

A SOCIOECOLOGICAL PERSPECTIVE:
THE "UPS AND DOWNS" OF LIVING WITH TYPE 2 DIABETES
AMONG WORKING ADULTS IN THE RURAL SOUTH

A Dissertation
presented to
the Faculty of the Graduate School
at the University of Missouri-Columbia

In Partial Fulfillment
of the Requirements for the Degree
Doctor of Philosophy

by
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DECEMBER 2019

The undersigned, appointed by the dean of the Graduate School, have examined the
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A SOCIOECOLOGICAL PERSPECTIVE:
The "Ups and Downs" of Living with Type 2 Diabetes
among Working Adults in the Rural South

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ACKNOWLEDGEMENTS

I would like to thank my doctoral committee for their support in this endeavor. My doctoral chair and advisor, Dr. Maithe Enriquez, has inspired creativity, diversity, and critical thinking in my work. Her calmness and positivity have been invaluable to enduring the difficult times in this process. I would like to thank Dr. Gina Oliver for encouraging future nurse educators to uphold our profession. Dr. Tina Bloom has been a role-model in the fight to give the most vulnerable a powerful voice. Dr. David Mehr has given me valuable input as a seasoned researcher and health care provider.

Dr. Carolyn Jenkins and her research staff at Medical University of South Carolina provided invaluable knowledge, experience, skills and support as I launched my research career. I would like to acknowledge Rural Primary Care Research, Education and Practice collaborative for providing funding and support. I deeply appreciate the opportunity to collaborate with the local community and Regional Medical Center of Orangeburg, South Carolina in this research project. All of your time and support has been much appreciated.

To my family and friends, I would like to extend deep gratitude for your support, endless prayers, and patience. To my children, Elizabeth, Paul and Sarah, thank you for the privilege of being your mother and pursuing our dreams together. Many thanks to my beloved husband, who has helped me laugh, learn and become a compassionate, wise health care professional. You have taught me more than I ever need to know! When I walk on that stage to graduate, I will be enormously proud of all of you more than myself.

To all of my fellow colleagues and patients, thank you for a rewarding, fulfilling nursing career. I have learned the joys and challenges of trying to stay healthy. In memory of Michael Watson M.D., the “cloud chaser”, thank you for teaching me the value of listening and treating others with utmost respect and dignity.

“I don’t know what your destiny will be, but one thing I know: the ones among you who will be really happy are those who have sought and found how to serve”

~Albert Schweitzer, philosopher, theologian, humanitarian, physician, Nobel Peace Prize winner

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ABSTRACT

Persons with higher patient activation levels are more likely to engage in preventive health behaviors. This qualitative study addressed a population that may be particularly vulnerable to poor diabetes outcomes: rural, working adults with type 2 diabetes (T2 DM) with low levels of patient activation. This study sought to gain a better understanding of the individual, interpersonal, health system, and community spheres of influence on engagement in diabetes self-management and recommended preventive health services among rural, working adults. A socioecological approach, based on Fisher's (2005) Resources and Supports for Self-Management Model, guided the study. The Patient Activation Measure (PAM-10) was used to identify individuals with low patient activation. Participants ($N = 20$) had PAM-10 scores less than 75 ($M = 59.4$) and were predominately African American ($n = 12$) and female ($n = 14$), earning incomes less than \$50,000 ($n = 13$). The overarching theme, "ups and downs" of living with diabetes, emerged from the data. Four other major themes emerged: "the struggle", "you don't talk about it", "diabetes is not the priority", and "we're lucky to have what we have". Most participants had social support, employer health benefits, and a trusting, satisfactory relationship with health care providers. However, a lack of equitable workplace and

community resources may have contributed to lack of engagement in diabetes self-management and preventive health services.

CHAPTER ONE: INTRODUCTION

Health disparities in rural and minority populations have been well established. Diabetes is more prevalent in minority and rural populations, approximately 50% higher in African Americans compared to non-Hispanic whites and 17% higher in rural areas compared to urban areas (Centers for Disease Control [CDC], 2017a). Furthermore, diabetes-related mortality rates are much higher in rural, non-metropolitan areas compared to urban, metropolitan areas and persist among rural African Americans compared to rural whites at estimated rates of 42.8 per 100,000 versus 33.2 per 100,000, respectively (Callaghan, Towne, Bolin, & Ferdinand, 2017, 2019). Diabetes-related complications, such as stroke and kidney disease, disproportionately affect rural and minority populations (CDC, 2017; Garcia et al., 2017). Health disparities persist despite better management of risk factors and declining rates of diabetes-related complications (Gregg et al., 2014; Scott & Wilson, 2011; Williams, McClellan, & Rivlin, 2010). Socioeconomic factors contribute to health disparities within rural and minority populations (Towne et al., 2017). Rural hospital closures continue to rise, and rural populations are more likely to delay care because of costs, to be uninsured, and to be living in persistent poverty (Kaufman et al., 2016; Meit et al., 2014; Towne et al., 2017). These factors place a significant burden upon rural, working adults with type 2 diabetes and may impede engagement in preventive health services and consistent medical care (Hale, Bennett, & Probst, 2010; Ziller, Lenardson, Paluso, & Janis, 2019).

