

Reimagining Empowerment: A Critical Review of Empowerment Theory in Diabetes Research

Keywords: Diabetes; Empowerment; Change; Critical review; Community-based methods, Participatory design, Systems change

Abstract

Diabetes, well documented as a complicated condition, has been the focus of self-management studies for over three decades. Empowerment theory has co-developed within diabetes literature at the same time. However, this literature lacks a core and standard definition, which has led to incongruencies in theory and relative terminology. In this critical review, the construct of empowerment in diabetes literature is dissected and examined. Prominent measures and methods are problematized to highlight their overreliance on individual behavior rather than systemic social change. Current interventions targeting empowerment focus almost exclusively on individual behavior-change, inadvertently suggesting that the location of the problem of poor management lies within the abilities, attitudes, and beliefs of individuals. This paper argues that there has to be a socially-based power-related shift from one group to another in the process of empowerment for its construct to be complete, and that the ultimate agent of change must shift from the patient to systemic barriers in their way. Examples of online patient community-generated definitions, resources, and practices of empowerment are highlighted, leading to an argument that researchers and healthcare providers ought to add nuance to the construct of empowerment by weaving in community and systems levels change goals.

Introduction

Diabetes is a condition that seeps into life physically, mentally, emotionally, and socially. As such, there is an impact on sense of self among people with diabetes (PWD) as one must consider their day-to-day activities, social positioning, environment and economic factors. There are multifarious stigmas attached to diabetes that color the ways in which one develops and adjusts their self-concepts. Despite the deep impact diabetes is known to have on identity, the psychosocial impact of diabetes has only been taken up as an area of study since the early 1990s, after a major shift in the treatment of diabetes occurred.

In 1993, a groundbreaking study, the Diabetes Control and Complications Trial (DCCT), was published. For the first time, there was significant evidence linking tight diabetes self-management to decreased incidence of diabetes-related complications [1]. For healthcare providers, this study redefined the goals of practice and treatment. It called for increased diabetes patient education with a focus on self-efficacy and activation. For patients, the DCCT drastically transformed the obligation and responsibility of risk mitigation from being provider-based to being patient-based, increasing the psychosocial burden of diabetes on the patient [2]. For example, having a sense that one can cause or avoid their own complications has been linked to higher rates of stress, guilt, and distress within diabetic populations [3]. Today, the individualized challenges of diabetes extend far beyond the practice of doing self-management, to the art of coping with them.



Advances in Diabetes & Endocrinology

Walker HR^{1*} and Litchman ML²

¹Medical Group Analytics, University of Utah, Salt Lake City, USA

²College of Nursing, University of Utah, Salt Lake City, USA

*Address for Correspondence

Walker HR, Medical Group Analytics, University of Utah, Salt Lake City, UT 84102, USA; Phone: 530-755-7673; E-mail: heather.walker@hsc.utah.edu

Submission: 08 June, 2022

Accepted: 06 July, 2022

Published: 07 July, 2022

Copyright: © 2022 Walker HR, et al. This is an open access article distributed under the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Individuals with diabetes must engage in daily self-management practices, such as physical activity, healthy diet, taking medications, stress reduction, and sleep. For those on insulin, it is the gold standard to calculate insulin doses based on insulin-to-carbohydrate ratios and insulin sensitivity ratios with every meal and snack. Diabetes calls for advanced and thorough planning with day-to-day activities, including travel, driving, sleeping, eating, exercising, etc. Our previous research, further, suggests that diabetes requires individuals to shape their sense of self around the demands of the illness – requiring they incorporate descriptors like planner and responsible into their self-concepts [4]. Additionally, accounting for the time PWD spend thinking about diabetes [5], it is no surprise that studies of diabetes management have moved toward the realm of distress, depression, empowerment, activation, and self-efficacy.

This movement in the research and treatment of diabetes toward the psychosocial most heavily relies on nurturing patients' self-efficacy. Self-efficacy, a concept developed by noted Psychologist Albert Bandura, is a person's belief in their own ability to control their life circumstances and effect change through behavior modification [6]. Self-efficacy relates to a person's ability and willingness to enact behavior modifications toward disease management betterment. Self-efficacy is a hyper-individualized approach to diabetes care and treatment because it implies that control is ultimately a matter of willingness to perform a set of behaviors that will lead to change. This approach however, fails to capture or critically reflect on the social, political, and economical considerations people with diabetes face. Self-efficacy as a construct closely parallels empowerment as it is most generally applied to diabetes in research and healthcare. This paper critically reviews the construct of empowerment in diabetes literature and argues for a more sociopolitical approach.

Empowerment in Diabetes Research

Empowerment blossomed in the diabetes space prior to the DCCT, however, the DCCT amplified its construct. In 1991, diabetes researchers introduced the need for a shift toward empowerment within diabetes care arguing that the traditional medical model relied too heavily on health care providers as decision-makers [7]. Originally, the construct of empowerment was described as a form of accepting

responsibility for oneself and one’s own health [7]. However, over time, the common constructs of empowerment in the literature have shifted and now represent several factors related to who is responsible for empowerment, what is required for empowerment to take place (e.g. a process, a treatment, etc.) and how empowerment might occur. This article explores these areas and calls for a reimagining of empowerment in the diabetes space. As an entry point into these ideas, Table 1 provides definitions from leading and top cited works on diabetes empowerment (Table 1).

