign.

(1 = not at all reflected, 10 = completely reflected)

Unifies community : _____ (1)
Embraces empathy : _____ (2)
Relies upon empathy : _____ (3)
Respects differences : _____ (4)
Appreciates differences : _____ (5)
Respects similarities : _____ (6)
Appreciates similarities : _____ (7)
Aspires for improved individual outcomes : _____ (8)
Aspires for improved collective outcomes : _____ (9)
Total : _____

Q31 I believe the "I Hear you" campaign does justice for the diabetes online community, because it:

_____

Q32 As I further reflect on my experience in this group so far, I feel:

_____

APPENDIX A.   PEER COLLABORATOR EXIT SURVEY (continued)

Q33 As I think about moving forward with the "I Hear you" campaign, I feel:

_____

Diabetes Online Community Narrative Survey

Thank you for your interest in this survey about narratives across diabetes online communities. This survey is confidential and should take about 2-5 minutes to complete.

Completing this survey is voluntary.

You can choose to not to respond or decline to participate.

By clicking this button, I consent to participate in this research ◯

On a scale from 1-5, please rate how often you see social media posts sharing messages related to the following quotes.
1 = never;
2 = rarely;
3 = sometimes;
4 = very often;
5 = always.

_____ "Diabetes is a very serious disease" (1)
_____ "Having diabetes doesn't mean I am a sick person" (2)
_____ "All people with diabetes deserve access to affordable insulin"   (3)
_____ "People don't understand diabetes, but they need to" (4)
_____ "Diabetes does not discriminate"(5)
_____ "The emotional toll of diabetes is immense"(6)
_____ "It is a myth that people with diabetes "don't take care of themselves""   (7)
_____ "Diabetes has shaped me into a better person" (8)
_____ "Diabetes makes me stronger" (9)
_____ "Diabetes does not limit me" (10)
_____ "Living with diabetes is really hard" (11)
_____ "Living with diabetes is possible if you put in the work" (12)
_____ "You are not alone" (13)
_____ "Me too" (14)
_____ "Diabetes does not control me, I control it" (15)
_____ "Diabetes sucks" (16)
_____ "I have diabetes, but it does not have me" (17)
_____ "You can't understand what it is like to have diabetes if you don't live with it" (18)
_____ "Diabetes comes in all shapes and sizes" (19)
_____ "Type 1 and type 2 should have different names" (20)
_____ "People with type 1 didn't cause their diabetes" (21)
_____ "Type of diabetes does not define one's level of engagement in self-management" (22)
_____ "Diabetes is not a joke" (23)
_____ "Diabetes is a part of me, but it doesn't define me" (24)

The phrase going around diabetes online communities that I hear the most often is:

_____
_____
_____
_____
_____

The phrase going around diabetes online communities that resonates the most with me is:

_____
_____
_____
_____
_____

APPENDIX C.   COMMUNITY BLOG POSTS

THE CHRONIC SCHOLAR
BRIDGING PATIENT EXPERIENCE AND THE IVORY TOWER

HOME · ABOUT THE AUTHOR · CONTACT OR HIRE

LIVE-STREAMING AN ACADEMIC AFFAIR (SEPT 27TH)

August 27, 2019
Edit

WOW! So, I've been at work all day and until now didn't realize that I will be in Chicago one month from today in this very hour, defending my **dissertation**.

What does that mean, you ask?

Well, as you likely know, I've been doing this masssssssive research project called a dissertation for the last year and a half in order to earn my PhD in Disability Studies.

My dissertation research is a dual-study project, meaning I conducted two studies within it. I did this for many reasons. First, I'm too ambitious for my own good. And secondly, and most importantly, I am not a fan of doing research without an action component. I can't just study something and say " well I found x, y, and z, and now world, go and change based on that." We all know that most research published goes straight to nowhere-town. So few people ever read it and the world keeps on as it is.

So the first part of my research was to get at that action piece. To *directly* benefit the community in some way, I saw to it that something was done. And as you may recall, the action group of peer collaborators I organized for this study did an amazing job of creating an action. The #IHearYou campaign was a success!

The second study was also participatory, but in a very different way. The second study within my wider dissertation study was a netnography (study of an online culture) across Twitter, Tumblr, and Instagram. Specifically this study asks how the condition of diabetes

Interesting huh? Well, HA! I am totally going to leave you hanging.

I will post some more material between now and then, but...

IF YOU WANT TO LEARN MORE, TUNE INTO MY LIVE-STREAMED DISSERTATION DEFENSE ON SEPTEMBER 27TH FROM 2-3PM CST.

I will post details, but save the date now!

I can't wait to share my work with you.

SHARE THIS:

[ ] Press This   [ ] Twitter   [ ] Facebook

[ ] Reblog   [ ] Like
Be the first to like this.

Posted in: *Uncategorized*

← #IHearYou

- THE AUTHOR -

Hi! I'm Heather Walker and I write this blog about where academia and patient life meet. If you have any interesting articles, send them my way!