Background of the Problem

Transitions in Health Care Delivery

Over the past two decades, there have been efforts to improve the delivery of health care in primary care settings. The Chronic Care Model (CCM) was developed in order to transform the health care system into delivery of patient-centered care and improve overall health, especially for those with chronic health conditions (Wagner, Austin, & Von Korff, 1996). The CCM transformed the traditional health care system from physicians having a paternalistic relationship with patients to gradually allowing patients to be more informed and involved in their health care (Emanuel & Emanuel, 1992). This transition to patient-centered care has resulted in lower rates of hospitalizations, lower Medicare costs, and higher quality of care reported by patients in areas with higher proportions of primary care physicians to specialists (Jabbarpour, DeMarchis, Bazemore, & Grundy, 2017; Laing, Bodenheimer, Phillips, & Bazemore, 2008). Having patient-centered care can also mediate diabetes health outcomes and is associated with better glycemic control (Walker, Gebregziabher, Martin-Harris, & Egede, 2014).

Concept of Patient Activation

A key component of the CCM is “patient activation”. Hibbard, Mahoney, Stockard, and Tusler (2005) delineated the concept of patient activation as one’s knowledge, skills, ability, and willingness to manage their own health care. Patient activation is a developmental, cognitive process that ultimately leads to health behavior. The process of patient activation is a continuum that consists of the patient utilizing knowledge about their health condition and developing confidence to take action (see

Appendix A). Initially, this process is operationalized as a variety of health behaviors, such as making lifestyle changes, talking to health care providers, and knowing when to seek help (Harvey, Fowles, Xi, & Terry, 2012; Hibbard et al., 2004). The next step in patient activation is gaining more independence in self-management of health care, following health care providers' recommendations, and making necessary lifestyle changes to prevent potential complications of chronic health conditions. The final step of the patient activation continuum involves maintaining lifestyle changes and necessary medical treatments, even under times of stress (Graffigna & Barello, 2018; Hibbard et al., 2004). Thus, the patient maintains an active role in their health care and learns how to manage health problems independently, without health-related activities interfering in everyday life (Hibbard et al., 2004; Rask et al., 2009; Rijken, Heijmans, Jansen, & Rademakers, 2014).

Patient Activation and Health Behaviors

There is growing momentum for patient-centered care and promoting individuals to be actively involved in their own health care (Hibbard & Greene, 2013). Higher levels of patient activation or taking a more active role in managing one's health care have been associated with an increased likelihood of preventive behaviors, such as regular exercise and receipt of foot and eye exams (Rask et al., 2009). Overall, the use of preventive health services should be judicious, cost-effective, and include goals that promote healthier behaviors and prevent serious complications of chronic diseases (Hibbard & Greene, 2013). These goals parallel the "triple aim" set forth by the Institute of Medicine (2001): improving patient quality and satisfaction, improving health of populations, and decreasing health care costs.

Significance

Engagement in Diabetes Preventive Health Services

A significant number of adults with diabetes fail to engage in recommended, preventive health services despite expanded health care access by the Affordable Care Act, more technology, and improved quality of diabetes care (Villarroel, Vahratian, & Ward, 2015). Younger adults (i.e., below age 65) with diabetes are less likely than older patients to engage in preventive health services, such as blood pressure checks, cholesterol screening, and contact with an eye or foot specialist (Chou et al., 2012; Towne et al., 2017; Villarroel et al., 2015). Moreover, compared to top wage earners, low-wage earners are less likely to engage in preventive care and more likely to experience poor diabetes outcomes (Harris, Huang, Hannon, & Williams, 2011; McMorrow, Kenney, & Goin, 2014). Low-wage earners experience more than double the rate of diabetes-related deaths (Saydah & Lochner, 2010).

Engagement in diabetes preventive health services is crucial for working adults to remain healthy and productive. The places where adults spend most of their time are at work and home; therefore, these places should be considered with regard to one's ability to engage in preventive health services. There is a growing trend among employers to offer workplace health promotion programs to their employees (Baicker, Cutler, & Song, 2010; CDC, 2019). However, comprehensive programs, such as diabetes self-management programs, are seldom offered in smaller businesses and rural communities (Harris, Hannon, Beresford, Linnan, & McLellan, 2014; McPeck, Ryan, & Chapman, 2009; Stiehl et al., 2018). Innovative, cost-effective strategies are needed to facilitate the engagement of rural, working adult populations in diabetes preventive health services.

Diabetes-related Complications

Serious consequences associated with diabetes, including diabetic retinopathy, neuropathy, cardiovascular disease, peripheral vascular disease, chronic kidney disease, and a higher risk for lower-extremity amputations, persist (Gregg et al., 2014; Gregg Hora, & Benoit, 2019). The rate of stroke is 1.5 times higher for populations with diabetes compared to those without diabetes (CDC 2017b; Gregg et al., 2014). Chronic kidney disease continues to affect more than one-third of persons with diabetes. While the rate of end-stage renal disease has declined, the reduction has been small (Gregg et al., 2014).