The construct of “who” in empowerment

Historically, health researchers have viewed the person responsible for empowerment to be focused on the patient, provider, or the patient-provider relationship (Table 1). This posits that in order for patients to be empowered, they are to become knowledgeable [13], reflective about their willingness to engage in diabetes self-care [10], and choose to be responsible by engaging in diabetes self-care activities [7,11]. Providers, on the other hand, are to empower patients by providing psychological support [8], facilitating patient self-reflection [9], and providing diabetes self-management tools [15]. Within a patient-provider relationship, empowerment can take place if power hierarchies are reduced [12,15], and knowledge is effectively transferred [12].

While the literature varies in stating who is responsible for enacting empowerment, the onenessonus is always ultimately on the

patient. For example, the provider can give patient tools, but the patient has to choose to use them beyond the walls of the clinic or research site. Providers can hand over decision-making power to the patient, but the patient still has to use that power to weigh self-management options and actively choose the path best suited for them. The illusory variance in the construct of ‘who ‘in the diabetes empowerment literature may be representative of a social phenomenon contributing to worse health outcomes in diabetic populations.

In one community-based study, diabetes incidence was found to be constructed as a failure of the individual. Staff persons in at the Community Health Center of study believe that diabetes is a signal of a defective individual who is ignorant of self-care strategies necessary to manage diabetes effectively [16]. Perhaps more telling, patients expressed a tendency to internalize the attributions made by staff persons. Patients themselves believed that if they were better educated had more education and made “better” choices, their health would be better. This form of internalized ableism, which can be theoretically linked to the treatment philosophies and practices used in diabetes care today, is particular particularly insidious within diabetes populations because of the way diabetes is associated with poor choices [17]. When prompted during interviews with questions related to structural inequalities, participants in the Chaufan study reverted back to individual attributions and solutions. This implies that both patients and community-service staff function under a belief that the “proper locus of intervention” ought to occur at the individual rather than the social level [16]. When only individualized

Table 1: Definitions of Empowerment in Diabetes Care Literature.

Author	Definition	Who	What	How
(Funnell et al., 1991, 38)	“The discovery and development of one’s inherent capacity to be responsible for one’s own life.”	Patient	Process	Responsibility
(Funnell & Anderson, 2004, 123).	“Patient empowerment is defined as helping patients discover and develop the inherent capacity to be responsible for one’s own life”	Provider	Treatment	Psychological support
(Anderson & Funnell, 2005, 11)	“The process of empowerment is the discovery and development of one’s inborn capacity to be responsible for one’s own life. People are empowered when they have enough knowledge to make rational decisions, control, resources to implement their decisions and experience to evaluate the effectiveness of their actions.”	Patient	Process and outcome	Knowledge acquisition, resources, adaptability skills
(Anderson & Funnell, 2010, 281)	“The empowerment approach involves facilitating and supporting patients to reflect on their experience of living with diabetes. Self-reflection occurring in a relationship characterized by psychological safety, warmth, collaboration, and respect is essential for laying the foundation for self-directed positive change in behavior, emotions, and/or attitudes.”	Provider	Treatment, process and outcome	Modeling behavior: self-reflection
(Henshaw, 2006, 134)	“Empowerment, as a concept, is based on the assumption that individuals, if given the freedom to choose and the opportunity to reflect, would be able and willing to select appropriate diabetes goals.”	Patient	Outcome	Reflection and choice
Asimakopoulou, Newton, Sinclair, & Scambler, 2012, 281 & 288)	“...empowerment, as construed in diabetes, is about levelling-off the power between health-care professionals (HCPs) and patients, giving patients some choice and control over how they self-manage their illness.” ... “...empowerment incorporates providing patients with the necessary tools to manage their illness”	Patient-provider relationship /provider	Process and outcome	Power-dynamics; choice; management tools
(Naccashian, 2014)	“the context of health care, empowerment is the process of conversation and contemplation that facilitates health maintenance, well-being, and coping in patients with diabetes”	Patient-Provider relationship	Process	Conversation and contemplation
(Meetoo & Gopaul, 2005, 28)	“Empowerment is an enabling processthrough which individuals make informed decisions about their own illness behavior and to be fully responsible members of the healthcare team.”	Patient	Process	Responsibility
(Fumagalli, Radaelli, Lettieri, Bertele’, & Masella, 2015, 390)	“Patient empowerment is the acquisition of motivation (self-awareness and attitude through engagement) and ability (skills and knowledge through enablement) that patients might use to be involved or participate in decision-making, thus creating an opportunity for higher levels of power in their relationship with professionals”	Patient provider relationship	Process and outcome	Reflection, skill development, and power dynamics

approaches to diabetes empowerment are taken, social and structural inequalities and possibilities for social change are ignored. The problem remains then within the individual seen as responsible for any potential change: the patient [16].

