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Running head: DIABETES IN THE IMPOVERISHED POPULATION; HOW CAN WE HELP?

Diabetes in the Impoverished Population; how can we help?

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### Abstract

**Purpose:** Diabetes mellitus presents a major disease burden globally. This project set out to discuss the experiences of living with diabetes with a group of low-income patients with poorly controlled diabetes at a particular clinic to determine barriers to care that they face. Responses were analyzed to determine if diabetes self-management education (DSME) would be an approach sufficient to address the needs of these patients.

**Methods:** Clinic staff selected 15 patients from a pool of patients diagnosed with diabetes that had been designated by the clinic as low-income and poorly-controlled. These patients were interviewed using a series of 17 questions. Interviews were recorded and transcribed. Pertinent responses were selected from the text and moved to an Excel spreadsheet. Responses were then analyzed for thematic content.

**Findings:** Patient responses demonstrated existing barriers that they faced to controlling their diabetes. These barriers could be categorized under four areas that are specifically addressed by DSME. These areas can be described as improvement of disease based knowledge, emphasis on behavior change, increasing self-efficacy, and implantation of a support system.

**Conclusions:** While they might require an adapted approach that is culturally appropriate, patients at the participating clinic would benefit from an organized, structured DSME program.

### **The Clinical Problem**

The problem that this project seeks to address is whether Diabetes Self-Management Education (DSME) is an approach sufficient to overcome the barriers to care that beset impoverished diabetic patients of a particular clinic. DSME is an effective way to treat type 2 diabetes (Norris, Engelgau, & Narayan, 2001; Trento et al., 2004; Rachmani, Slavacheski, Berla, Frommer-Shapira and Ravid, 2005; Deakin, Cade, Williams and Greenwood, 2006; Davis et al., 2008; Brunisholz et al., 2014; Haas et al., 2014). Diabetes disproportionately affects low-income and racial and ethnic minorities (Sarkar, Fisher, & Schillinger, 2006; Peek, M.E., Cargill, A., Huang, E.S., 2007; Chow, Foster, Gonzalez & McIver, 2012). However, most DSME programs are developed to address the needs of patients with diabetes who have adequate income, high literacy, good social support systems, and readily available resources (Harris, Chamings, Piper and Levick, 2000). The purpose of this project is to interview patients at one clinic who have type 2 diabetes and live in poverty and collect data about their diabetes self-management experiences. The survey results will be reviewed to determine barriers and facilitators to diabetes care, and to make recommendations for implementation of a DSME program.

### **Literature Review**

A literature review was performed to explore the most recent and relevant data on DSME. Electronic searches were conducted using Ovid MEDLINE without Revisions 1996 to current. Search terms included the words: “Diabetes Mellitus, Type 2”, “diabetes complications”, “Self Care”, “Self-Management”, “Exercise”, “Exercise Therapy”,

“Exercise Movement Techniques”, “Physical Fitness”, “Health Behavior”, “Health Education”, “Counseling”, “Life Style”, “Risk Factors”, “Homeless”, “Group Visit”, and “Poverty.” One-hundred-twenty-four articles were found and of these sixteen were used for this literature review. The other ninety-nine were discarded because they did not provide insight or information about diabetes self-management education for type 2 diabetics seen in an outpatient setting. Additional articles were found through searching the bibliographies of these articles. Based on these extant data, the objectives of the literature review are to review the current literature regarding components of successful self-management programs for Type 2 Diabetes Mellitus and regarding what components are successful and effective with low-income patients.

### **Improvement of disease-based knowledge and emphasis on behavior change**

A DSME program, which increases knowledge about diabetes, provides patients with necessary skills for managing diabetes, and motivates patients to meet established goals, increases the likelihood that patients will be able to successfully control their diabetes. In the primary care setting, diabetes is managed using the three-pronged approach of diet, exercise and medication. Patients are encouraged to make changes in food intake, increase participation in acceptable forms of exercise, and adhere to a medication regimen prescribed by their provider. However, patients frequently do not fully understand the disease process of diabetes. Without this understanding, patients do not understand why diet, exercise and medication effectively treat their diabetes and thus frequently fall out of compliance with treatment recommendations.