Furthermore, rural-dwelling and minority populations face a higher risk of diabetes-related complications (Garcia et al., 2017; Hale et al., 2010). Uncontrolled diabetes has demonstrated a strong link to the development of diabetes complications (Stratton et al., 2000). Approximately 15% of adults in the U.S. have uncontrolled diabetes or an HgA1C level greater than 9% (CDC, 2017a). Glycemic control is typically worse in younger adults (18–44 years), non-Hispanic blacks, Hispanics, non-married individuals, and uninsured populations than their respective counterparts (Ali, McKeever Bullard, Imperatore, Barker, & Gregg, 2012).

Economic Burden of Diabetes

Working adults with diabetes contribute to a significant economic burden in health care costs, particularly those with poorly controlled diabetes or less engaged in self-management of their chronic disease (Crowley et al., 2014; Greene & Hibbard, 2012). The costs are estimated to be more than 20% higher for individuals with diabetes who are disengaged or poorly adherent to recommended medical treatment (Hibbard,

Greene, & Overton, 2013). The health care costs related to diabetes are twice as high compared to other leading chronic diseases and more than 5 times higher for an employee with diabetes than for an employee without diabetes (American Diabetes Association, 2018a; Mehr, 2014).

Working adults who are uninsured, low-wage earners, or live in states that did not expand Medicaid eligibility guidelines are particularly vulnerable to the financial impact of health care costs (Sommers, Blendon, & Orav, 2016). Despite expanded access to health care under the Affordable Care Act (ACA), 20% of rural dwelling adults report difficulty paying medical bills and up to 25% of uninsured adults reported a delay in medical care because of costs (Karpman & Long, 2015; National Center for Health Statistics, 2018).

Social Determinants of Health

Other socioeconomic factors, such as community-level characteristics, have been associated with use of preventive health services (Luo et al., 2014). Having insurance coverage does not fully account for the disparities in use of preventive health services among low-income adult populations (Fox & Shaw, 2015; Luquis & Kensinger, 2017; McMorrow et al., 2014). While controlling for individual factors, persons with diagnosed diabetes living in areas with higher physician density were found to be more likely to receive preventive services (Luo et al., 2014). Moreover, residing in an economically advantaged residential area has been associated with 2.5 higher odds of glycemic control compared to living in a disadvantaged neighborhood (Tabaei et al., 2017).

The use of health services can also be influenced by competing family priorities, not having a regular health care provider, and patient–provider rapport (Ross, Benavides-

Vaello, Schumann, & Haberman, 2015; Spleen, Lengerich, Camacho, & Vanderpool, 2014). Social support also facilitates healthy behaviors and can improve diabetes outcomes (Bardach, Tarasenko, & Schoenberg, 2011; Hammond, Matthews, & Corbie-Smith, 2010; Smalls, Gregory, Zoller, & Egede, 2015).

More research is needed to gain a better understanding of the social determinants of health that impact the ability of rural, working adults to engage in preventive health services. Such factors, including the neighborhood, workplace, and home environment, play significant roles in health outcomes (Braveman, Egerter, & Williams, 2011).

Aims

This dissertation study focused on a population of rural, working adults with type 2 diabetes and lower patient activation levels. First, the construct of patient activation is introduced with results from a secondary analysis of Patient Activation Measure (PAM) scores from the study population. These data examined the positive relationship between patient activation and engagement in diabetes preventive services. Results from the secondary data analysis of PAM scores provided the foundation for using the PAM in the qualitative study. The PAM identified working, rural-dwelling adults with type 2 diabetes and lower patient activation levels who were potentially poorly engaged in diabetes preventive health services.

The specific aim of this qualitative study was to gain a better understanding of critical, and potentially modifiable, social and economic factors influencing the ability of rural, working adults to engage in diabetes preventive health services. Influential factors, such as the use of social and community resources, were explored as well as how they facilitate the use of preventive health services for rural, working adults with type 2

diabetes. This study addresses the research gap concerning the distinct issues that limit patient activation of rural, working adult populations. Findings from this study will inform future interventions and help form an important foundation for the candidate's future research goals, which include the development of community-based interventions to enhance the health of rural, working adults with diabetes.

Research question 1:

What are the individual, interpersonal, health system, and community factors that facilitate, modify or hinder engagement and use of recommended, preventive health services among rural, working adults with type 2 DM and low patient activation scores (<75), as measured by Patient Activation Measure?

Research question 2:

How do the individual, interpersonal, health system, and community factors facilitate, modify, or hinder engagement in recommended, preventive health services according to rural, working adults with type 2 DM and low patient activation scores (<75), as measured by Patient Activation Measure?

Theoretical Framework

Becoming engaged in one's health care, or patient activation, necessitates adequate socioecological resources and support. The self-management skills needed for health behavior change are influenced by individual, interpersonal, institutional, and environmental factors (Fisher et al., 2005). The theoretical framework that informed this qualitative study was the Resources and Supports for Self-Management Model (Fisher et al., 2005). Fisher et al. (2005) asserted that individual self-management skills cannot be effective in health behavior change without support of others in social networks,

continuity of care in health systems, and access to resources in the community. Fisher's self-management model is a socioecological model that integrates four spheres of influence on individual health behavior with the services and support they receive from their environment and community; see Figure 1. These four spheres of influence will be discussed with respect to diabetes self-management and health utilization behavior.