The construct of “what” in empowerment

The mechanism through which empowerment may occur varies throughout the literature. Some studies describe empowerment as an outcome which can be measured and treated clinically [10,13,18]. The most common research tool used to measure empowerment as an outcome is the Diabetes Empowerment Scale (DES). Researchers who developed the DES describe the purpose of the empowerment approach to treatment “as helping patients make informed choices about their diabetes self-management” [19]. The scale is designed to measure a patient’s behavior change and thus has been used primarily as a pre-and post- intervention measurement. Topics covered in the scale relate to three categories: 1) managing the psychosocial aspects of diabetes; 2) assessing dissatisfaction and readiness to change; and 3) setting and achieving diabetes goals [6]. The Diabetes Empowerment Scale has been translated into several languages and into short form as recently as 2021, suggesting it is still being used on a global scale [19-22].

Though the tool is called an empowerment scale, the journal article introducing it describes it as a measure of self-efficacy, indicating a conflation in terminology [6]. The questions used in the scale focus on the patient’s belief in their ability to identify and act on diabetes-related issues as well as their attitude toward living with the daily requirements and demands of diabetes. Though the validity and reliability of the scale have been confirmed, classifying the DES as a psychometric survey, the researchers do not measure or comment on the social validity of the scale.

Social validity can be defined as “the extent to which potential adopters of research results and products judge them as useful and actually use them” [22]. Though the tool is called an empowerment scale, the journal article introducing it describes it as a measure of self-efficacy, indicating a conflation in terminology [6,19]. The questions used in the scale focus on the patient’s belief in their ability to identify and act on diabetes-related issues as well as their attitude toward living with the daily requirements and demands of diabetes. Though the validity and reliability of the scale have been confirmed, classifying the DES as a psychometric survey, the researchers do not measure or comment on the social validity of the scale.

Social validity can be defined as “the extent to which potential adopters of research results and products judge them as useful and actually use them” [23]. In this way, potential adopters can mean fellow researchers, members of the population of study, healthcare providers, and so on. Though the DES has been used in many studies since its publication in 2000, the social validity to the patient population remains unexplored. Methodologically, this means we have yet to develop a meaningful understanding of the relevance and significance of the results of this scale to diabetic populations and service organizations serving them. Furthermore, we do not know yet of its usability by and for community members, which has been taken into consideration by some health researchers [23,25]. It may be the case that members of diabetes communities would want an empowerment scale such as this one to also capture aspects of social

and community empowerment. However, if they are not brought into the research process beyond piloting the survey for validity and reliability purposes, researchers will remain ignorant of this gap.

Empowerment has also been described in the literature as a process of becoming empowered. Studies that take this approach either argue that empowerment happens within the effort made to reach diabetes-related goals, but is not necessarily an end goal in itself [11,24,25], or that empowerment is an unfolding internal process leading to a state of being [26]. Studies that describe empowerment as a process require healthcare provider input through education, therapy, or skill and knowledge transference. Though the construct of empowerment as a process revolves around individual patient growth, it suggests that said growth cannot occur without provider involvement. This philosophical incongruity defies the underlying aim of current empowerment constructs arguing for self-directed patient change studies that take this approach argue that empowerment happens within the effort made to reach diabetes-related goals, but is not necessarily an end goal in itself [11,24,25], or that empowerment is an unfolding internal process leading to a state of being[28]. Studies that describe empowerment as a process require healthcare provider input through education, therapy, or skill and knowledge transference. Though the construct of empowerment as a process revolves around individual patient growth, it suggests that said growth cannot occur without provider involvement. This philosophical incongruity defies the underlying aim of current empowerment constructs, another problematic aspect of the way diabetes empowerment is constructed in clinical research.

To better link the way aforementioned definitions and uses of empowerment within diabetes literature, we developed a flowchart of responsibility and outcome. The flowchart in Figure 1 visually summarizes our critical review of the construct of empowerment and its definitional components within diabetes literature.

To drive this point home, of the masse of literature covering empowerment within the context of diabetes, few studies offer definitions of the concept. These studies seem to take the position that the concept of empowerment is a given, and does not need to be thoroughly defined [27-30]. As further evidenced by our critical review here, the construct of empowerment is not a given. There is no universal or standard understanding or conception of what empowerment is how to harness it, or what it looks like when it is intervened on.

When considering what empowerment is, the literature is evermore wrought with incongruencies and discrepancies. There are also gaping holes which are made deeper upon reflection of the construct of how in diabetes empowerment literature.

The construct of “how” in empowerment

Thematically, when the definition of empowerment implicates the patient as the agent of change, the mechanisms revolve around individual internalization processes like self-reflection and accepting responsibility [7,10,11,13,24]. To drive this point home, despite ample research articles covering empowerment within the context of diabetes, few studies offer definitions of the concept. These studies seem to take the position that the concept of empowerment is a given, and does not need to be thoroughly defined [29-32]. As further

evidenced by our critical review here, the construct of empowerment is not a given. There is no universal or standard understanding or conception of what empowerment is, how to harness it, or what it looks like when it is intervened on.

When considering what empowerment is, the literature is evermore wrought with incongruencies and discrepancies. There are also gaping holes which are made deeper upon reflection of the construct of how in diabetes empowerment literature.