The following group of studies gives strong examples of the effectiveness of DSME and the improved outcomes patients receive from participation in DSME. There were

similarities in the type of patient selected, data collection methods, and improvement in outcomes. Most studies divided participants into a control group, which received standard diabetes education through individual visits with their primary care providers, and an intervention group that received DSME in addition to standard education (Trento et al., 2004; Rachmani, Slavacheski, Berla, Frommer-Shapira and Ravid, 2005; Deakin, Cade, Williams and Greenwood, 2006; Davis et al., 2008; Brunisholz et al., 2014). Rachmani et al. (2005) built upon their study by providing each participant in the control group with an individualized plan of lifestyle modification and a fitness program. Davis et al. (2008) altered their study to ensure that results were not affected by the amount of time patients spent with providers/educators. In order to ensure that equal amounts of time were spent with each group, Davis et al. (2008) provided additional resources to control practices to ensure that patients were provided contact time with healthcare professionals equivalent to that provided for the intervention group. Intervention groups showed improved knowledge of diabetes (Trento et al., 2004; Davis et al. 2008). Trento et al. (2004) found that disease-based knowledge about diabetes worsened over time among patients in the control group. After receiving DSME, intervention groups also showed improved health outcomes such as lower blood pressure, HbA1c, and BMI, as well as improved lipid profiles (Trento et al., 2004; Rachmani et al. 2005; Deakin, Cade, Williams and Greenwood, 2006). Trento et al. (2004) found that the above health outcomes actually worsened over time in the control group. Deakin, Cade, Williams and Greenwood (2006) found that the intervention group experienced a reduction in waist circumference, a risk factor that has been linked to diabetes. For Davis et al. (2008), the intervention group showed a significant reduction in their 10-year risk estimate of coronary heart disease or

stroke. The intervention group also showed a significant reduction in tobacco use, increase in physical activity, and fewer symptoms of depression.

The outcomes of these studies demonstrate that DSME is associated with increased knowledge and health conscious behaviors. DSME helps patients control their diabetes and improve their overall quality of life through education, motivation to incorporate healthier behaviors into their lives, and reinforcement/remediation at regular intervals. The benefits gained by DSME are not short-lived, but continue to benefit patients for years afterwards (Trento et al., 2004; Rachmani et al. 2005). These studies also demonstrated that a traditional primary care approach to treating diabetes is associated with progressive deterioration of lab results, knowledge about diagnosis, and quality of life (Trento et al., 2004; Deakin, Cade, Williams and Greenwood, 2006). A structured DSME program that focuses on increasing knowledge and changing behaviors can produce greater improvements in outcomes than standard clinical education. Brunisholz et al. (2014) found that patients who received DSME were 1.5 times more likely to improve their health outcomes than patients who did not receive DSME. Increasing disease based knowledge, providing patients with an understanding of beneficial life style modifications and empowering them to participate more actively in their healthcare is useful in improving outcomes among type 2 diabetics. This acquisition of new knowledge and skills leads to improved self-care behavior. However, adherence to new self-care behaviors requires self-efficacy.

### **Increasing self-efficacy**

Self-efficacy is a term frequently used when discussing successful treatment of diabetes. The origin of the term is credited to Albert Bandura (1977) and refers to the

belief of individuals in their ability to perform the actions necessary to achieve specific goals. Self-efficacy is a reflection of a person's confidence, motivation, and feelings of control over his or her own environment. Without a sense of self-efficacy, any patient who endeavors to overcome diabetes will likely fail, regardless of the tools provided them by education and training. The judgment of self-efficacy may determine how much effort a patient will put into self-care. If a patient does not believe in their own ability to manage their disease, it is unlikely that they will adhere to treatment regimens. This is especially important when one considers that daily self-management is essential to the successful treatment of diabetes. A lack of self-efficacy will undermine the daily self-management activities that patients need to perform to overcome their disease.