- DIABETES BLOG WEEK 2016 -

7th Annual
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May 16-20

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Tweets by @Heather_RoseW   ⓘ

Heather Rose Walker, PhD (Diabetes) Retweeted

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♡   [→   Oct 5, 2019

THE CHRONIC SCHOLAR
BRIDGING PATIENT EXPERIENCE AND THE IVORY TOWER

HOME   ·   ABOUT THE AUTHOR   ·   CONTACT OR HIRE

#IHEARYOU

August 1, 2019

Edit

Living with diabetes requires sooooo much effort. The daily requirements of staying alive are relentless and unending. It is messy, unpredictable, and damn frustrating most of the time. The biggest thing though, is that unless you have a friend or community who also has it, you are likely to feel misunderstood. And even when you have friends and community, at times you can still feel largely alone.

Across diabetes online communities, people with diabetes are publicly sharing their stories – stories about their life, their triumphs, and their challenges. We are sharing our own vulnerabilities to elevate diabetes as a condition worthy of awareness, and to help our fellow PWD feel a little less alone. And as communities, our stories generally have an arc of hope, possibility, and strength. We fight for recognition and acknowledgment of the incredibly intense labor we put in everyday, simply to continue breathing.

In recognizing this, I added an action component to my dissertation research. A promise I made to myself when I began my PhD journey was to *never do research for the sake of research*. I will always do research for the sake of change. Rather than hope that some change would happen once I put results into the world, I worked in a method to elicit change in-real-time. The action group I convened was made up of 8 PWD, called **Peer Collaborators**. Over the course of a month, they went through a process of identifying 'the best of what is' and 'imagining what could be' for diabetes online communities. At the end of the month, having reflected a great deal on the strengths and assets of their communities, they designed the #IHearYou campaign.

I hear you.

One of the Peer Collaborators, Kim Hislop, commented during one of our initial meetings,

> *"I know I am a support person for other people with complications, but where is that person for me?"*
>
> – KIMBERLY HISLOP

When Kim said this, the group took pause. We racked our brains and wondered why there weren't more people with diabetes-related complications vocal across diabetes online communities. We wondered if the messages about what it means to succeed with diabetes were too narrow across these groups, and if maybe that was a deterrent to sharing their voice? We also wondered if they were already here, but in effect silenced by all the anti-complication stories taking precedence.

The Peer Collaborators wondered what action could be taken within communities to **acknowledge** the voices that aren't often heard, to **affirm** voices who aren't on the arc of hope and possibility, and to **recognizing** the ongoing effort people with diabetes are putting forward to live another day.

- THE AUTHOR -

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Tweets by @Heather_RoseW ℹ

Heather Rose Walker, PhD (Diabetes) Retweeted

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Heather Rose Walker, PhD (Di
@Heather_RoseW

This is an incredible thread with dynamic responses. Reminds me of why we need initiatives and efforts like #WhyWeRevolt. #patientsarepeople
https://twitter.com/hwitteman/status/118059 7570998951936

♡   ↪   Oct 5, 2019

Heather Rose Walker, PhD (Diabetes) Retweeted

Dr. Rebecca Kreitzer
@rebeccakreitzer

I have gotten four separate emails or DMs today asking me about how to mitigate bias in teaching evaluations. Because I think everyone should have this information, here is a short thread. (You can get a lot of resources here: rebeccakreitzer.com/bias-in-teachi...)

♡   ↪   Oct 4, 2019

At the end of the day, diabetes is just hard. While there are major bonuses, like gaining a community, and learning to know your own body really really well, it sometimes still just sucks. #IHearYou

The #IHearYou campaign was designed by the Peer Collaborators as a *listening* campaign. The goal is to offer an "#IHearYou" to the people who make the community what it is, with the hope that doing so will promote *inclusion*.

This may look like posting the campaign image and tagging someone in your community who you want to acknowledge. It may look like adding "#IHearYou" in a comment on a blog post or tweet that speaks to you. The campaign was designed to be **low-entry**.

It is supposed to meet you where you are at.

I hope you will join us in promoting this campaign in whatever form is most comfortable to you.

Without further adieu, I'd like to acknowledge the **peer collaborators** who designed this campaign. I'm so grateful for the creativity and vulnerability you shared throughout this process.

I wish so so badly that Kim was here to see this campaign come to fruition. She made such a mark on its creation. I'm thinking of her today, and hoping she is feeling heard.