The construct of “how” in empowerment

Thematically, when the definition of empowerment implicates the patient as the agent of change, the mechanisms revolve around individual internalization processes like self-reflection and accepting responsibility [7,10,11,13,26]. When the definition of empowerment implicates the provider as the agent of change, the mechanisms revolve around modeling behaviors, psychological support, and providing management tools [8,9]. And lastly, when the definition of empowerment implicates the patient-provider relationship as the agent of change, the mechanisms revolve around power dynamics, self-reflection, and skill development [12,18,25,27]. The way in which empowerment occurs, then, is described as dependent upon the identified agent of change, a facet of the construct which we’ve problematized hit her to here.

Problematizing the Construct of Empowerment

Empowerment has been problematized on the basis that use of the term is confounded within the literature with patient activation, patient engagement, patient participation and patient enablement [12]. Fumagalli et al. further argues that empowerment is defined across studies as an active patient behavior, as an achievable state of being, and as a process of transformation, much of which our critical review discusses. This inconsistency in the literature leaves the construct wrought with apertures, both theoretical and practical. The study concludes with a provocative proposal: could empowerment be an illusion of power that ultimately maintains top-down power dynamics present within the parlance of clinical interactions? [12]. Considering that, across definitions, empowerment is ultimately the responsibility of the patient, this provocation merits further critical consideration.

When it comes to active participation in one’s own care, this literature is saturated. However, there is a dearth of literature related to social and political empowerment. What would sociocultural and sociopolitical research on diabetes an empowerment look like? How could methods and measures be modified to capture a more nuanced construct of empowerment which takes into account considers social conditions and positioning, stigma, economic, and capital resources? Where could researchers go for guidance on incorporating sociocultural and sociopolitical facing elements to their diabetes empowerment research?

Empowerment as a Social Process

As previously mentioned, community-oriented conceptualizations of empowerment are blatantly missing from the literature on diabetes and empowerment. Empowerment, when conceptualized as a social process rather than an individualized one, takes on a more critical and nuanced meaning.

Disability activist and scholar, Jim Charlton’s book, *Nothing About Us Without Us: Disability Oppression and Empowerment*, presents some of the theory behind the concept of empowerment as a social process [31,33]. To introduce and contextualize the book, Charlton describes a paradigm shift which occurred that critically opened up the study of disability. He calls this shift “a historical break with traditional perception of disability as a sick, abnormal, and pathetic condition” [10,33]. This historical shift, in part, resulted in disabled activists starting the Disability Rights Movement. To Charlton and the international disability rights advocates he interviewed in the writing of his book, “empowerment must translate into a process of creating or acquiring power” for the collective [33]. That is, there has to be a socially-based power-related shift from one group to another in the process of empowerment. In this way, empowerment is not about an individual, but about the social positioning of the group as a whole.

In diabetes, there is no shortage of stigma and prejudice creating and maintaining the social positioning of people with diabetes as an inferior class [17]. The attribution of both diagnosis and poor self-management to laziness is but one example [16,32]. That is, when a person is diagnosed with diabetes, they are categorized as one who does not take care of themselves. In a recent study, it was found that those who report having “poor diabetes control” experience disproportionately more social stigma from family, friends, and the public [33]. Similarly, in one Hong Kong-based study, participants reported that due to perceived social stigma, they felt obligated to only perform diabetes-related tasks in private, which then led to the omission of blood glucose testing and insulin administration before group meals [16,34]. That is, when a person is diagnosed with diabetes, they are categorized as one who does not take care of themselves. In a recent study, it was found that those who report having “poor diabetes control” experience disproportionately more social stigma from family, friends, and the public [35]. Similarly, in one Hong Kong-based study, participants reported that due to perceived social stigma, they felt obligated to only perform diabetes-related tasks in private, which then led to the omission of blood glucose testing and insulin administration before group meals [36]. Together, these studies demonstrate a bi-directional relationship between perceived social stigma and self-management.

Socially, the interventions for improving self-management through empowerment principles, like action-planning, goals setting, and problem solving [35,36], identifying and addressing personal challenges [37], and integrating coping strategies [38], actually work to authenticate the stigmatization faced by people with diabetes. That is, it suggests that the location of the problem of poor management lies within the abilities, attitudes, and beliefs of individuals. When our empowerment research fails to account for the social and community aspects of power, they also fail to challenge dominant discourses and inequities actively reproducing power differentials. This stigma-reproducing dynamic has been shown to negatively impact research recruitment in minority populations, as well [39].

Calling for More Participatory Methods

In part, previous research on empowerment has failed to address social concepts of power and positioning because the methods and measures used to explore it have been largely top-down. To reiterate: the dominant construct of empowerment understands self-management