There are many studies that establish the link between improving feelings of self-efficacy and improving self-management behavior. The following group of studies is a typical example and demonstrates the importance of self-efficacy in diabetes self-management. There were similarities between the studies in the method of data collection, which employed a questionnaire and an evaluation of the patient's lived experience with diabetes. Each study found that self-efficacy has a significant impact on adherence to treatment plans for diabetic patients such as blood glucose self-monitoring, physical activity, diet, and oral medication intake (Sarkar, Fisher and Schillinger, 2006; Mishali, Omer and Heymann, 2011; Al-Khawaldeh, Al-Hassan, & Froelicher, 2012; Gao et al., 2013). The researchers found significant positive correlations between the frequency of adherence to treatment recommendations and the self-efficacy rating of each patient according to the questionnaire. In addition to self-efficacy, Sarkar, Fisher and Schillinger (2006) used a questionnaire to measure health literacy and self-management

behaviors in patients with type 2 diabetes at two primary care clinics at a public hospital. They were able to demonstrate that self-efficacy was significantly associated with improved diet, exercise, blood glucose monitoring, and foot care. In addition, they were also able to demonstrate that race/ethnicity and health literacy did not influence the relationship between self-efficacy and self-management.

The findings of these studies demonstrate that presenting knowledge to patients alone is not as efficacious in improving treatment compliance and outcomes for diabetic patients as combining knowledge with the promotion of self-efficacy in a DSME program. Evaluating the patient's lived experience with diabetes and how they feel they are able to manage their disease can allow a provider to target specific barriers to improvement and create a more patient-centered plan of care. However, even with the acquiring of new knowledge, new skills and new confidence in their abilities, a patient's enthusiasm for diabetes self-management may flag. Thus it is important for patients to have a support system to turn to in times of fatigue and decreased motivation.

### **Implementation of a support system**

The idiom, "a problem shared is a problem halved" holds especially true for diabetes self-management. Heisler (2007) theorizes that patients need between-visit support to improve their ability to successfully sustain effective self-management behaviors. Although clinic-based diabetes services improve health outcomes, diabetic patients also benefit from support found outside the clinic. Patients report that developing a collaborative relationship with a healthcare provider and having a support person who gives encouragement and assistance are among the most effective strategies for facilitating self-management (Nagelkerk, Reick and Meengs, 2006).

The following studies look at the role that a support system plays in the maintenance of self-management practices for type 2 diabetics. Researchers (King et al. 2010; Gao et al. 2013) evaluated the amount of support each patient received from the health care team as well as the amount of support received from the broader community in which each patient lived. Gao et al. (2013) found that better provider-patient communication and having social support was associated with performing diabetes self-care behaviors. Findings from the study performed by King et al. (2010) indicated that while community support helped to improve patient outcomes, support from the health care team was not associated with improved clinical outcomes. Deakin, Cade, Williams and Greenwood (2006) used DSME as an opportunity to provide social support for their patients. The researchers conducted a randomized, controlled trial to test the effectiveness of a patient-centered, group-based DSME. After 14 months, the intervention group showed improved health outcomes over the control group. There are many examples where researchers have been able to demonstrate that group visits among diabetic patients are able to improve health outcomes in comparison to the traditional patient-physician dyad (Clancy, Huang, Okonofua, Yeager, and Magruder, 2007; Salinas-Martinez et al. 2009; Reitz, Sarfaty, Diamond, Salzman, 2012; Riley, 2013). These findings suggest that a network of social support may help patients with diabetes increase adherence to self-management practices and thus improve overall health outcomes. However, Heisler (2007) maintains that patients benefit most from peer support. A successful “peer” must have experiential knowledge of diabetes and similar characteristics as the patient.

The conclusions from these studies reinforce the report of the Institute of Medicine, that the provision of health care is not a solitary endeavor but requires a team approach

(Mitchell et al. 2012). DSME programs stand to benefit from recruiting outside assistance for patients with type 2 diabetes. This support can include family and friends of patients or peer support approaches in the form of face-to-face group meetings with peers, peer coaches or mentors, or telephone-based peer support. The shared experiences of diabetics managing their disease can create an environment from which patients can draw strength to persevere in times when their dedication to self-management begins to falter. If a clinic or provider is unable to recruit outside social support then social support could be included in a DSME program through the use of group-based education (Deakin, Cade, Williams and Greenwood, 2006).