Picture	Bio
	Christopher Snider was diagnosed with type 1 diabetes in 2002. He has engaged in the diabetes online community through a variety of platforms since 2009. Christopher is the Community Manager at Tidepool, a 501(c)(3) nonprofit organization dedicated to making diabetes data more meaningful, accessible, and actionable.
	Karen Graffeo has been living with type 1 diabetes since 1979. She is currently the Program Manager at DiabetesSisters. She has been an active member of the DOC since 2008, when she created her blog Bitter-Sweet. Seven years in a row, Karen has hosted Diabetes Blog Week, bringing together over 150 diabetes bloggers.
	Stephen Shaul has been living with type 1 diabetes since 1991 and has been blogging about life with diabetes since 2012. Steven is currently serving as a member of the State of Maryland's Advisory Council on Health and Wellness, where he is co-chair of the Diabetes committee. In addition, He serves on the 2018 Reader Panel at Diabetes Forecast magazine.
	Kerri Sparling is an internationally recognized diabetes advocate. She is the creator and author of Six Until Me, established in 2005 and remains one of the most widely-read diabetes patient blogs. Kerri is a highly-rated speaker and has presented the patient perspective to audiences around the world. She works to raise awareness for diabetes, patient advocacy, and the influence of social media on health outcomes. Her first book, Balancing Diabetes (Spry Publishing), looks at type 1 diabetes in the context of "real life."
	Bill is a diabetes speaker and motivator that shares his personal challenges living with diabetes while participating in ongoing diabetes research. In 2015 Bill authored an essay "Bionic Pancreas Patient Perspective" in the Canadian Journal of Diabetes.
	Beatriz (Bea) Sparks lives with diabetes and has authored multiple diabetes blogs over the last 10 years. Bea has been a voice for type-2 diabetes, fiercely advocating for the reduction of stigma across all diabetes types and community inclusiveness.
	Mike Lawson lives with diabetes and is a digital artist. He has worked at diabetes-related non-profits and written several diabetes blogs in the past. He has been a part of many DOC initiatives throughout the years, including podcasts and campaigns. He also authored a diabetes-related children's book. Mike is currently authoring a monthly zine and working in the theater industry.
	Kimberly Hislop lived with diabetes and was an advocate for rebranding diabetes across online communities and in-real-life peer support events. She wrote a diabetes blog and participated in Twitter, Facebook, and Instagram diabetes groups. She often was the one voice in the room who advocated for an ideological shift in thinking around diabetes complications and what it means to succeed with diabetes. Kim was a fierce leader and presence in her community, and her loss was felt deeply by them.

For a wonderful post by Stephen Shaul describing the campaign in more detail, click here.

Embed   View on Twitter

- RECENT POSTS -

Live-Streaming an Academic Affair (Sept 27th)

#IHearYou

Open Access Study of Diabetes Online Communities Now Available

Seven interviews later...

#DSMA for Research, Option to Opt-Out

- CATEGORICAL DATA -

#IHearYou Ableism Advocacy chronic illness dblog dblogweek Diabetes Diabetes Advocacy Diabetes and staring diabetes awareness diabetes awareness message diabetes blog Diabetes Blog Week Diabetes community Diabetes Community Events Diabetes Event Diabetes message diabetes mom Diabetes Online Community Diabetes Research diabetes stories Diabetes Support Network Diabetes video diabetes vlog Diabetic diabetic mom disability Disability and Ableism Disability in media Disability Theory Discourse DOC DPAC Health Advocacy Healthcare Heather Gabel heather gabel video Heather Rose Diabetes Heather Walker Heather Walker Diabetes identity-first language In Person Community Event Diabetes IRL Malcom Gladwell MasterLab Medtronic Messages motherhood motherhood with diabetes My Research open access research Our story pain narrative patient-provider Patient Researcher person-first language Person with diabetes Peter Ubel et. al. Power is knowledge Representations of diabetes Research social aspects of diabetes Social desirability social science research stigma and staring heather gabel systemic issue Systems Problem The

THE CHRONIC SCHOLAR

BRIDGING PATIENT EXPERIENCE AND THE IVORY TOWER

SEVEN INTERVIEWS LATER...

May 10, 2019
Edit

In the last week I have interviewed seven people with diabetes from various social media platforms for my dissertation research. If you haven't read this blog before or aren't familiar with me, here is a quick run down of my project:

- I am studying narratives and counter narratives in diabetes online communities crossing social media platforms. I am doing this under the assumption that public posts talking about diabetes are inherently political because they aim, to some extent, to create change.
- My study is multi-pronged – involving multiple steps and activities. I am collecting social media data, interviewing people who post, and hosting a peer collaborator group to generate a community action.
- As a researcher, I am committed to producing new knowledge AND building capacity within the communities I study. I am also dedicated to providing credit and further

Throughout the course of my graduate program I have used this blog space to talk about my research and the goals I have for the work. Today I want to share some of the insights coming from the interviews and web-scraping I have done so far.

BEHOLD...

One of the most important things to people with diabetes who post content online is to counter the idea that diabetes is easy. This is being executed in many different ways. For some, it looks like intentionally sharing the hard parts of living with diabetes (like the highs and lows). For others, it looks like posting a bill for insulin or a long list of supplies. Regardless of the way it is shared, people online are talking a lot about how the relentlessness of diabetes goes unacknowledged or overlooked. As a person with diabetes, myself, I have also experienced the frustration that arises when someone says, "so you just have to take insulin and you're fine, right?" So I totally resonate with this one.

Some of the interviewees have surprised me and provided stories and ideas that I wouldn't have expected, all of those moments of surprise have come with nuance. For example, one interviewee was discussing the difference between surviving and thriving with diabetes. They said that thriving didn't mean being perfect, nor did it mean never giving up. Thriving meant doing the best one can with what one has. I'm learning that there are little intricacies in the stories we tell, backed up by years of lived-experience and an intense mental processing of that experience.

Another thing I am learning is that for every story (or narrative), there is a counter-story, and a counter-counter story. And so far, I'm finding that people who post about diabetes online are well aware of the story, the counter-story, and the counter-counter story.

