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The Address of Psychological Impacts of Diabetes in MEND's Diabetes

Health Education Program

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**Abstract**

With a large population of their community facing diet-related illnesses, a non-profit organization in Pacoima, California, Meet Each Need with Dignity (MEND), attempts to alleviate the stressors of diabetes on these individuals through their educational programs. While their Diabetes Health Education seems to address the physical health component of diabetes, this research was conducted to explore how MEND is addressing the psychological component to this disease. As MEND's clients fall under the governmental poverty line, affecting their access to healthcare, MEND serves as a source of relief and hope for individuals facing hardship. This position of opportunity MEND holds to leave a sustainable impact on these individuals is endless and should be utilized to create positive changes within these individuals.

The Address of Psychological Impacts of Diabetes in MEND's Diabetes  
Health Education Program

### **Introduction**

In California, over four million people suffer from diabetes and, despite that excessive number, that does not begin to account for those who have diabetes and simply do not know it (In My Community: Southern California). As diabetes plays a conducting role in one's life, how an individual manages their disease and their disease perception are core components related to their quality of life. The ways in which individuals interact with their disease, how they view their role in controlling it, and how they allow others to influence their adherence to treatment all impact an individual's coping with this lifelong illness. When diagnosed with diabetes, the individual's ability to produce and respond to insulin, a hormone that impacts metabolism and blood sugar levels, is impaired. While this disease is often spoken about as a function of a physical reaction within one's body, the role that diabetes has on a person's mental health needs to be addressed in order to understand how they can cope with the life altering disease and make the necessary lifestyle changes to improve their quality of life.

In Pacoima, California, located in the northern San Fernando Valley, Meet Each Need with Dignity (MEND), a nonprofit organization with a mission to break the bonds of poverty through a pathway towards self reliance, is attempting to address diabetes within its community. Due to the fact that approximately 48% of MEND's client base suffers from a weight-related illness, MEND offers a Diabetes Health Education program that looks to address the physical symptoms of diabetes, specifically reducing the blood sugar levels within participants. While the physical aspects of this Diabetes Health Education program cannot be overlooked in attempting to manage their disease, how the topic is addressed and presented to their clientele has the

potential to lead to more efficient management of diabetes and greater overall quality of life for these individuals. In order to truly benefit participants and leave a sustained impact on their lifelong journey with this disease, MEND's program must address how diabetes adds additional mental health stressors to the lives of individuals impacted by the disease, as well as how to mediate these stressors. This current research looks to understand how MEND is addressing the psychological impacts of diabetes within their Diabetes Health Education program.

### **Literature Review**

Playing a significant role in a person's life, diabetes holds a notably large impact on an individual's physical and psychological health. While the majority of the discussion around diabetes focuses on the physical side of the disease, addressing the psychological component to diabetes is vital to have a true sustainable impact on the individual and their lifestyle. In addition to increasing blood sugar levels and other physical factors affected by diabetes, the disease often brings along the struggle of diabetes distress, mood and anxiety disorders, and issues with self-management and adherence to treatment. Due to the fact that many diabetes education programs lack sufficient address of the mental health aspects of coping with a life of diabetes, individuals are often unable to live out their best quality of life and make the changes necessary to cope with a life of illness.

While diabetes is often comprehended as a physical disease, it impacts the psychological health of those diagnosed with as well. As individuals are diagnosed with diabetes, they often face diabetes distress as the demands of the disease for self-management and emotional adjustment leave individuals struggling with new burdens and worries that affect their daily life through self-care as well as their interpersonal interactions (Berry, Lockhart, Davies, Lindsay, & Dempster, 2015). Diabetes distress affects as many as 40% of people diagnosed with diabetes

and the numbers are shown to grow over time (Berry et al., 2015). Along with diabetes distress, individuals faced with diabetes encounter a higher prevalence of depression if left uncontrolled, compared to those who work towards management of their disease (Anderson, Freedland, Clouse, & Lustman, 2001). The interaction between diabetes and depressive symptoms has the potential to lead to significantly worse adherence to treatment and regimens as an individual's ability to cope with their disease in their daily life is affected by their personal concepts of competency, efficiency, and coherence (Katon, 2010; Due-Christensen, Hommel, & Ridderstråle, 2016). Additionally, there is a significant association between diabetes and mood and anxiety disorders (Lin, Von Korff, & WHO WMH Survey Consortium, 2008). That being said, all of these impacts on psychological health need to be addressed in order to efficiently and comprehensively discuss the role of diabetes in a person's life.