DSME can be a successful way to treat diabetes in low-income, disadvantaged populations. When enrolled in a DSME program, low-income patients are able to increase disease-based knowledge and improve health outcomes related to diabetes (Brown et al., 2005; Balamurugan, Ohsfeldt, Hughes, & Phillips, 2006; Glazier, Bajcar,, Kennie, & Willson, 2006; Liebman, Heffernan, & Sarvela, 2007; Ryan, Jennings, Vittoria, & Fedders, 2012). There are studies that have been conducted to determine facilitators and barriers to care for low-income, diabetic patients, using different methods for data collection. Some studies used structured, one-on-one, qualitative interviews (Brewer-Lowry, Arcury, Bell, & Quandt, 2010; Shaw, Killeen, Sullivan & Bowman, 2011; Rendle et al., 2013; Winkley at al., 2015). Some studies used focus groups as their approach to patients. (Peyrot & Rubin, 2008; Onwudiwe et al, 2011). Marcy, Britton and Harrison (2011) administered an anonymous survey. However, data about barriers and facilitators was often gathered passively according to what was noted by researchers from a specific group of patients who were participating in a DSME program.

In low-income patients, researchers have identified many barriers to care that lead to poorer health outcomes. A commonly cited barrier to care is a deficit in disease-based knowledge (Nagelkerk, Reick and Meengs, 2006; Brewer-Lowry, Arcury, Bell, & Quandt, 2010; Onwudiwe et al. 2011). This finding typically coincides with a generally low level of health literacy commonly found in low-income patients (Onwudiwe et al., 2011; Ricci-Cabello et al., 2013). Knowledge deficits and low health literacy may be the result of poor memory and other cognitive challenges experienced by low-income patients (Levinthal, Morrow, & Tu, 2008; Von Wagner, Steptoe, Wolf, & Wardle, 2009). Additional knowledge deficits include a lack of knowledge about the existence and availability of DSME programs. Often this is due to a lack of availability of DSME programs within their community (Shaw, Killeen, Sullivan, & Bowman, 2011; Ryan, Jennings, Vittoria, & Fedders, 2012; Winkley et al., 2015). When DSME programs are available to patients, a lack of referrals from providers serves as a continual barrier to care (Harris, Chamings, Piper and Levick, 2000; Peyrot & Rubin, 2008; Kluding et al., 2010; Shaw, Killeen, Sullivan & Bowman, 2011; Ryan, Jennings, Vittoria, & Fedders, 2012; Winkley et al., 2015). Another common barrier to care in the low-income community is a lack of economic resources (Harris, Chamings, Piper and Levick, 2000; Nagelkerk, Reick and Meengs, 2006; Ryan, Jennings, Vittoria, & Fedders, 2012; Rendle et al., 2013). Low-income patients have competing demands and are forced to make choices about how to spend limited funds. Diabetes places a heavy financial burden on those who suffer from the disease and patients often have difficulty finding funds for expenditures like transportation, glucometer test strips and gym memberships. The most commonly cited financial burden faced by low-income diabetics is the cost of healthy

foods (Harris, Chamings, Piper and Levick, 2000; Marcy, Britton, & Harrison, 2011; Seligman, Jacobs, Lopez, Tschann, & Fernandez, 2012; Rendle et al., 2013; Frellick, 2015). Often patients cannot afford to purchase the kinds of healthy food options necessary for managing diabetes. This is of particular significance since poor diet leads to poor glycemic control which in turn leads to increased need for medication, thus putting a greater financial burden on the already impoverished patient. Attrition is often cited as a problem for DSME programs that target low-income patients. Low-income patients that are unemployed have time to attend DSME programs. However, those that are employed and considered “the working poor” can end up working long hours at low-wage jobs. According to the U.S. Bureau of Labor Statistics (2014), the term “working poor” describes anyone who, during the year, spent 27 weeks or more working but whose income still fell below the official poverty level. This leads to high attrition rates in DSME programs as patients drop out due to scheduling conflicts and difficulty with time management (Gucciardi, Demelo, Offenheim, Grace & Stewart, 2007; Gucciardi, DeMelo, Booth, Tomlinson, & Stewart, 2009; Ryan, Jennings, Vittoria & Fedders, 2012, Rendle et al., 2013) Other barriers to care come from the emotional and psychological stress of being poor and having diabetes (Pandit et al., 2014; Winkley et al., 2015). This stress can lead to a lack of motivation (Nagelkerk, Reick and Meengs, 2006) or a refusal to take responsibility for one’s own actions (Harris, Chamings, Piper and Levick, 2000). Stress can also lead to over-eating, unhealthy food choices and difficulty resisting the temptation to eat unhealthy food (Marcy, Britton, & Harrison, 2011).