EVEN THOUGH PEOPLE WITH DIABETES CANNOT BE UNIFIED DUE TO PERSONALITY/SITUATIONAL DIFFERENCES, THERE IS SOMETHING CONNECTING US ALL.

I haven't quite gotten to what that something is, but it seems to be there, lingering, waiting to be unconvered.

- THE AUTHOR -

Hi! I'm Heather Walker and I write this blog about where academia and patient life meet. If you have any interesting articles, send them my way!

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Heather Rose Walker, PhD (Di...
@Heather_RoseW

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https://twitter.com/hwitteman/status/118059 7570998951936

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THE CHRONIC SCHOLAR
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#DSMA FOR RESEARCH, OPTION TO OPT-OUT

April 24, 2019

Edit

Happy #DSMA day! Thank you for visiting this page to learn more about the study. This is also the post where you have the option to opt-out. All study details are below.

Here is the opt-out form. If you would like to participate in the twitter chat but do not wish to have your responses collected as data for this study, please fill out this form. If you would like your tweets to be included, please leave this form blank.

Twitter Handle (required)

☐ I would like to opt-out (required)

SUBMIT

Information about this study:

This #DSMA chat is a research opportunity which is one part of my larger dissertation project. The purpose of the overall study is to identify and analyze dominant and counter-narratives within a sample of diabetes online communities (DOCs) in order to better understand how the condition of diabetes is being politicized via online social media spaces. This means I am collecting diabetes-related social media data and analyzing it for narrative themes and their connection to social phenomena.

There are some risks to participation. Because the data collected for this study is public-facing social media data, there is a high risk that your privacy and confidentiality will be compromised. While measures have been taken to protect your privacy after the data has been collected (removal of identifiers), there are no protections to privacy within the group or outside because anyone can see or track the content shared on Twitter. There is no compensation provided for this activity. This research may not benefit you directly, however it is possible that the published findings will eventually benefit diabetes communities at a wider level.

Please note that **by NOT opting out**, you are consenting to allow the research to collect your responses and use them in the data analysis process. In this way, you are considered a research subject. Your tweets will be analyzed thematically. If the researcher would like to quote you directly, you will receive a DM asking for your email address, and a personalized email will be sent to you with the quote requested. If you do not approve, the quote will not be used. This is in line with the Twitter Terms of Service.

Again, if you do consent to use of your data (not opt-out), you will be considered a participant of this research study. This study will enroll a maximum of 2,180 subjects. Your participation does not involve any other activities. However, if you would like to be contacted for other study- related opportunities (eg. in-depth interview), please fill out the form below.

Email (required)

Name (required)

☐ I would like to be contacted about other research opportunities involved in this study.

(required)

SUBMIT

More Information:

- THE AUTHOR -

Hi! I'm Heather Walker and I write this blog about where academia and patient life meet. If you have any interesting articles, send them my way!

- DIABETES BLOG WEEK 2016 -

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Tweets by @Heather_RoseW

🔁 Heather Rose Walker, PhD (Diabetes) Retweeted

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authors.elsevier.com/c/1ZrXD_Z37mrS...
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Rethinking Resilience
Resilience plays an im...
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♡   ⤴   Oct 5, 2019

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https://twitter.com/hwitteman/status/118059 7570998951936

♡   ⤴   Oct 5, 2019

🔁 Heather Rose Walker, PhD (Diabetes) Retweeted

WHY IS THIS STUDY BEING DONE?	The purpose of the overall study is to identify and analyze dominant and counter-narratives within a sample of DOCs in order to better understand how the condition of diabetes is being politicized via online social media spaces. While the overall study has multiple phases, this #dsma tweet chat is a part of phase 2. During this phase, the researcher will be collecting social media data over a 3- month from individuals who share about diabetes through various social media platforms. The purpose of phase 2 is to understand the cultural context of the research site in an empowered and nuanced way.
WHAT WILL I BE ASKED TO DO DURING THE STUDY?	Participation in this tweet chat will mimic regular #DSMA chats. There will be a set of questions asked and you may answer them however you see fit. You are encouraged to interact with others involved in the chat as well. The chat will last 60 minutes and will ask 6 questions. You will be asked about common diabetes misconceptions, how diabetes is a part of you, and what you want people to know about diabetes. You may also be asked to consent to the quoted use of your social media data, which is optional.
HOW MUCH TIME WILL I SPEND ON THE STUDY?	The 60-minute tweet chat will take on [DATE] at 9pm EST.
ARE THERE ANY BENEFITS TO TAKING PART IN THE STUDY?	Being in this research study may not benefit you directly, but it is possible that the findings produced by this inquiry may indirectly benefit your respective diabetes online community.
WHAT ARE THE MAIN RISKS OF THE STUDY?	The primary risks presented by this research study are breaches of privacy (others outside of the study may find out you are a subject) and/or confidentiality (others outside of the study may find out what you did, said, or information that was collected about you during the study). Although we ask everyone in the group to respect everyone's privacy and confidentiality, and not to identify anyone in the group or repeat what is said during the group discussion, please remember that other members of the group may accidentally disclose what was said.
DO I HAVE OTHER OPTIONS BESIDES TAKING PART IN THE STUDY?	This research study is not designed to provide treatment or therapy, and you have the option to decide not to take part at all or withdraw your participation at any time without any consequences.