While many psychological theories look to explain the relationship between patients and their behavior in relation to their disease, the self-regulation theory specifically provides a useful framework to understanding how individuals develop their own personal models of their disease. This framework is helpful in terms of comprehending how individuals perceive their disease and how it impacts their ability to cope. Functioning as a component of the social cognitive theory, the self-regulation theory supposes that patients develop their own models of their condition, the severity, and how it will impact their life, all of which affect their coping strategies (Chew, Shariff-Ghazali, & Fernandez, 2014). With the understanding that individuals are located at the center of this theory, self regulation proposes that all actions and motivations are done because they are beneficial, self-constructive, pro-social, and respectable (Chew et al., 2014). When individuals receive positive feedback self-love arises, however, when there is a mismatch of standards and performance, depression or hopelessness often transpire (Chew et al, 2014). The

self-regulation theory shows the need for a positive increase in self-efficacy, self-esteem, and resilience within patients in order to see lasting, sustainable changes in their lifestyle habits and improvements (Chew et al, 2014). Self-regulation theory places a significant amount of desired change as a function of the individual and, while the physical aspects are essential, when addressing diabetes, sustainable impacts will not occur without addressing the intrinsic motivations of individuals first.

Self-efficacy, a concept embedded in the self-regulation theory addresses one's self-confidence or their belief in their own ability to carry out and overcome tasks they perceive as inherently difficult or complex. Albert Bandura's social learning theory allows a connection to be drawn between self-efficacy and disease perception. Bandura's theory addresses how feelings of self-efficacy are vital to one's ability to cope (1986). In addition, Chew et al. discuss how higher self-efficacy leads to a positive self-feedback and, therefore, leads to higher goals in their progressive efforts (2014). With a goal to increase self-confidence, thought to grow through experiences, Johnson concludes that how individuals attribute value to experiences impacts how they cope in situations and their levels of satisfaction following outcomes (2002).

Despite the challenges faced by individuals diagnosed with diabetes, social and peer support are often linked to improved management of their illness. The social support theory explores how supportive social networks have the possibility to positively improve motivation, coping, and the overall psychological well-being of individuals when it comes to diabetes (Gallant, 2003). While greater levels of social support are linked to better self-management within individuals coping with diabetes (Gallant, 2003), a lack of social support from family members, friends, and healthcare providers can be tied to an increased level of distress in individuals (Berry et al., 2015). In addition to the increased benefits of social support outside of

educational programs, peer support methods within diabetes education programs themselves often allow individuals to share the burdens of their disease and personal self-management strategies that allow them to overcome barriers to successful management of their disease and improve their overall well-being (Due-Christensen et al., 2016). This experience presented by educational programs to connect with peers offers an opportunity to feel recognized for their challenges with their disease and share their experiences with others faced with the same burdens (Due-Christensen et al., 2016). Increased social support has the possibility to prevent individuals from feeling like an outsider around their healthy loved ones. In addition to the social support theory, the social learning theory dives deeper into the specific roles peers can play, helping individuals develop habits by seeing behaviors and adopting them, receiving reinforcement for good behavior. The social learning theory promotes credibility, empowerment, and reinforcement, all of which promote their good behavior and improves their self-efficacy (Bandura, 1986).

The current state of diabetes health education programs does not sufficiently address the cognitive affective side to coping with the illness. Despite the recommendation for the utilization of structured diabetes education programs by National Institute for Health and Care excellence, the majority, if not all, of the diabetes education programs lack an emphasis on emotional struggles faced by both the individual as well as their families (Berry et al., 2015). In order to improve the quality of life of those faced with diabetes, previous research done by Claiborne and Massarro (2001) suggests enhancing mental health assessments and services in diabetes programs and primary care settings has the potential to increase coping abilities and overall functioning. While psychological support for individuals with diabetes is generally insufficient due to the complex nature of the healthcare system (Chew et al., 2014), formal educational



diabetes interventions will lack efficacy if they continue to fail to incorporate psychological processes and emotional factors of the illness into their curriculum (Berry et al., 2015). Despite the lacking address of the psychological component in educational programs, Chew et al. discussed the potential that arises with the introduction of positive psychological health; not only does allow for sustained, long-term coping efforts, but also protection from negative outcomes that are associated with the diseases, such as prolonged emotional issues and illness perception, all of which lead to better self-management behaviors and overall better physical health. This current research looks to address the possible gap in MEND's programming and attention to diabetes to promote positive psychological health in participants in a more impactful manner. Specifically, this research looks at the address of

### **Method**

The research objective of this current study was to explore the address of psychological impacts of diabetes on participants within MEND's Diabetes Health Education program. Due to the role of MEND as a community partner in completing this research, a community-based participatory research approach was utilized to incorporate the active voice of community members, organizational representatives, as well as the researchers in the research process (Israel, Schulz, Parker, & Becker, 2001).