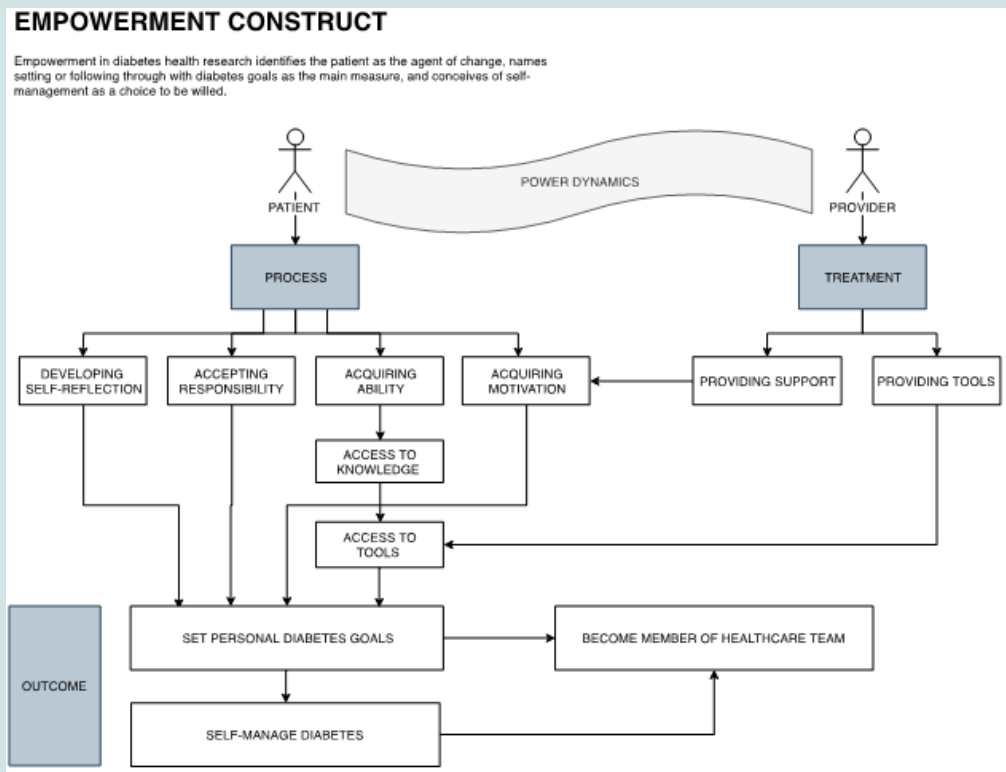


Figure 1: Empowerment Construct: Visual Summary.

as a set of strategies that once adopted will move a patient to change their health behaviors. However, as is noted in sociocultural-focused diabetes studies, self-management does not happen in a vacuum [16,40,41]. Socially, the interventions for improving self-management through empowerment principles, like action-planning, goals setting, and problem solving [37,38], identifying and addressing personal challenges [39], and integrating coping strategies [40], actually work to authenticate the stigmatization faced by people with diabetes. That is, it suggests that the location of the problem of poor management lies within the abilities, attitudes, and beliefs of individuals. When our empowerment research fails to account for the social and community aspects of power, they also fail to challenge dominant discourses and inequities actively reproducing power differentials. This stigma-reproducing dynamic has been shown to negatively impact research recruitment in minority populations, as well [41].

Calling For More Participatory Methods

In part, previous research on empowerment has failed to address social concepts of power and positioning because the methods and measures used to explore it have been largely top-down. To reiterate: the dominant construct of empowerment understands self-management as a set of strategies that once adopted will move a patient to change their health behaviors. However, as is noted in sociocultural-focused diabetes studies, self-management does not happen in a vacuum [16,42,43]. As such, the dominant construct of empowerment and the ways in which we study it must shift to better reflect the rich lived-experiences of this population. From a

community perspective, being empowered is politicized when the individual focus expands into the public/community sphere [4]. Empowerment, therefore, is an emancipatory construct when rooted in community experience. Where we see overlap between clinical and community-based definitions and constructs of empowerment comes by way of the central aim: mobilization.

Within diabetes online communities (DOC), 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[42], mobilization looks like social media-based social movements through hash tags, the formation of grassroots organizations, and public outcries in response to stigmatizing media portrayals of diabetes.

While clinical and behavioral benefits have been identified [43,44], the psychosocial [45,46], and community benefits are the cornerstone of DOC participation [47-49].

Events and meet ups within DOCs are abundant, as are calls to influence diabetes research and outcomes by initiating and co-designing workshops and collaborative events like those hosted by diabetes community organizations, Diabetes Mine, The Diabetes Empowerment Summit, Diabetes Patient Advocacy Coalition (DPAC), Diabetes Social Media Advocacy (DSMA), We Are Diabetes, The College Diabetes Network, Diabetes Sisters, and more.

DOC users have also actively advocated against research methodologies which focus exclusively on summative metabolic

measurements pre- and post- intervention research. The hemoglobin A1C is a blood test which measures the concentration of glycated hemoglobin in the blood, representative of an individual's 3-month average blood glucose level. A1C is the most commonly used clinical measure of glucose and is often used in the context of how well someone is managing their diabetes in research. In response, members across DOCs initiated a conference called "Beyond A1C" bringing together stakeholders, including researchers and professional organizations, to generate research ideas for measuring change beyond A1C [50]. Within diabetes online communities (DOCs), 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 [44], mobilization looks like social media-based social movements through hash tags, the formation of grassroots organizations (like Insulin4All), and public outcries in response to stigmatizing media portrayals of diabetes. While clinical and behavioral benefits have been identified [45,46], the psychosocial [47,48], and community benefits are the cornerstones of DOC participation [49-51].

Events and meet ups within DOCs are abundant, as are calls to influence diabetes research and outcomes by initiating and co-designing workshops and collaborative events like those hosted by diabetes community organizations, Diabetes Mine, The Diabetes Empowerment Summit, Diabetes Patient Advocacy Coalition (DPAC), Diabetes Social Media Advocacy (DSMA), We Are Diabetes, The College Diabetes Network, Diabetes Sisters, and more.