Your identifiable data will be kept only on a master list on a passcode locked computer that is not Wi-Fi-enabled to prevent access by unauthorized personnel. Once data analysis is complete, your identifying information in the master list will be destroyed. The data you shared, once de-identified (within 24-hours of the time the PI receives your signed consent form), will be stored in a password protected UIC Box file for a period of five years.

This message has been approved by the ethical review committee at my university. For questions, concerns, or complaints about the study, please contact the PI, Heather Walker at 530.755.7673 or email at hgabel3@uic.edu or the faculty advisor, Dr. Joy Hammel, at 312-996-3513 or hammel@uic.edu.

If you have questions about your rights as a study subject; including questions, concerns, complaints, or if you feel you have not been treated according to the description in this form; or to offer input you may call the UIC Office for the Protection of Research Subjects (OPRS) at 312-996-1711 or 1-866-789-6215 (toll-free) or e-mail OPRS at uicirb@uic.edu.

Dr. Rebecca Kreitzer
@rebeccakreitzer

I have gotten four separate emails or DMs today asking me about how to mitigate bias in teaching evaluations. Because I think everyone should have this information, here is a short thread. (You can get a lot of resources here: rebeccakreitzer.com/bias-in-teachi…)

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Live-Streaming an Academic Affair (Sept 27th)

#IHearYou

Open Access Study of Diabetes Online Communities Now Available

Seven interviews later…

#DSMA for Research, Option to Opt-Out

- CATEGORICAL DATA -

#IHearYou Ableism Advocacy chronic illness dblog dblogweek Diabetes Diabetes Advocacy Diabetes and staring diabetes awareness diabetes diabetes blog Diabetes Blog Week Diabetes community Diabetes Community Events Diabetes Event Diabetes message diabetes mom Diabetes Online Community Diabetes Research diabetes stories Diabetes Support Network Diabetes video diabetes vlog Diabetic diabetic mom disability Disability and Ableism Disability in media Disability Theory Discourse DOC DPAC Health Advocacy Healthcare Heather Gabel heather gabel video Heather Rose Diabetes Heather Walker Heather Walker Diabetes identity-first language In Person Community Event Diabetes IRL Malcom Gladwell MasterLab Medtronic Messages motherhood motherhood with diabetes My Research open access research Our story pain narrative patient-provider Patient Researcher person-first language Person with diabetes Peter Ubel et. al. Power is knowledge Representations of diabetes Research social aspects of diabetes Social desirability social science research stigma and staring heather gabel systemic issue Systems Problem The Chronic Scholar The ideology of ability Type 1 Type 2 UnitedHealthcare DME Who Decides medical regimen?

THE CHRONIC SCHOLAR

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OFFICIALLY RECRUITING! #DSMA TWEET CHAT APRIL 24TH

April 17, 2019

Edit

I've been updating you about my dissertation research via this blog for quite a while now and I am happy to share a new IRB approved research opportunity happening on Wednesday, April 24th during the regularly scheduled #DSMA chat. Below are some details about the projects as well as the who, what, and when!

PROJECT DETAILS

The following research opportunity is one part of my larger dissertation project. The purpose of the overall study is to identify and analyze dominant and counter-narratives within a sample of diabetes online communities (DOCs) in order to better understand how the condition of diabetes is being politicized via online social media spaces. This means I am collecting diabetes-related social media data and analyzing it for narrative themes and their connection to social phenomena. Up to **2,180** participants will be enrolled in this study.

THE CURRENT RESEARCH OPPORTUNITY

I will be hosting a **1-hour long #DSMA tweet chat** as one component of my larger project. #DSMA was selected as a research site because it has been a regular meeting place for people with diabetes and caregivers of people with diabetes for a very long time. I, myself, have participated in the chat too many times to count over the last five years! For this study, I will use both my personal twitter account, @Heather_RoseW, as well as the official diabetes social media advocacy (DSMA) account, @diabetessocmed. Please follow both accounts in preparation for the chat.

WHO CAN PARTICIPATE?

Any one touched by diabetes is welcome to participate! A tweet chat is designed to be open and free flowing. All who would like to join in can. There will be an opt out procedure linked out several times during the chat. You can participate in the chat AND opt out. This just means that your tweets will not be used for research purposes. If you want to join the conversation but not be a part of the project, clink on one of the opt-out links during the chat.

WHAT WILL BE ASKED?

Below are the questions that will be asked during the chat. Please feel free to prepare your responses ahead of time!

- What is the most common diabetes misconception you hear and how do you react when you hear it?
- What do you wish people knew about diabetes?
- To what extent is diabetes a part of who you are? 4) How would you describe your diabetes-related online interactions to a person without diabetes?
- Why do you participate in the #dsma tweet chat?
- Imagine a diabetes-related hashtag you made up went viral, what would the # be and it what would it be about?
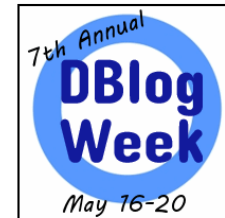
WHEN WILL THE CHAT TAKE PLACE?