To carry out this research, a series of seven interviews took place among six participants of MEND's Diabetes Health Education program and one MEND's staff member involved in the programming and logistics of their diabetes program. Participants of MEND's program who served as interviewees for this study were required to have gone through at least four complete weeks of the program to ensure they had enough time to comprehend the meanings and the outcomes of

program on their lives. Participants that served as informants of the research were recruited with the help of MEND's medical staff who identified individuals who met the criteria for the study. All potential informants were contacted by phone, explained the basis of the research, and explained that their role would be primarily sharing their experiences in the program as well as their takeaways. They were informed that their participation in the study would not only serve as beneficial in the academic setting, but also for MEND's future programming of the Diabetes Health Education program. If the participant agreed to taking part in the study, a time was set up to conduct a 20 to 30 minute interview in person at MEND's medical clinic or over the phone.

Interviews with participants utilized a semi-structured interview style, allowing the voice of the participant to be heard and inform the data based on their stories and experiences. Interview questions addressed topics such as the role of social support, their perception of their disease and its controllability, and their quality of life. Conducting interviews on the participants of the program allowed for first hand insight of the program's impacts both physically and psychologically, as well as their perception of their disease as a factor in their life. Interviewing a member of the staff involved in the program provided insight of the intentions of the program and how the program design intended to address specific topics as they related to physical and mental health of the individuals within the program.

All interviews were audio recorded with the consent of the participants and later transcribed and translated into English word-for-word. Due to the fact that the majority of MEND's client base speaks primarily Spanish, both the transcription and translation were completed with the help of a UCLA student from the UCLA Spanish Department who received course credit for their involvement. Following transcription, the data was analyzed for themes of reliance, knowledge versus skill, positive mental health impacts, self-efficacy, empowerment,

and sustainability across participants. Participants involved in the data collection were given pseudonyms in order to maintain confidentiality.

### **Results**

For many individuals utilizing MEND's Diabetes Health Education program, MEND's Diabetes Health Education program, as well as the other services they offer to individuals serve as last sources of hope. Four out of six participants stated that their use of the program began as a result of a financial or healthcare related benefit. As these individuals face burdens both financially, needing to qualify under the governmental poverty line to utilize MEND's service, and medically, lacking advantages such as access to adequate healthcare, MEND's services offer these individuals a sense of relief and way to address the barriers of their disease.

According to the MEND staff member, the main goals of the Diabetes Health Education program are to lower the hemoglobin A1c levels in participants and lower the weight of participants by at least one body mass index (BMI) point. That being said, when asked where participants seem to fall short in terms of participant outcomes across cohorts, the MEND staff member, Rebecca, mentioned that they would like to see better behavioral changes and improvement physically in terms of hemoglobin A1c levels within participants. While these are not simple changes, if MEND's program is failing to reach its primary goals, the question becomes why or what else are they addressing? Based off the knowledge from the previous research, the importance of addressing both the physical and psychological aspects of diabetes is crucial to sustaining a positive impact on participants. Through the data collection, themes emerged of positive perception of diabetes control, the role of social support, increased desire to live, and an increased knowledge, but lack of skill.

### **Mental Health Outcomes of Participation**

### A) Perception and Management of Disease

Across the interviews the informants portrayed a positive shift in their perception of their disease and its role in controlling their life. At the beginning of their journey with their disease, informants mentioned they felt as if they were out of control and as though their disease governed their life. However, through their participation in the program, participants claimed that they began to feel as though there was a shift in the locus of control over the disease to them. This shift in their perception of how the disease plays a role in their life allowed individuals to take initiative in managing their diabetes.

All six participant mentioned they had an increase in self-management and control following their participation in the program. When asked about her perception of her diabetes, Julie stated that taking part in the program has changed her perception of the disease as she is aware that it does not define her life. She felt more focused on the positive, recognizing that the disease did not control her and she must move forward and keep going. Similarly, Anna and Lena mentioned that through their increasing understanding, they were able to little by little learn to take care of themselves on a daily basis. Anna added that one's ability to take care of themselves and cope daily is dependent on the individual's form of self-esteem. She said that she is now aware that her illness can be controlled and she can have a better life with the appropriate disease management. Compared to the feelings of despair and hopelessness that the individuals mentioned feeling upon diagnosis, during the interview, each one of the participants acknowledged that they feel more in control of their diabetes since beginning the program.