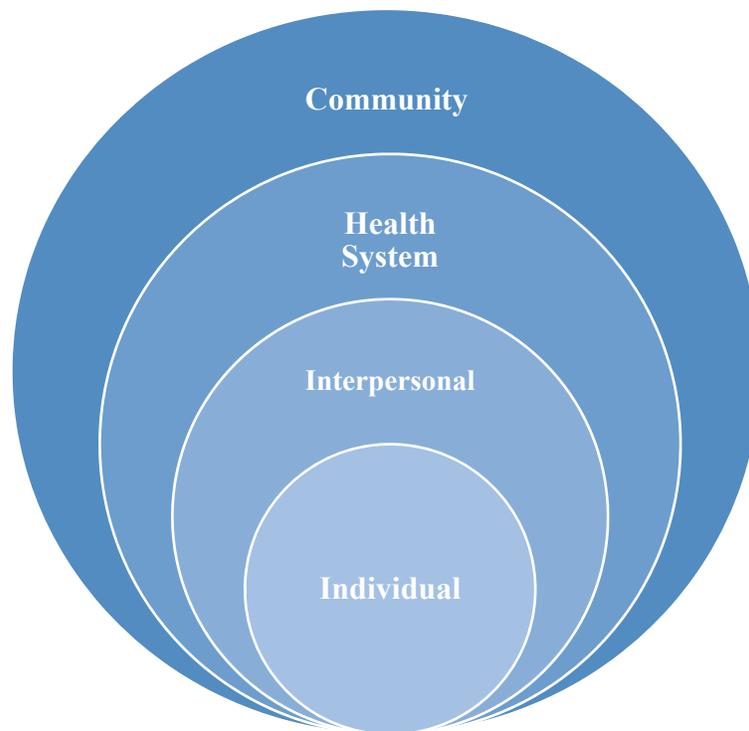


Figure 1. Resources and Supports for Self-Management Model. Adapted from “Ecological Approaches to Self-Management: The Case of Diabetes” by E. B. Fisher, C. A. Brownson, M. L. O’Toole, G. Shetty, V. V. Anwuri, and R. E. Glasgow, 2005, *American Journal of Public Health*, 95(9), pp. 1524.

Assumptions

The first assumption is that lower levels of patient activation can predict being poorly engaged in diabetes care and preventive health services (Hibbard & Greene,

2013). The next theoretical assumption is based on the model from Fisher et al. (2005).

Due to a lack of social and economic capital or resources, rural, working adult populations with type 2 diabetes are poorly engaged in diabetes preventive services compared to their urban counterparts or those with higher socioeconomic status. Thus, the significant factors to engaging in diabetes preventive health services were presumably due to lower patient activation levels along with a lack of adequate support and socioeconomic resources among low-income, rural, working adults.

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Operational Definitions

Type 2 diabetes (DM) defined as “individuals who have relative insulin deficiency and peripheral insulin resistance” (American Diabetes Association, 2018). The parameters for the initial diagnosis of type 2 DM are fasting plasma glucose ≥ 126 mg/dL, 2-hour glucose tolerance test ≥ 200 mg/dL, or HgA1C greater than 6.5% (American Diabetes Association, 2018b).

Glycemic control is considered HgA1C less than 7% or less than 8% for certain cases, such as those with history of severe hypoglycemia, limited life expectancy, or extensive comorbidities. To maintain HgA1C levels less than 7%, the equivalent glucose readings for self-monitoring are fasting average 135–150, postprandial average 159–169, and bedtime average 145–160 (American Diabetes Association, 2018b).

Diabetes preventive health services are the recommended standards of care set forth by the American Diabetes Association (American Diabetes Association, 2018b). The following seven recommendations will be considered “diabetes preventive services”: dilated eye exams, foot exams by health care professional, blood pressure screening, Hemoglobin A1C (HgA1C) testing, cholesterol testing, urine screening for microalbumin and/or serum estimated glomerular filtration rate (eGFR) testing, and diabetes education. The diabetes preventive services that should be done on an annual basis are dilated eye exams and urine screening and/or serum eGFR testing, and dental visits. For those with one or more normal dilated eye exams and glycemic control, the exams can be performed every 1 to 2 years. Foot exams by the health care provider should be done every visit and include skin inspection, neurologic and vascular assessment, and annual monofilament testing for neuropathy. Blood pressure screenings are recommended at every visit with the health care provider. HgA1C testing should be performed at least twice a year, or quarterly for those who have medication changes or less than adequate glycemic control. Cholesterol testing is recommended annually for those on lipid-lowering therapy or every 5 years for those under the age of 40 years. Cholesterol testing may be done periodically after initiating or changing medical therapy. Diabetes education is recommended on an annual basis, as well as when complications or transitions in care arise.