The #DSMA chat will take place on Wednesday, April 24th during the regular #DSMA time, 9pm EST. The chat will last one hour.

- THE AUTHOR -

Hi! I'm Heather Walker and I write this blog about where academia and patient life meet. If you have any interesting articles, send them my way!

- DIABETES BLOG WEEK 2016 -

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Oct 5, 2019

Heather Rose Walker, PhD (Di
@Heather_RoseW

This is an incredible thread with dynamic responses. Reminds me of why we need initiatives and efforts like #WhyWeRevolt. #patientsarepeople
https://twitter.com/hwitteman/status/118059 7570998951936

Oct 5, 2019

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MY RESEARCH IS APPROVED... ALMOST!

January 31, 2019
Edit

I'm thrilled to spread news today that my dissertation committee approved my project. I now am ready to share more of the study details and story of how we got here. I will note up front, however, that I am still waiting on approval from the ethical review board at my home university before I can officially begin with data collection and participant recruitment and all that fun stuff!

Hence, my research is approved, sort of.

Before sharing the details of the project, I'd like to explain a part of the process which has haunted me a little bit. I got a bit over eager when I first put all the pieces together for my first proposal defense. I even conducted some of the research activities under the impression that it was feasible since it was helping me develop the project. I was wrong about that. I was gently scolded by my committee and then reprimanded by the IRB! To those community members who I have worked with on dissertation-related projects, I will be able to contact you again regarding this after the proposal is approved by the ethical review board!

Now, on to the project details!

BACKGROUND

Across social media platforms, persons with diabetes engage in discourses on the condition of diabetes. Topics discussed range from basic illness symptomology and treatment to taboo intrapersonal tips on how to have sex while wearing an insulin pump. Among these topics is representation. Persons with diabetes discuss stereotypes and

COOL, HUH?

At this point, I am sharing for the sake of releasing this information up front. I will continue to post about the progress of this project and list any engagement opportunities moving forward.
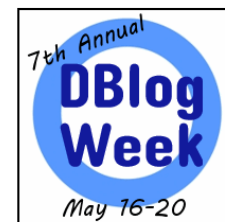
For now:

- THE AUTHOR -

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♡ ↪   Oct 4, 2019

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Seven interviews later...

232

THE CHRONIC SCHOLAR
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FUNDING! GET OUT?!?

December 5, 2018

Edit

I am still in a state of shock and disbelief about what I am about to share... It's good news, no, great news. It's the news I needed to 'just keep swimming.'

You see, I had recently failed my proposal defense. The defense was brutal; it totally kicked me down. I was excited and engrossed in the carrying out of my project going into it, and completely deflated by the end. In just two hours, too. Three years of planning, networking, learning, and heart-investment just felt a waste. I took about two weeks to feel that ickiness. I allowed myself the time to think about it and process. And then, I moved on.

I started throwing myself into projects. The result of which is three completed manuscripts and four more in progress. Also, I am **writing a book** with two friends and colleagues (more on that in another post). I shifted modes and started giving more time to the academic work of others, helping them work through hang-ups like I was, in that same moment, experiencing. I scoured the internet for funding opportunities, open collaborations, speaking engagements, and the like. I've been applying to so many things the last month I had to start a spreadsheet to keep track!!!

Having emerged from that haze of applications, I can say with undue honesty that my underlying goal was to find a source(s) of external validation. I desperately needed to feel of value *in this particular way*. And in that process, I went from feeling like a failure with bunk ideas to a thoughtful and masterful researcher again. Rather than build myself a ladder to climb out of the hole I was in, I dug a system of tunnels!

All of this is to share the impetus behind the GREAT STINKIN' NEWS! One of the applications I submitted was a grant for the UIC Provost's Graduate Research Award. It's $5,000 grant to support preliminary dissertation research. And guess what?

I WAS SELECTED!

MY DISSERTATION IS FUNDED!

This is huge news in the academic world, but also for the community members I am and will be working with throughout the rest of my journey as a graduate student.

YOU ALL, I GET TO PAY YOU FOR YOUR TIME AND IDEAS.

I'm over the moon and back on the horse. I am planning to share a series of blog posts to discuss what my project is and how I will be doing it. I can't wait to get this thing finally approved and move onward, my friend, onward.

For now, I will leave you with the suggested title:

POLITICIZING THE CONDITION OF DIABETES ONLINE: COUNTER-NARRATIVES AND THE PURSUIT OF NORMALCY

Whoo hoo!! Let's do this thingy!

SHARE THIS:

- THE AUTHOR -

Hi! I'm Heather Walker and I write this blog about where academia and patient life meet. If you have any interesting articles, send them my way!

- DIABETES BLOG WEEK 2016 -

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HEATHER WALKER, PhD

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RESEARCH SUMMARY

My research sits at the intersection of social media, social movements, health disparities, and peer health. I have thus far focused on diabetes and social media movements across web-platforms, using a combination of qualitative and quantitative methods borrowed from community-based participatory action research and netnographic frameworks. My research interests are currently pivoting toward social network and organizational analysis as it relates to health disparities and disability more generally. I have particular interest in producing ethnographies of health systems.