### B) Desire to Live

Upon diagnosis of their disease, all six participants mentioned their feelings of depression and despondency, feeling as though their will to live was being compromised. Through the

program as an intervention, one participant, Julie, mentioned more feelings of positive and a greater appreciation for life. She stated, "We are adults and sometimes we have a very closed mind and we say, 'anyway, I am going to die and I have to die of something,' but it's not like that. Life is very beautiful; one has to live, not for the people that surround you, but for oneself." Others discussed how they felt good when they were seeing positive results, but when they are not receiving the feedback they were expecting, they begin to trickle back into feelings of depression and begin to lose their course. The program has the potential to increase the willingness and desire to live in their participants, but there is a component missing that leads to a lack of sustainable change within participants.

### **Positive Comprehension of Social Support Role**

When asked about the role of social support within the curriculum, all of the six participants mentioned that it was a beneficial component to the classes. All individuals touched on how the peer support component of the program allowed them to gain a new perspective, but most importantly the comfort of not feeling like an outsider due to their disease. Julie and Megan mentioned the peer support component of the program was influential because they were able to learn from other individuals going through the same situation as they were. Additionally, Anna discussed how the peer support aspect allowed them to discuss everything from how they felt to strategies used to manage their disease, both of which gave her the sense that she had someone to talk to. Christina, Lena, and Benjamin all touched upon how the peer support component allowed them to learn about their peer's different experiences and the varying ways they taking care of themselves. Benjamin also continued to talk about how the peer support aspect helped him to feel comforted, supported, and motivated when dealing with his illness.

As discussed in the literature, both peer support within the educational setting as well as the social support from loved ones outside serve a beneficial role in coping with diabetes. Four of the six participants addressed the role of their personal support system, each discussing how the support allows them to be closer to their loved ones, but also how they bring another component of motivation to their diabetes management. Julie discussed her family's role in motivating her to eat healthier; she mentioned how the support of her children and partner were helpful as she was the only one with diabetes in her family. In order to support her, her family learned to eat like her, which not only ensured that she did not feel like an outsider, but also helped her family to make healthier choices about their behaviors. Christina and Anna both mentioned that their families were their motivation to continue working to better themselves and continue fighting to uphold their self-management so they can be present for their families. Megan spoke about her family's role in keeping her active, specifically how her young granddaughter inspires her: "I love to jump and my granddaughter that I have says: dance, dance, dance... Barely three years old and she says dance and move." Furthermore, Benjamin discussed how his participation in the program has inspired him to help those he is close to by providing information to them and being there for them like they are for him.

### **Knowledge Versus Skill**

Across participants, there was a drastic increase in the knowledge of diabetes and what it means for individuals as an outcome of participation in MEND's Diabetes Health Education program. All six participants mentioned that the program allowed them clarity of what diabetes was and how it impacted their lives. Megan mentioned the importance of gaining knowledge, stating that the program gave her, "more information... as I say, one goes crazy without the information." Additionally, Benjamin mentioned that despite all the knowledge he has gained, he

wants to learn more; he said that one never truly stops learning. Despite the vast knowledge that participants gained from MEND's program, they fail to attain the skills necessary to acquire self-reliance and make the necessary changes within their life for a sustainable control of their disease. While knowledge is extremely important, individuals should not be walking out with simply awareness, but also the skills necessary to pursue health behaviors and improve quality of life. In her interview, MEND's staff member, Rebecca, mentioned the importance and vitality of knowledge and awareness, but continued on to state the need to develop skills within participants based off this knowledge. Rebecca mentioned that the ability to foster these skills within participants will lead to a better sense of self-efficacy within them. Knowledge alone will lead to a short-term impact on individuals to understand what is going on around them, but will not promote long-term changes as they lack the skills necessary to do so.

### **Discussion**

MEND's Diabetes Health Education program seems to impact individuals positively in terms of offering an opportunity to gain confidence in their self-management, a connection to others, and expand their knowledge on diabetes. That being said, MEND lacks a rigorous address of the psychological impacts of diabetes and intentionality behind their discussion of mental health. With a lack of intentionality and lack of skills fostered within individuals, we see continued reliance on MEND and their Diabetes Health Education program. Individuals find comfort in the program and continue to utilize it as a means to survive in crisis mode, not developing their capability and skills to address their disease on their own. While the amount of time individuals have been attending the program varied across participants, one informant, Julie, mentioned that she has been attending the program for eight years. Individuals have become reliant on MEND's services and consistently refer to the fact that they do not know how

they would survive without the program and their services. This development of reliance upon the organization directly contradicts MEND's mission to great a pathway towards self reliance. Base on the previous literature, if MEND wants to leave a sustained impact on participants, they need to more rigorously address the psychological component of diabetes in addition to the physical component. Being more intentional behind their programing to implement internal changes within participants has the ability to allow for a long-term, rounded impact on individuals, allowing them to gain the necessary skills to be self-reliant and improve their quality of life.