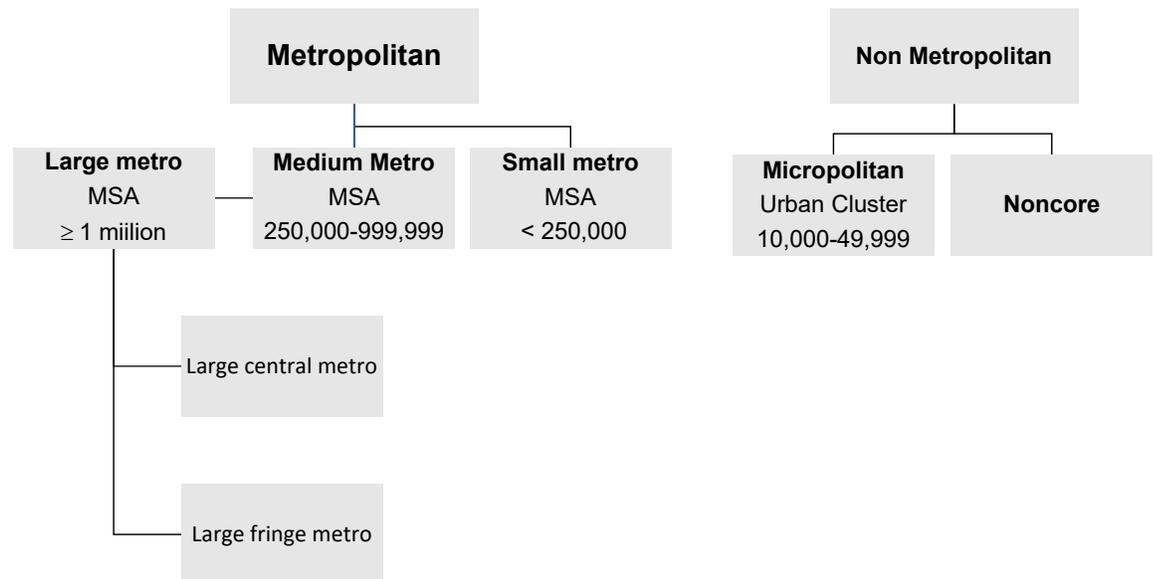
Patient activation is being informed and having the knowledge, skills, ability, and willingness to take part in managing one’s health and care and one of the many factors that can affect diabetes self-management (Hibbard et al., 2004). Patient activation is a developmental, cognitive process that leads to healthy behaviors. Low levels of patient activation have been associated with fewer preventive care behaviors, such as cholesterol and HgA1C testing (Hibbard & Green, 2013; Remmers et al., 2009); see Appendix A.

Patient engagement is the active participation of patients or performance of specific behaviors to manage one’s health care (Mittler, Martsolf, Telenko, & Scanlon, 2013). Engagement is also the actions individuals must take to obtain the greatest benefit from the health care services available to them (Gruman et al., 2010). Hibbard et al. (2013) described patient engagement as the interventions designed to increase patient activation and the health behavior that results.

Low-wage earners can be classified as below median U.S. household income. According to U.S. Census Bureau, the 2012–2016 U.S. median household income was \$55,322 (U.S. Census Bureau, 2018). The median household income is substantially lower in the rural counties where the research was conducted, ranging from \$32,321 to \$42,779 (U.S. Census Bureau, 2018). Health disparities, including self-reported poor health, fewer preventive screenings, and high-risk behaviors such as smoking and physical inactivity, were found to be significantly lower for workers with incomes less than \$35,000 (Harris et al., 2011).

Younger adult populations are classified as those persons from 18 to 65 years of age. The National Health Survey sub-classifies under 65-year populations into 18–39 and 40–64 age categories (Villarroel et al., 2015), and BRFSS further sub-classifies under 65-year populations into 18–24, 25–34, 35–44, 45–54, and 55–64 age categories.

Rural populations are classified based on the 2013 National Center for Health Statistics (NCHS) Urban-Rural Classification Scheme for Counties (Ingram & Franco, 2014). This classification scheme is based on the widely used metropolitan and non-metropolitan areas defined by the Office of Management and Budget (OMB). OMB classifies counties as metropolitan statistical areas (metro or MSAs) or non-metropolitan statistical areas (non-metro or non-MSAs). NCHS further classifies the metropolitan counties into four levels as described below. Both counties that will be targeted for recruitment of participants are classified as non-metropolitan, one county is considered micropolitan, and the other county is non-core (Rural Health Information Hub, 2018).



Adapted from 2013 NCHS Urban-Rural Classification Scheme for Counties.

Self-management implies that the individual is an active participant in their medical care and is striving towards a wellness (rather than illness) perspective in daily management of their chronic disease (Lorig & Holman, 2003). Self-management tasks include medical, role, and emotional management (Lorig & Holman, 2003). An example of medical management would be taking medications to effectively control blood sugar for persons with diabetes. New roles and health behaviors, such as healthy eating, are needed for diabetes self-management. Additionally, learning to cope with the psychological impact of chronic disease is an example of emotional management. The five essential self-management skills needed for self-management of chronic disease are problem solving, decision making, resource utilization, forming a patient–provider relationship, and taking action (Lorig & Holman, 2003).

Diabetes self-care or diabetes self-management activities can include diet, exercise, self-monitoring blood glucose, foot care, and taking medications (Toobert, Hampson, & Glasgow, 2000).

Diabetes self-management education (DSME) is defined by the American Diabetes Association as the “process of facilitating the knowledge, skill, and ability necessary for diabetes self-care” (Powers et al., 2015). The recommendations by the ADA include DSME at initial diagnosis of diabetes, annual review, and when diabetes-related complications and transitions in care arise (American Diabetes Association, 2018b). DSME should include the following seven topics: healthy eating, being active, monitoring, taking medication, problem solving, reducing risks, and healthy coping (American Diabetes Association, 2018b). Effective DSME programs are to be patient-centered, culturally relevant, and address psychosocial and health literacy needs (Powers et al., 2015).