In order to overcome the barriers faced by low-income patients, researchers found facilitators to assist in connecting patients with DSME and increasing its effectiveness. A

common facilitator to DSME is culturally appropriate curriculum (Glazier, Bajcar, Kennie, & Willson, 2006; Kluding et al., 2010; Spencer et al., 2011; Ryan, Jennings, Vittoria, & Fedders, 2012; DePue et al., 2013; Ricci-Cabello et al., 2013). In addition to materials printed in Spanish for the Hispanic community, providers must be aware of the cultural beliefs and difficulties with language some African-Americans experience (Ricci-Cabello et al., 2013). Another aspect of a culturally competent approach to low-income patients involves the use of community educators (Glazier, Bajcar, Kennie, & Willson, 2006; Spencer et al., 2011). Community educators should be culturally and ethnically similar to the patients who they assist and are educated in diabetes and methods of treatment. Community educators can even be called upon to make home visits or facilitate referrals to social services. Whether at visits in the clinic or at home, researchers found that frequent contact with educators, providers and coordinators enabled low-income patients to find the support they need to continue self-management of their diabetes (Glazier, Bajcar, Kennie, & Willson, 2006; Brewer-Lowry, Arcury, Bell, & Quandt, 2010; Spencer et al., 2011).

### **Methods**

A survey was administered to a sample of patients who have been diagnosed with Type 2 Diabetes Mellitus and were receiving healthcare coverage through the Oregon Health Plan. The survey comprised questions used in a similar survey that was used to explore the barriers and practices of low-income patients managing diabetes in safety-net clinics in Southern California (Rendle et al., 2013).

**Setting**

The clinic for which this project was developed is Richmond Clinic, a Federally Qualified Health Center. The clinic serves Medicaid and Medicare patients and offers a sliding fee discount to patients without insurance. Over twelve thousand patients visit Richmond annually and average approximately four visits per year (Kirk, 2015). Sixty percent of Richmond patients receive Medicaid, and another twenty percent receive Medicare. The clinic has a total of 120 staff members. There are thirty-two providers divided among four care teams. Providers in each team are either MDs, PAs, or FNPs. Each care team also contains the following: an RN Care Manager, a mental health professional, a Team Coordinator, a Clinical Pharmacist, and multiple MAs. Diabetes education and management is provided through individual visits with primary care providers and one-hour case management visits with RNs. Richmond Clinic has a growing pool of RNs to facilitate contact with diabetic patients. RNs provide education, coaching and insulin titration as needed. They also track patient engagement, number of coaching sessions and changes in A1c. Providers and RNs are able to track patients using electronic medical records and a Diabetes Registry. The care of the clinic's diabetic patients is overseen by a Population Health Care Manager who provides coaching and support to RNs. Team Coordinators perform outreach to schedule regular visits with RNs. If after 2 phone calls they are not able to reach a patient, then they will send a letter. The goal of the clinic is to have diabetic patients return every six months or if A1c > 8, every three months.

In order to show how well they are improving care, making quality care accessible, eliminating health disparities, and curbing the rising cost of health care,

Richmond Clinic is using the quality health metrics established by the Oregon Health Authority (OHA). One of the quality metrics selected is to reduce the number of patients with poorly controlled diabetes to under nineteen percent using the benchmark set by the OHA (2016). The OHA (2015) defines a patient with poorly controlled diabetes as any patient with a diagnosis of type 1 or type 2 diabetes and an HbA1c > 9%. In 2015, Richmond clinic's population of patients with poorly controlled diabetes was between 17.7% and 19.5% (Kirk, 2015).

The readiness for change is reflected in Richmond currently investing in provider education and expanding its pool of RN's in an effort to create lasting and sustainable change that improves patient outcomes.