DOC users have also actively advocated against research methodologies which focus exclusively on summative metabolic measurements pre- and post- intervention research. The hemoglobin A1C is a blood test which measures the concentration of glycated hemoglobin in the blood, representative of an individual's 3-month average blood glucose level. A1C is the most commonly used clinical measure of glucose and is often used in the context of how well someone is managing their diabetes in research. In response, members across DOCs initiated a conference called "Beyond A1C" bringing together stakeholders, including researchers and professional organizations, to generate research ideas for measuring change beyond A1C [52]. This example demonstrates that diabetes online communities are actively interested and involved in ensuring research methods make sense to their lived experience, in itself an act of social empowerment .

Patients with diabetes who post diabetes-related content online are actively engaging in self-empowerment by inserting their argument into the research process and agenda, making the need for a measure of social validity paramount. When measuring social validity, researchers ask what is the social importance and community acceptability of this study and the resulting findings [51]?[53]? Including a measure of social validity would add to the knowledge produced by the field and allow findings to be translated into the real-world more seamlessly. However, this is not enough. The historical movement away from reliance on metabolic outcomes and toward psychosocial ones in diabetes is an indication that making a more drastic shift is a possibility [38,40].

Methodological Gaps

To quell the over-reliance of individually-based measures of empowerment predominantly used in the diabetes space, more

participatory frameworks are needed. When methods incorporate participatory elements, the scope and concepts of what empowerment means to communities will shift. It will become more possible for research to build capacity within communities by recognizing the potential importance of identification with the group as a form of stigma management. Rather than seeing diabetes empowerment as a form of self-efficacy to be gained by individuals, it can be translated more into a process of creating or shifting power toward the diabetes community as a whole. Some studies have done this by inviting influencers of varying levels in social media spaces relevant to their study populations to engage with the research [52]. One recent study argues that beyond increasing the social validity of a study, engaging with influencers through participatory design facilitates the flow of information about the study and its subsequent findings [53,54]. One recent study argues that beyond increasing the social validity of a study, engaging with influencers through participatory design facilitates the flow of information about the study and its subsequent findings [55]. What's more, participatory frameworks are also often paired with social change.

The spirit of participatory action research is based on the concept of participation and change theorized by Paulo Freire [54,56]. 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" [55,57]. Not only are community members included as partners in the research process using this framework, they also may more directly benefit. Participatory action research has been regaled 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" [56,58].

There are examples beyond diabetes literature which embrace the concept of empowerment as a process of creating or shifting power in the health fields. One Australia-based study which used a participatory design, brought together individuals from patient, advocacy, industry, tech, research, and academic stakeholder groups to ask "What is currently working and not working in digital health in Australia?" and "Where should digital health go in the future?" [57,59]. By virtue of its design, this study actively engages patients in empowerment principles by giving them a seat at the table - something we need to see more of as we reimagining empowerment within diabetes research and care [60,61].

Reimagining Empowerment in Diabetes

It is imperative we use strategies intended to mobilize the community when selecting participatory action research methods, rather than those which perpetuate stigmatizing representations of a diabetic person as lazy or unwilling to self-care. We acknowledge that diabetes advocates in online spaces are already actively calling for a more nuanced construct of empowerment, one which implicates social conditions and inequities they face in their daily lives. We call researchers in the fields of health, healthcare, and health services to move toward participatory study designs which consider and acknowledge online diabetes advocates so that we may collectively reimagining diabetes empowerment.