Diabetes self-management education (DSME) interventions include the delivery of educational components classified as DSME topics, such as diet, exercise glucose monitoring, medications, reducing risks, and problem-solving strategies. DSME interventions include education as well as interventions designed to facilitate healthy behaviors and diabetes self-management skills.

Patient activation interventions are a set of behavioral interventions that promote “increased knowledge, motivation or confidence and skills needed for self-management of chronic diseases” (Bolen et al., 2014; Hibbard & Mahoney, 2009).

Social determinants of health include upstream and downstream factors that influence health (Braveman et al., 2011). “Downstream” or “intermediary” factors include biological and non-medical factors, such as sex, race/ethnicity, health behaviors, knowledge, attitudes, or beliefs (Braveman et al., 2011; Commission on Social Determinants of Health, 2008). “Upstream” or “structural” determinants of health include socioeconomic position, neighborhood conditions, education level, income and financial

assets, living conditions, and work conditions (Braveman et al., 2011; Commission on Social Determinants of Health, 2008).

Resources will be defined as economic, social and cultural resources that offer health benefits (Weaver, Lemonde, Payman, & Goodman, 2015). Economic resources are financial resources, such as money and personal property, that are used to supply material possessions and necessities. Examples of economic resources would be food stamps, an apartment or home, and medical supplies for the management of diabetes (i.e., medications, glucose monitor, and insulin syringes). Cultural resources are values, beliefs, customs, and knowledge regarding health and health behavior (Abel, 2008). Cultural capital is acquired through social learning and uses cultural resources for action but can vary widely based on social class or status (Abel, 2008). Social resources are sources of support in social networks (e.g., family, friends, or coworkers) needed to attain health or opportunities to maximize health. Social capital, established from informal and formal relationships and through social networks, can benefit health as a result of one's position in social contexts (Vest et al., 2013).

Individual factors are psychological, cultural, and social factors that influence individual health beliefs. Health beliefs include concepts of illness, fate, death, and health (Fisher et al., 2005).

Interpersonal factors include family, friends, small groups, or social networks that serve as resources or supports to enhance skills for self-management, such as healthy cooking, physical activity, or diabetes foot care (Fisher et al., 2005).

System factors are health system, groups, or culture that provide clinical care, resources, or support for diabetes self-management (Fisher et al., 2005).

Community factors include access to healthy food and safe places for physical activity, diabetes education activities, and neighborhood environment (Fisher et al., 2005). The "built" environment refers to physical parts of where we live and work, such as streets, buildings, homes, and open spaces for activity (Braveman et al., 2011).

CHAPTER TWO: IMPACT OF A COMMUNITY-BASED APPROACH TO
PATIENT ENGAGEMENT IN RURAL, LOW-INCOME ADULTS WITH TYPE 2
DIABETES

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(Public Health Nursing, in press, November, 2019)

Abstract

Objective: This secondary analysis examined the relationships between Patient Activation Measure (PAM) scores, use of health services, and HgA1C. Design: A feasibility study was conducted for a community-based intervention for high-risk adults with uncontrolled diabetes. Data were collected at baseline and monthly, including PAM and modified Diabetes Self-Management Assessment Report Tool. Intervention: Participants ($N = 48$) were randomized to a 3-month nurse (RN) telephone management or community health worker (CHW) in-home intervention, focusing on medication adherence, timely follow-up, diabetes self-management coaching, and linkage to resources. Results: Sample was mostly female (73%), African American (90%), low-income (75%), high school education or less (80%) and mean age 59 years. A positive association between PAM score and self-reported diabetes care recommendations was found ($r = .356, p = .014$) and significant correlation between baseline PAM score and HgA1C levels ($r = -.306, p = .029$). A paired samples t-test showed statistically significant increases in PAM scores in the CHW intervention group (mean increase +8.5, CI [+2.49 –+14.65]); baseline ($M = 60.31, SD = 13.3$) to end of study [$(M = 68.89, SD =$

16.39), $t(22) = 2.924$, $p = .008$ (two-tailed)]. Conclusion: A community-based approach to diabetes management demonstrated a positive effect on patient activation. Although disparities in healthcare access among rural, low-income populations exist, community-based interventions show potential for improving patient engagement in diabetes management and recommended health services.

Keywords: Patient engagement, Patient activation, Community Health Worker, Diabetes Mellitus-Type 2, Poverty, Rural population, Health Promotion, Self-Management, Patient Activation Measure

MANUSCRIPT

Impact of a Community-Based Approach to Patient Engagement in Rural, Low-Income Adults with Type 2 Diabetes

Background

The prevalence of diabetes is substantially higher in rural populations compared to urban populations (Towne et al., 2017). Diabetes is also more common among African-Americans compared to non-Hispanic whites (Centers for Disease Control & Prevention [CDC], 2019). Furthermore, diabetes-related mortality rates are much higher in rural, non-metropolitan areas compared to urban, metropolitan areas and persist among rural African-Americans compared to rural whites at estimated rates of 42.8 per 100,000 versus 33.2 per 100,000, respectively (Callaghan, Towne, Bolin, & Ferdinand, 2017, 2019). Glycemic control is typically worse in younger adults, non-Hispanic blacks, Hispanics, non-married individuals, and uninsured populations than their respective counterparts (Ali, McKeever Bullard, Imperatore, Barker, & Gregg, 2012). For example, approximately 17% non-Hispanic Blacks have higher rates of uncontrolled diabetes, or HgA1C levels greater than 9.0%, compared to 9% in Whites. Diabetes-related complications, such as stroke and kidney disease, disproportionately affect rural and minority populations as well (CDC, 2017; Garcia et al., 2017). Such disparities must be urgently addressed to improve health outcomes in these communities.