## **Sample**

### **Inclusion and exclusion criteria**

The sample included current diabetic patients with poorly controlled diabetes as defined by the aforementioned OHA criteria (i.e. HbA1c > 9). According to Richmond Clinic, the number of patients in this "high risk pool" were 150 at the time of administration of the survey. Participants were eighteen years of age or older, with a confirmed diagnosis of type 2 diabetes, and receiving healthcare coverage through the Oregon Health Plan. Pregnant women and patients who did not speak English as a first language were ineligible.

### **Size**

Fifteen subjects were chosen at random by the clinic from the high risk pool of 150 diabetic patients. The target sample size represented ten percent of the high risk diabetic population identified by Richmond Clinic.

### **Recruitment plan**

Patient names were maintained on a master list that remained in the clinic and was secured by the investigator. Participants were contacted via telephone by the Population Health Care Manager or their coordinating RNs and asked to participate. The RNs described the project and the measures taken to protect the patient's privacy, informed the patient that they could withdraw from the project at any time without affecting their care, and offered a ten dollar Fred Meyer gift card upon completion of the survey. During the phone call, the RNs obtained verbal consent from the patients, extended an offer to send them information containing the interview tool and coordinated with the patients to have the survey administered as part of an upcoming scheduled visit. The interaction occurred either before or after regularly scheduled RN visits.

### **Protection of participants**

No personal identifying information was kept with the study data. De-identified data will be kept until the final database papers are published. The interviewer was responsible for the receipt and transmission of the data. After the data was analyzed, the participants were notified that the project has concluded and given the opportunity to be provided with the findings.

### **Implementation**

Patients met with the interviewer during an office visit with a provider or RN at the clinic. Participants were educated regarding the benefits and risks of the project. A recording device was used to capture the survey responses. The age, gender and ethnicity were recorded. The participant was asked by the interviewer to verbally respond to the

questions on the questionnaire as openly and honestly as possible. The interviewer then asked the participant each question as it appeared on the questionnaire. The interview time ranged from eight to twenty-eight minutes.

Patients were interviewed face-to-face to eliminate misunderstandings and limit barriers to answering the questions due to health literacy. Also, participants were given the chance to answer questions verbally to elicit more information than would be provided by written answers. The survey tool can be found in Appendix A. Responses were recorded and transcribed to text on an encrypted computer. The laptop computer was only accessible to the study investigator. The laptop computer was either at the home office of the investigator or in the possession of the investigator at all times.

Interviews were transcribed to text. Responses that were pertinent to a patient's experience with diabetes were selected and moved to an Excel spreadsheet where they were color coded according to thematic content. The four major themes of the DSME were each assigned a color: disease based knowledge, lifestyle changes, self-efficacy, and support structures. Responses from patients were then categorized into the four major themes and additional thematic content was identified.

### **Outcomes**

Ages among participants ranged from 22 years to 68 years, with the average age being 52 years old. Ten participants were male and five were female. Twelve participants were white, two were black, and one was Hispanic.

While no one would suggest that diabetes is an easy disease to live with or overcome, patient responses to question one, "Please tell me what it's like for you to have diabetes"

were significant in that they were overwhelmingly negative. Examples of patient responses are, “It sucks”, “It’s terrible” and “It’s like pure hell”. These statements seem strongly worded and indicative of how challenging living with diabetes is for these patients. Only one response, “It’s a lot better than it used to be because I moved up here and have better treatment”, was somewhat positive.

Lifestyle changes were a common theme among patients. Of those comments about making lifestyle changes, the majority addressed the dietary challenges of diabetes. Many patients found it difficult to make appropriate food choices. When asked about obstacles to controlling their diabetes, patients answered, “Food choices are hard”, “It’s the diet mostly”, “Remembering to eat vegetables and eat healthier”, “I’m not used to not having carbs”, “Overcoming my normal or past eating habits and improving eating habits.” They seem to be aware of the need to consume fresh fruits and vegetables and to avoid carbohydrates, suggesting that they have the appropriate disease-based knowledge concerning diet. Few patients mention poverty and their inability to afford healthy food as a problem. Only two patients cited cost and the expense of healthy food as an obstacle to obtaining the nutrition they needed to treat their diabetes.