References

1. Peyrot MF (2001) Theory in Behavioral Diabetes Research. *Diabetes Care* 24: 1703-1705.
2. Nicolucci A, Kovacs Burns K, Holt RIG, Comaschi M, Hermanns N, et al. (2013) Diabetes Attitudes, Wishes and Needs second study (DAWN2TM): Cross-national benchmarking of diabetes-related psychosocial outcomes for people with diabetes. *Diabet Med* 30: 767-777.
3. Baek R, Tanenbaum M, Gonzalez JS (2014) No Diabetes Burden and Diabetes Distress: the Buffering Effect of Social Support. *Ann Behav Med* 48: 145-155.
4. Walker HR, Litchman ML (2021) Diabetes Identity: A Mechanism of Social Change. *Qual Health Res* 31: 913-925.
5. Hilliard M, Sparling K, Hitchcock J, Oser TK, Hood KK (2015) The Emerging Diabetes Online Community. *Curr Diabetes Rev* 11: 261-272.
6. Anderson RM, Funnell MM, Fitzgerald JT (2000) The diabetes empowerment scale: A measure of psychosocial self-efficacy. *Diabetes Care* 23: 739-743.
7. Funnell MM, Anderson RM, Arnold MS, Barr PA, Donnelly M, et al. (1991) Empowerment: An Idea Whose Time Has Come in Diabetes Education. *Diabetes Educ* 17: 37-41.
8. Funnell MM, Anderson RM (2004) Empowerment and Self-Management of Diabetes. *Clin Diabetes* 22: 123-127.
9. Anderson RM, Funnell MM (2010) Patient empowerment: Myths and misconceptions. *Patient Educ Couns* 79: 277-282.
10. Henshaw L (2006) Empowerment, diabetes and the National Service Framework: a systematic review. *J Diabetes Nurs* 10: 128-135.
11. Meetoo D, Gopaul H (2005) Empowerment: giving power to people with diabetes. *J Diabetes Nurs* 9: 28-32.
12. Fumagalli LP, Radaelli G, Lettieri E, Bertele P, Masella C (2015) Patient Empowerment and its neighbours: Clarifying the boundaries and their mutual relationships. *Health Policy (New York)* 119: 384-94.
13. Feste C, Anderson RM (1995) Empowerment: from philosophy to practice. *Patient Educ Couns* 26: 139-144.
14. Clifford SA (2013) A Narrative Inquiry of Self Advocacy: Rethinking Empowerment from Liberal Sovereignty to Arendtian Spontaneity. *Disabil Stud* 33: 3.
15. Asimakopoulou K, Newton P, Sinclair AJ, Scambler S (2012) Health care professionals' understanding and day-to-day practice of patient empowerment in diabetes; time to pause for thought? *Diabetes Res Clin Pract* 95: 224-229.
16. Chaufan C, Constantino S, Davis M (2013) 'You Must Not Confuse Poverty with Laziness': A Case Study on the Power of Discourse to Reproduce Diabetes Inequalities. *Int J Heal Serv* 43: 143-166.
17. Walker HR, Frazer BC (2021) The metanarrative of diabetes: Should you be eating that? In: Bolt D, ed. *Metanarratives of Disability: Culture, Assumed Authority, and the Normative Social Order*. New York and London: Routledge Taylor and Francis Group 156-68.
18. Asimakopoulou K, Gilbert D, Newton P, Scambler S (2012) Back to basics: Re-examining the role of patient empowerment in diabetes. *Patient Educ Couns* 86: 281-283.
19. Anderson RM, Funnell MM, Fitzgerald JT, Marrero DG (2000) The Diabetes Empowerment Scale. *Diabetes Care* 23: 739-743.
20. Sousa MR, Almeida M, Loureiro H, Martins T (2019) Study of the Psychometric Properties of the Diabetes Empowerment Scale Short Form (DES-SF). *Port J Public Heal* 37: 66-72.
21. Jahanpeyma P, Karaman E, Yildirim Y, Sahin S, Aykar FS, et al. (2020) Adaptation of Diabetic Empowerment Scale-Short Form to Older Individuals and to Turkish Language: Validity and Reliability Study. *Eurasian J Med* 52: 120-125.
22. Kaveh N, Jokar F, Ziaeirad M (2021) Psychometric Assessment of the Diabetes Empowerment Scale among Iranian Adolescents with Type 1 Diabetes. *Int J Pediatr* 9: 13349-13358.
23. Seekins T, White GW (2013) Participatory Action Research Designs in Applied Disability and Rehabilitation Science: Protecting Against Threats to Social Validity. *Arch Phys Med Rehabil* 94: S20-S29.
24. Seekins T, White GW (2013) Participatory action research designs in applied disability and rehabilitation science: Protecting. *Arch Phys Med Rehabil* 94: S20-S29.
25. Blandford A, Gibbs J, Newhouse N, Perski O, Singh A, et al. (2018) Tutorial Seven lessons for interdisciplinary research on interactive digital health interventions. *Digit Health* 1: 1-13.
26. Zoffmann V, Kirkevold M (2012) Realizing Empowerment in Difficult Diabetes Care: A Guided Self-determination Intervention. *Qual Health Res* 22: 103-118.
27. Naccashian Z (2014) The Impact of Diabetes Self-Management Education on Glucose Management and Empowerment in Ethnic Armenians With Type 2 Diabetes. *Diabetes Educ* 40: 638-647.
28. Anderson BJ, Funnell MM (2005) The Art of Empowerment. In: *American Diabetes Association*. Alexandria..
29. Whitney E, Kindred E, Pratt A, O'Neal Y, Harrison RCP, et al. (2017) Culturally Tailoring a Patient Empowerment and Diabetes Education Curriculum for the African American Church. *Diabetes Educ* 43: 441-448.
30. Castillo A, Giachello A, Bates R, Concha J, Ramirez V, et al. (2010) Community-based Diabetes Education for Latinos: The Diabetes Empowerment Education Program. *Diabetes Educ* 36: 586-594.
31. Peña-Purcell NC, Boggess MM, Jimenez N (2011) An Empowerment-Based Diabetes Self-management Education Program for Hispanic/Latinos. *Diabetes Educ* 37: 770-779.
32. Sugiyama T, Steers WN, Wenger NS, Duru OK, Mangione CM (2015) Effect of a community-based diabetes self-management empowerment program on mental health-related quality of life: a causal mediation analysis from a randomized controlled trial. *BMC Health Serv Res* 5: 115.
33. Charlton J (2000) *Nothing about us without us: Disability oppression and empowerment*. Berkeley University of California Press.
34. Bock S (2017) Contextualization, Reflexivity, and the Study of Diabetes-Related Stigma. *J Folk Res* 49: 153-178.
35. Liu NF, Brown AS, Younge MF, Younge MF, Guzman SJ, et al. (2017) Stigma in People With Type 1 or Type 2 Diabetes. *Clin Diabetes* 35: 27-34.
36. Tak-Ying Shiu A, Kwan JJY-M, Wong RY-M (2003) Social stigma as a barrier to diabetes self-management: implications for multi-level interventions. *J Clin Nurs* 12: 149-150.
37. Cheng L, Sit JWH, Choi K-C, Chair S-Y, Li X, et al. (2018) Effectiveness of a patient-centred, empowerment-based intervention programme among patients with poorly controlled type 2 diabetes: A randomised controlled trial. *Int J Nurs Stud* 79:43-51.
38. Tang TS, Funnell MM, Brown MB, Kurlander JE (2010) Empowerment Self-management support in "real-world" settings: An empowerment-based intervention. *Patient Educ Couns* 79: 178-184.
39. Zoffmann V, Kirkevold M (2012) Realizing Empowerment in Difficult Diabetes Care. *Qual Health Res* 22: 103-118.
40. Khazrai YM, Buzzetti R, Del Prato S, Cahn A, Raz I, et al. (2015) The addition of e (Empowerment and Economics) to the ABCD algorithm in diabetes care. *J Diabetes Complications* 29: 599-606.
41. Mitchell S, Bragg A, Moldovan I, Woods S, Melo K, et al. (2021) Stigma as a Barrier to Participant Recruitment of Minority Populations in Diabetes Research: Development of a Community-Centered Recruitment Approach. *JMIR Diabetes* 6: e26965.
42. Joensen LE, Filges T, Willaing I (2016) Patient perspectives on peer support for adults with type 1 diabetes: a need for diabetes-specific social capital. *Patient Prefer Adherence* 10: 1443-1451.