Health disparities among rural and minority populations have been well established. These disparities can be partially explained by a lack of access and participation in routine preventive care services (Spleen, Lengerich, Camacho, & Vanderpool, 2014). Rural and minority populations continually face challenges related to

diabetes care. African-Americans have a 1.5 higher risk of forgoing medical care due to cost compared to whites, despite recent Medicaid expansion and health insurance reform efforts (Towne et al., 2017). Rural residents are also more likely than urban residents to delay seeking health care and to receive diabetes preventive health services [i.e. diagnostic tests (glucose, urinalysis, A1C, and blood pressure) or patient education (diet/nutrition, exercise, and stress management)], largely due to cost (Hale, Bennett, & Probst, 2010; Towne et al., 2017). Lack of engagement in diabetes preventive services may result in poor health outcomes (Hibbard & Greene, 2013).

Other barriers, such as transportation and competing family priorities, further constrain access to diabetes-related preventive health services. Limited access to specialists, such as eye care professionals, can reduce rural residents' likelihood of obtaining diabetes-related preventive services (Chou et al., 2012, 2016; Lee et al., 2014). Younger adults, especially those between 18 and 39 years old, are lagging behind their older counterparts in diabetes preventive services, such as dilated eye exams, cholesterol checks, blood pressure screenings, and urine albumin testing (CDC, 2017; Villaroel, Vahratian, & Ward, 2015; Ziller, Lenardson, Paluso, & Janis, 2019). Higher uninsured rates, lower educational attainment, reduced access and lower perceived need for services among younger, rural and minority residents may partially explain lower receipt of preventive services (Ziller et al., 2019).

Conversely, participation in health services may lead to better diabetes health outcomes (Greene & Hibbard, 2012). Individuals who are actively involved in their health are more likely to have lower overall health care costs, obtain recommended diabetes preventive services, and exhibit better health outcomes (Aung, Coll, Williams, &

Doi, 2016; Rask et al., 2009; Rogvi, Tapager, Almdal, Schiotz, & Willaing, 2012; Sacks, Greene, Hibbard, Overton, & Parrotta, 2017). Engagement, defined as the active partnership between patients and health care professionals, is necessary for improved health outcomes (Carman et al., 2013). However, scant research has validated the relationship between the level of engagement in diabetes care and health outcomes, especially among rural and minority populations (Schoenberg, Ciciurkaite, & Greenwood, 2017).

Community-based interventions have been known to improve diabetes outcomes, with most evidence for minority, under-resourced, and urban populations; however, increasing evidence is available regarding rural communities (Lepard et al., 2015; Palmas et al., 2015). A recent study of rural-dwelling, African-American women found no significant improvements in glycemic control or blood pressure in the community health worker (CHW) intervention group compared to the control group, but significant weight loss (-1.35 +/- 6.22 kg) was reported (Lutes, Cummings, Littlewood, Dinatale, & Hambridge, 2017). Greater reductions in HgA1C have resulted from exposure to more contact hours from CHW's or peer advisors, otherwise known as the "dosage effect" (Lepard et al., 2015; Palmas, 2014; Samuel-Hodge et al., 2009; Tang et al., 2014).

The purpose of this secondary data analysis was to examine the association between the level of engagement and utilization of diabetes preventive health services in a rural, Southeastern U.S. community of predominantly African-American adults with type 2 diabetes. The analysis also illustrates the construct of engagement, which Hibbard, Stockard, Mahoney, and Tusler (2004) operationalized as patient activation. Findings from this study can help confirm the potential of community-based interventions to

enhance patient engagement and, more importantly, to lessen health disparities among rural, minority adults with diabetes.

In the context of this study, the chosen community is classified as ‘rural’ based on the 2013 National Center for Health Statistics (NCHS) Urban-Rural Classification Scheme for Counties and the estimated county population being 14,275 (U.S. Census Bureau, 2018). According to NCHS, a rural population is generally defined as one that meets the criteria for a non-metropolitan statistical area (non-MSA), or core urban area less than 50,000 population.

Conceptual Framework

The concept of engagement has evolved with patient-centered health care delivery models, specifically the Chronic Care Model (CCM) (Wagner, Austin, & Von Korff, 1996). This model transformed the conventional health care system, allowing for a more collaborative, patient-focused approach (Emanuel & Emanuel, 1992; Wagner et al., 1996). The CCM emphasizes patients as active participants and informed consumers of health care while gaining skills to promote disease self-management (Wagner et al., 1996). The concept of engagement has also been framed as patient activation, namely “[one’s] knowledge, skill and confidence for managing his/her own health and health care” (Hibbard, Mahoney, Stockard, & Tusler, 2005, p. 1919). In this case, patients learn how to participate as effective members of the health care team.