Instead, patients seem unable to avoid consuming foods that are high in carbohydrates. Often patients discussed the difficulty they had with resisting the temptation to eat food that was inappropriate for managing diabetes. Specifically, one third of patients mentioned that sugar-sweetened beverages (SSBs) were a particular problem for them to avoid. One patient, when asked to clarify, made a point to say that soda pop was more difficult to avoid than other junk food.

Fewer than half of patients interviewed mentioned exercise. With so few patients discussing physical activity as a means of treating diabetes, it is difficult at this time to surmise why patients are not exercising. Of those who did mention exercise, half cited some difficulty or obstacle that prevented them from exercising such as a physical constraint (pain, dizziness) or a lack of desire or motivation.

As part of the discussion involving lifestyle changes, patients commonly cited difficulty remembering to take their medications and taking them appropriately. More than two thirds of patients indicated that memory and forming a routine was a problem that they experienced. “I have a hard time finding a routine”, “forming a routine is difficult”, “I have a hard time remembering”, “everything should be consistent day after day and in my life that doesn’t work”, are examples of patient statements that demonstrate the difficulty they have with making diabetes treatment a habitual part of their lives. Only one patient briefly mentioned a strategy that she used to create a routine. She stated that she used technology, a cell phone alarm, to help her remember to take her medications.

Two thirds of patients discussed relying on blood sugar testing as a means of monitoring their diabetes, suggestive of an accurate foundation in disease-based knowledge. However, when asked “What do you do if you’re not doing well?”, several patients responded in the following manner: “I don’t know what to do about these kinds of things”, “I just have to lay there because there’s not really much I can do”, “A lot of times I try to ride it out”, “Nothing”. One patient seemed unaware that she could use insulin to bring down her blood sugar throughout the day. Instead she thought that she could only take it twice a day, once in the morning and once at night. If she forgot to take

a dose, she believed she had to wait until the next dose. An approach like this could lead to seriously out of control blood glucose levels.

The absence of a plan or strategy for addressing diabetes is further reflected in answers that were given to the question, “How do you overcome these obstacles?” This question was a follow up on the previous two questions asking about day-to-day and global obstacles that patients face in managing their diabetes. More than a third of patients responded with one of the following responses: “I don’t”, “I don’t know”, “I haven’t really found a strategy yet”, or “I haven’t come up with a solution yet.” Three patient’s responded with “I don’t”, suggesting that not only do they lack a strategy or plan for overcoming obstacles they face to improving their diabetes, they are also resigned to possibly never overcoming these obstacles. By responding “I don’t”, these patients imply a lack of self-efficacy and a resignation to never controlling their diabetes. They do not seem to feel as though controlling diabetes is possible: “I’ve always been a person who has been in control. With this, I’m not in control”, “I don’t have control over anything.” What is probably most tragic about this group of patients is that not only do they lack the confidence to address their disease, there is a level of genuine fear: “I’ve seen people with missing limbs”, “I’ve had scares of all types”, “I’m more afraid than I let on”, “I don’t want to die.”

For assistance and support, patients predominantly turn to family. Eighty percent of patient responses to the question “What are the things that help you manage your diabetes?” reference family members such as parents, children or a spouse. Other responses include friends, and medical professionals such as diabetic counselors. Patients also held a favorable view of the support they received from their primary care physician.

Responses to the question “What role does your primary care provider play in helping you manage your diabetes?” were eminently positive. Every patient responded with a favorable opinion about the contributions of their primary care provider. Not one patient seemed to have reservations nor express dissatisfaction.

However, when asked “What role does your nurse play in helping you manage your diabetes?”, several patients responded as follows: “She doesn’t talk to me about my diabetes”, “I don’t see her anymore”, and “What nurse?” Under the clinic model, each patient should have regular contact with at least one nurse. According to survey results, two-thirds of patients reported having a relationship with a nurse while one third of the patients interviewed reported not having an identifiable relationship with Nursing.