To begin this shift towards a true pathway towards self-reliance, MEND should begin to transition from the traditional medical model used to address diabetes within the Diabetes Health Education program as centering the focus around physical goals does not inspire long-term motivational changes within participants. Without intrinsic motivation, individuals will falter when it comes to altering their quality of life despite their disease. Rather, the program needs to adopt an empowerment-person centered model that focuses on the discovery and development of an individual's capability to be responsible for their own life (Funnel et al., 1991). While patient empowerment may be an unintended outcome of MEND's program and other similar programs, empowerment should be an inherent goal of the program. **Funnel et al.** state that an individual becomes empowered when they have the knowledge, skills, attitudes, and self-awareness necessary to improve their behaviors and their quality of life (1991). Adopting this model can also help individuals develop the framework to make the connection between their knowledge and skills. Once individuals have the tools to understand their role in terms of their disease, this model helps them utilize their personal goals to develop skills and see changes. By promoting individual's strengths, informed choices, and personal goals, MEND has the ability to leave a



sustainable impact on individuals through empowerment and, in turn, improve self-efficacy and overall quality of life.

Civic engagement encompasses what it means to a member of society for each individual as a whole. Subjected to systemic issues, such as poverty, MEND's clients are faced with daily burdens and unjust treatment by society. That being said, an individual's health is a basic component of human life and should not be dismissed when it comes to the possibility of its improvement. Serving as a last source of hope to these individuals, MEND has the opportunity to truly work to change the situations of these participants and move them down a pathway towards self-reliance. However, MEND needs to utilize this opportunity in a way that looks to the ways they can improve these core components of their program to allow a comprehensive and intentional address of both physical and mental health in a holistic manner, providing individuals with a chance to live out their best quality of life despite their disease.

The current study faced many limitations within the research process, primarily during the data collection process. One main limitation faced during the research presented itself through language barriers. With a client base that spoke primarily Spanish, conducting interviews meant relying on an outside source for the actual data collection process as well as translation and transcription of interviews. Additionally, the translation from Spanish to English inherently meant that certain details and important connotations about informant's answers were lost in translation. In addition to the language barriers, with the majority of the client base at MEND identifying as Latino, there were inherent cultural barriers that may have been looked past. Both of these barriers led to an increased role of coming into the community as an outsider performing research. While use of the UCLA's Spanish Department who guided the data collection process served as beneficial in this process, both the use of a translator during the

interviews as well as the outsider role most likely led to lack of comfort and lack of openness for participants. Along with language and cultural barriers, MEND's Diabetes Health Education program faced programmatic issues in terms of their instruction and their program retention. Utilizing a Kaiser Permanente curriculum to address Diabetes, MEND must rely on a Kaiser employee to volunteer at MEND to teach their program. Facing health issues, the current instructor of the Diabetes Health Education program had to take time away from their volunteer role at MEND, leaving MEND with no instructor for the program. Additionally, the program faces major retention issues as individuals find themselves needed to put their health second to providing for their family. The lack of instructor and major retention issues in the Diabetes Health Education program led to the current cohort at the time of this study to be cancelled. Despite these limitations, the results of this current research has major implications for the role of MEND in addressing serious, systemic issues of poverty.

### **Conclusion**

This current research highlights the need for MEND to address the impacts of diabetes on an individual's psychological health in addition to focusing on the impact of physical health. The results of this study underline the necessity of both a rigorous address of diabetes within their program, but also an overall increase in intentionality behind their address of the topic in order to leave a sustainable impact on individuals. Seen through the individual's mental health outcomes, both positive, yet unsustainable, as well as their lack of skill development despite their increase in knowledge, MEND is having a significant impact on these individuals, however, their impact is not as comprehensive as it could be. Attempting to create a pathway towards self-reliance to break the bonds of poverty, MEND needs to begin focusing on empowering individuals and inspiring their intrinsic motivation from within to address diabetes with more impact. An

individual's physical and psychological health function as basic human rights and should not be compromised or jeopardized by the systemic issues within society.

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