ISSN: 2475-5591

43. Rock M (2005) Classifying Diabetes; or, Commensurating Bodies of Unequal Experience. *Public Cult* 17: 467-486.
44. Litchman ML, Walker HR, Ng AH, Wawrzynski SE, Oser SM, et al. (2019) State of the Science: A Scoping Review and Gap Analysis of Diabetes Online Communities. *J Diabetes Sci Technol* 13: 466-492.
45. Litchman ML, Edelman LS, Donaldson GW (2018) Effect of Diabetes Online Community Engagement on Health Indicators: Cross-Sectional Study. *JMIR Diabetes* 3:e8.
46. Vaala SE, Hood KK, Laffel L, Kumah-Crystal YA, Lybarger CK, et al. (2015) Use of Commonly Available Technologies for Diabetes Information and Self-Management among Adolescents With Type 1 Diabetes and Their Parents: A Web-Based Survey Study. *Interact J Med Res* 4: e24.
47. Fergie G, Hilton S, Hunt K (2016) Young adults' experiences of seeking online information about diabetes and mental health in the age of social media. *Heal Expect* 19: 1324-1335.
48. Rasmussen B, Dunning P, O'Connell B. Young women with diabetes: using Internet communication to create stability during life transitions. *J Clin Nurs* 16: 17-24.
49. Greene JA, Choudhry NK, Kilabuk E, Shrank WH (2011) Online social networking by patients with diabetes: A qualitative evaluation of communication with Facebook. *J Gen Intern Med* 26: 287-292.
50. Litchman ML, Rothwell E, Edelman LS (2018) The diabetes online community: Older adults supporting self-care through peer health. *Patient Educ Couns* 101: 518-523.
51. Brady E, Segar J, Sanders C (2016) "I Always Vet Things": Navigating Privacy and the Presentation of Self on Health Discussion Boards Among Individuals with Long-Term Conditions. *J Med Internet Res* 18: e274.
52. Cefalu WT (2018) Need for Regulatory Change to Incorporate Beyond A1C Glycemic Metrics. *Diabetes Care* 41: e92-e94.
53. Foster SL, Mash EJ (1999) Assessing social validity in clinical treatment research: Issues and procedures. *J Consult Clin Psychol* 67: 308-319.
54. Wentzell K, Walker HR, Hughes AS, Vessey JA (2021) Engaging Social Media Influencers to Recruit Hard-to-Reach Populations. *Nurs Res* 70: 455-461.
55. Lutkenhaus RO, Jansz J, Bouman MP (2019) Tailoring in the digital era: Stimulating dialogues on health topics in collaboration with social media influencers. *Digit Health* 5: 1-11.
56. Khan KS, Bawani SAA, Aziz A (2013) Bridging the gap of knowledge and action: A case for participatory action research (PAR). *Action Res* 11: 157-175.
57. Flicker S, Maley O, Ridgley A, Biscope S, Lombardo C, et al. (2008) e-PAR: Using technology and participatory action research to engage youth in health promotion. *Action Res* 6: 285-303.
58. Hammel J, McDonald KE, Frieden L (2016) Getting to Inclusion: People With Developmental Disabilities and the Americans With Disabilities Act Participatory Action Research Consortium. *Inclusion* 4: 6-15.
59. Lupton D (2017) How does health feel? Towards research on the affective atmospheres of digital health. *Digit Health* 3:2055207617701276.
60. Bandura A (1982) Self-efficacy mechanism in human agency. *Am Psychol* 37:122-147.
61. Greenwood DA, Litchman ML, Ng AH, Gee PM, Young HM, et al. (2019) Development of the Intercultural Diabetes Online Community Research Council: Codesign and Social Media Processes. *J Diabetes Sci Technol* 13: 176-186.