### **Practice Implications**

Patients were able to demonstrate a fundamental grasp of certain aspects of diabetes. While survey participants seem to be aware of diabetic diet restrictions, they seem to need help adhering to these restrictions. The CDC has found that a higher rate of consumption of soft drinks can be observed among low-income persons than among those with higher income (Ogden, Kit, Carroll, & Park, 2011). Findings from the survey seem to agree with the CDC findings and discussion in public health circles about the need to reduce or eliminate SSBs from the American diet due to the positive association between SSB consumption and developing type 2 diabetes (Malik & Hu, 2012).

However, patients demonstrated gaps in their understanding of disease-based knowledge that, if addressed, could improve their ability to manage their disease. Their responses demonstrate a lack of understanding about the basic disease process of diabetes

and an absence of a plan for addressing the high blood sugars that invariably come with type 2 diabetes. Without an approach to bring blood sugar under control, patients could experience serious side effects that could be at best debilitating and at worst life-threatening.

As stated earlier, self-efficacy refers to the belief of individuals in their ability to perform the actions necessary to achieve specific goals (Bandura, 1977). Participants in this survey appear to need help achieving a sense of self-efficacy. The goal of overcoming the obstacles that prevent each patient from keeping their diabetes under control seems to be out of reach for them.

Survey responses suggest that Nursing is not making its presence known in the care of these patients. There were times when some patients seemed to be unclear about the role of a person they had been counselled by or received education from. Frequently they couldn't remember the job title of a person they had been in contact with, whether they be a nurse, a diabetic counsellor, or a person with an unidentified role. Nurses may not have regular enough contact with patients. However, it is also possible that Nursing is not effectively identifying itself and defining its function when caring for these patients.

Based on research and patient responses from the interviews, there is a case to be made for the implementation of an organized DSME program at Richmond Clinic. As stated by Funnell et al. (2008), there is no one 'best' education program or approach. However, an approach using the guidelines set out by Powers et al. (2015) could effectively meet the needs of patients in the diabetes high-risk pool at Richmond Clinic. Powers et al. (2015) recommend establishing an organizational structure within the clinic that supports self-management education, seeks input from external stakeholders and

experts, and periodically reassesses patients receiving DSME to ensure that barriers are addressed and new barriers are identified. A DSME program should also periodically be assessed by clinic staff to evaluate its effectiveness and to identify areas for improvement.

### **Summary**

This project surveyed a group of low-income patients at a particular clinic in hopes of identifying barriers to controlling type 2 diabetes. A group of participants were chosen from a pool of diabetic patients at a local clinic who were determined by staff to be high-risk and poorly controlled. The survey assessed the qualitative experiences of each patient to find trends that could be addressed by clinic staff. Survey responses demonstrated that a DSME program should be sufficient in addressing gaps and barriers to care faced by this patient population.

Providers need to be able to recommend a treatment path that addresses and incorporates the social, economic, and environmental supports and constraints that patients face each day. Imparting knowledge is only a part of the solution when it comes to diabetes. Patients must make dramatic lifestyle changes in order to manage their disease and will require help with motivation so they become more actively engaged in promoting their own health. Successful behavior change takes time and patients will face obstacles and setbacks. Simply offering advice or sharing knowledge without demonstrating a true understanding of a patient's life situation outside of the clinic might have no effect on health outcomes or even be off-putting and counterproductive. Without skillful intervention, a provider might increase a patient's resistance to change. Using a

qualitative approach to gathering data about patient experiences with diabetes might allow a provider to capture the detailed perspective of individual patients and help them strategize ways to incorporate important components of DSME into their challenging lives.

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## Appendix A

## Survey Tool

1. Please tell me what it's like for you to have diabetes.
2. What do you do to manage your diabetes?
3. What is hard?
4. What is not so hard?
5. Thinking about managing your diabetes day-to-day, what kind of obstacles do you face?
6. What gets in the way of managing your diabetes in the big picture?
7. How do you overcome these obstacles?
8. Which ones can you not overcome?
9. What are the things that help you manage your diabetes?
10. What role does your health care provider play in helping you manage your diabetes?
11. What role does your nurse play in helping you manage your diabetes?
12. How do you know if you are doing well?
13. What are the signs you look for?
14. How do you know if you are not doing so well?
15. What are the signs you look for?
16. What do you do if you're not doing well?
17. Is there anything else you would like to add that I have not asked?