EDUCATION

2019 Ph.D. Candidate Disability Studies – University of Illinois at Chicago, expected graduation date: 12/2019
2017 MS Disability and Human Development – University of Illinois at Chicago
2012 B.A Religious Studies – University of California at Berkeley

HONORS AND SCHOLARSHIPS

2019 Recipient of the 4S NOLA Childcare Award, $200
2017 1st Place Research Challenge Winner// Stanford Medicine X | Symplur Signals Everyone Included Research Challenge.
2017 HealtheVoices ePatient Scholarship
2017 Diabetes Hands Foundation MasterLab Scholarship
2016 Leadership Institute Chancellor's Student Service and Leadership Award recipient
2016 HealtheVoices ePatient Scholarship
2016 Diabetes Advocates MasterLab Scholarship recipient
2015 Diabetes Advocates Conference Scholarship: AADE National Conference
2015 Stanford Medicine X ePatient Scholar
2014 Diabetes Mine Innovation Summit: Patient Voices Winner
2014 Diabetes Advocates MasterLab Scholarship
2014 Diabetes Scholars Foundation Young Adult Scholarship for CWD FFL Conference
2012 Golden Key International Honor Society

GRANTS AND FUNDING

2019 Recipient of the 4S NOLA Graduate Student Travel Award, $300

2019 Recipient of the Spring President's Research in Diversity Travel Award, $800

2019 Recipient of the Charlotte A. Tate Multidisciplinary Research Award, $1,000

2018 Provost's Dissertation Research Award, $5,000

2017 Advisor for: Improving Clinical, Behavioral and Psychosocial Type 1 Diabetes Outcomes with an Online Peer Health Intervention. PI: Michelle Litchman. University of Utah Diabetes Metabolism Center, 05/01/2017 - present. Total project budget to date: $30,000.00

2012 Shinnyo-en Foundation Peace-Building Leadership Grant, $1,350

RESEARCH EXPERIENCE

Principle Investigator – 2016-present

University of Illinois at Chicago, Applied Health Sciences

Doctoral Research: Blended community-based participatory action research with mixed-method netnography; collected and analyzed social media data across platforms, use of python, Twitter API, DiscoverText, MAXQDA, Symplur Signals, twitter archiver tool via google, & narrative analysis.

Master's Research: Used participatory action research methods; Research products: 1) operational definition of peer-support as described by adults with diabetes, 2) a conceptual model of peer support best delivered

Research Analyst – University of Utah, College of Nursing – 2018-2019

Scoping reviews of literature on Diabetes Online Communities (DOCs) with multidisciplinary team; Insulin Trading Study; #OpenAPS & #WeAreNotWaiting patient hacktivist movements in diabetes online community groups; assisted with funded grant applications; serves as qualitative methods and theory expert

Research Assistant – Americans with Disabilities Act Participatory Action Research Consortium (ADA PARC) Project – Department of Occupational Therapy, College of Applied Health Sciences 2016-2019

Community-based participatory research, conducting interviews; recruitment; creating peer-informant/mentor protocol for multi-site use; conducting qualitative analysis; creating code books and visual representations of major findings; managing IRB applications and reviews for 12 active research studies under Dr. Joy Hammel's research lab.

PUBLICATIONS

ARTICLES

Refereed
Litchman, M.L., **Walker, H.R.,** Ng, A.H., Wawrzynski, S.E., Oser, S.M., Greewood, D.A., Gee, P.M., Lackey, M. & Oser, T.K. (2019). State of the Science: A Scoping Review and Gap Analysis of Diabetes Online Communities. Journal of Diabetes Science and Technology. 2019.

Walker, H.R., *#CripTheVote: How Disabled Activists Used Twitter for Political Engagement During the 2016 Presidential Election*. Participations: International Journal of Audience Research. In Press.

Litchman, M.L. **Walker, H.R.**, Rinker, J., Hodgson, L., Derose, P., Warshaw, H., Heyman, M., Oser, T.K. *Online and In-Person Peer Support in Diabetes Care: A Review of Reviews and Practice Recommendations*. The Diabetes Educator. In Press.

Angell, A., Goodman, L., **Walker, H.R.** Sheth, A., Hammel, J. "*Starting to live a life": Understanding full participation for people with disabilities after institutionalization*. American Journal of Occupational Therapy. In press.

IN PROGRESS PUBLICATIONS

BOOKS
Walker, H. R., Moutinho, S., & Goodman, L. [Working title] Stories of the Lost Cause: Colonized Potential in American Culture. In Progress.

REFEREED ARTICLES

Litchman, M.L., Jung, S.H., Wawrzynski, S. E., **Walker H.R.,** Ng, A.H., Oser, T.K. *Ethical Research Practices Among Diabetes Online Community Studies: A Systematic Review and Considerations for Investigators*. Cyberpsychology, Behavior, and Social Networking. Under Review.

Litchman, M.L. **Walker, H.R.,** Fitzgerald, C., Gomez Hyos, M., Lewis, D., Gee, P.M. Citizen Scientists Innovating Diabetes Technology: The #WeAreNotWaiting and #OpenAPS Movement. Journal of Diabetes Science and Technology. Under Review.

Walker, H.R., Litchman, M.L., Hammel, J. Empowerment Looks Different Online: A Critical Review of Empowerment Measurements and Methods in Diabetes Research. Social Theory and Health. Under Review.

Walker, H.R., Popova, E., Litchman, M.L., How one Social Movement Generated Discourses of Medical Oppression on Twitter. Heath Communications. In Progress.

Litchman, M.L., Oser, T., Walker, H. S., Wawrzynski, S.E., Jung, S. & Oser, S. The Underground Trading of Insulin: Is it Saving or Harming? *Journal of Family Practice.* In Progress.

PRESENTATIONS

Walker, H.R. #CripTheVote: How Disabled Activists Used Twitter for Political Engagement During the 2016 Presidential Election. 2019
Pacific/Western Disability Studies Symposium. Spokane, WA, 2019.

Walker, H.R., Norton, A., *Making Space for Lurkers in Peer Support: A Community-Supported Approach to Engagement.* American Association of Diabetes Educators National Conference. 2019; Houston TX.

Litchman, M.L., Walker, H.R., *Online and in person Peer support for underserved populations* American Association of Diabetes Educators National Conference. 2019; Houston TX.

Walker, H.R., Litchman, M.L., "*I went to sleep cradling my phone that night": Examining peer support in diabetes.* Poster presented at: Diabetes and Metabolism Research Center and Driving Out Diabetes Fall Retreat; October 2018; Salt Lake City, UT.

Walker, H.R., Popova, E., Litchman, M.L., A Story of #DoctorsAreDickheads: Discourses of Medical Oppression on Twitter. Society for Social Studies of Science Annual Meeting; New Orleans; September 4-7, 2019.

Wawrynski, S., Allen, N., Iacob, E., Gabel, H., Gee, P., Berg, C., Litchman, M. *Precision Health: A Self-Directed Online Peer Support Intervention for Adults with Type 1 Diabetes.* Poster presented at: The Council for the Advancement of Nursing Science; September 2018; Washington, D.C.

Litchman, M.L., Gabel, H., Fitzgerald, C., Hoyos, M.G., Lewis, D., Gee, P.M. #WeAreNotWaiting: The Medical Hacking Patient Movement. DData Summit. Palo Alto, CA. USA. Poster, Presented, 11/17/2017.

Litchman, M.L., Gabel, H., Fitzgerald, C., Hoyos, M.G., Lewis, D., Gee, P.M. #WeAreNotWaiting - "I Want Life": The Medical Device Hacking Patient Movement. Key

Note Presentation. DData Summit. Palo Alto, CA. USA. Invited Talk/Keynote, Presented, 11/17/2017.

Litchman, M.L., **Gabel, H.R.**, Head, R. & Gee, P. M. *The Power of "Me Too": An Analysis of Peer Health in the Diabetes Online Community.* 44th Annual Meeting of the American Association of Diabetes Educators; August 2017, Indianapolis, IN.

Walker, H.R., Cassoobhoy, A. *Creating credible, strong content – How to interpret and share scientific data with your audiences.* HealtheVoices; April 2017, Chicago, IL.

NON-ACADEMIC PUBLICATIONS

Social Scientist & Diabetes Blogger via www.TheChronicScholar.com

TEACHING EXPERIENCE

Invited Guest Lecturer – University of Illinois at Chicago; Fall 2017 & Fall 2019
DHD 561 Disability Policy & Participatory Action Research
Topic: Doing Participatory Action Research Online – How and Why

Co-Instructor – University of Illinois at Chicago; Spring 2017
DHD 202: Disability Health and Society

Teaching Assistant – University of Illinois at Chicago; Fall 2016
DHD 203: Disability and World Cultures

Conference Facilitator – Diabetes UnConference; March 2015
Facilitated five 100-person discussions; Lead three 20-person break out sessions using world-cafe facilitation method; Covered topics such as: diabetes burnout, depression, medical jargon, empowering language, workplace communication, sex, discrimination, financial issues, moving and exercise, family life, pregnancy, etc.

Student Instructor – Global Perspectives: Methods of Coping; January 2012
University of California, Berkeley; Democratic Education at Cal (DECal); Developed curriculum and lesson-plans for semester-long course; 12 enrolled students; lead lectures, activities, invited guest lectures.

Diabetes Advocate – Diabetes Online Community 2011-Present
Engage in diabetes events focused on technology innovation, psychosocial program development, social support, collective advocacy road-mapping, research, and co-design: integrating patient perspective; Disseminate the information learned via

WordPress and Twitter; Inspire continuing dialogue in-person and online; motivate peers to utilize resources that will benefit them and their diabetes management

EMPLOYMENT

Programs Assistant – DiabetesSisters 2015 – 2016
Bartender – Sleepy Dog Tap Room 2014-2015
Patient Media Engagement Scholar – Stanford Medicine X Conference 2014 & 2017
Administrative and Programs Assistant - Diabetes Hands Foundation 2012-2014
Server – Triple Rock Brewery 2012-2013

REFERENCES

Joy Hammel, Ph.D.; hammel@uic.edu; 312.996.4330
Michelle Litchman, Ph.D.; michelle.litchman@nurs.utah.edu; 801.558.9984
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