Patient activation comprises a broad definition and continuum of health behaviors, as opposed to the similar construct of self-efficacy that relates to a specific skill or health behavior (Hibbard et al., 2004). Patient activation is a developmental, cognitive process that ultimately promotes adoption of health behaviors (see Figure 1).

As patients gain knowledge about their health condition(s) and develop confidence to take corresponding action, patient activation develops. This process is comprised of four levels and starts with acknowledging the importance of patients' roles in their health care. The next level encompasses various patient-based health behaviors, such as making lifestyle changes, talking to health care providers about their health care, and knowing when to seek help (Harvey, Fowles, Xi, & Terry, 2012). The third level of patient activation consists of gaining more independence in self-management of health care, following providers' recommendations, and continuing to make necessary lifestyle changes to prevent potential chronic health complications. The final level involves maintaining lifestyle changes and necessary medical treatments, even during times of stress (Graffigna & Barello, 2018). Throughout this continuum, patients maintain active roles in their health care and have the opportunity to become increasingly more confident in self-managing health problems with minimal interference in everyday life activities (Hibbard et al., 2004; Rask et al., 2009; Rijken, Heijmans, Jansen, & Rademakers, 2014).



Figure 1: Conceptual Model - Levels of Patient Activation (PAM). Copyright 2018 by Insignia. Reprinted with permission.

The Patient Activation Measure (PAM) has been applied to predict health outcomes in numerous populations (Hibbard & Greene, 2013). Higher patient activation has been shown to be positively related to a variety of diabetes outcomes (e.g., control of blood glucose, cholesterol, and blood pressure) (Rogvi et al., 2012). Moreover, higher patient activation levels are associated with a greater likelihood of reported medication adherence, regular physical activity, and diabetes self-management behaviors (Frosch, Rincon, Ochoa, & Mangion, 2010; Mosen et al., 2007; Parchman, Zeber, & Palmer, 2010; Wolever & Dreusicke, 2016). Thus, the results of this secondary data analysis will validate the relationship between level of engagement, as measured by Patient Activation Measure scores, and preventive health behaviors.

The results will also add to the gap in literature concerning the relationship between patient engagement and enhanced health outcomes among rural, minority populations. The potential to enhance patient engagement and improve diabetes outcomes has been demonstrated in several interventional studies with various populations. Examples include African-Americans and Hispanics as well as patients with higher baseline HgA1C levels, low levels of medication adherence, and poor diabetes self-management (Bolen et al., 2014; D'Eramo Melkus et al., 2010; Lorig, Ritter, Ory, & Whitelaw, 2013; Moskowitz, Thom, Hessler, Ghorob, & Bodenheimer, 2013; Philis-Tsimikas, Fortmann, Lleva-Ocana, Walker, & Gallo, 2011; Wolever et al., 2010).

Methods

Design and sample

Data for this secondary analysis was obtained from a pilot study (Authors, 2016) which examined the feasibility of primary care medical homes using community health

workers as care extenders among high-risk persons with type 2 diabetes. High-risk persons targeted were those with uncontrolled diabetes or HgA1C greater than 8%, uncontrolled hypertension, recent hospitalization or urgent care/emergency room visit for diabetes-related diagnosis, reported problems with obtaining medications, or reported need for diabetes management from the primary care provider. The pilot study recruited persons with diabetes from primary care offices (60%), urgent care clinics (16%), hospital inpatient admissions (14%), and emergency departments (10%) within the identified small, rural county. The county's population characteristics where the study was conducted were comparable to the demographics of the study sample: African-American (60%), high school education or less (79%), and median 2017 income \$32,330 (U.S. Census Bureau, 2018). The mean age of the sample was 59 ± 11.6 years and participants were predominantly female (73%) and African-American (90%). More than 75% ($n = 33$) were low-income (earning less than \$25,000 annually) and had a high school education or less ($n = 39$). The sample included larger proportions of unemployed (34%) or retired (36%) adults compared with working adults (26%).

In the pilot study, participants ($n = 58$) were randomly assigned to one of three groups: a 3-month intervention group, receiving either nurse (RN) management via telephone ($n = 27$); a face-to-face management from a community health worker (CHW; $n = 26$); and a usual care/control group ($n = 5$). Interventions in the RN telephone management and CHW groups each focused on medication adherence, timely follow-up, diabetes self-management coaching, and referrals to community resources. Baseline and monthly data were collected using eight measures, including PAM scores. Patient activation levels assessed the readiness to change in increasing diabetes self-management

behaviors. Several other health behaviors were assessed, such as patients' eating patterns, tobacco and alcohol use, medication adherence, and diabetes self-efficacy.

The secondary data analysis focused on two variables of interest: PAM scores and the number of diabetes recommendations met. The purpose of this analysis was to examine the relationship between patients' level of engagement, as quantified by PAM scores, and use of diabetes preventive health services in a rural community of predominantly African-American adults with diabetes. The proposed secondary data analysis was reviewed and approved by the Institutional Review Board of XXXXX.

Research Questions

- 1) Is there a relationship between PAM score and number of diabetes recommendations met?
- 2) Is there a relationship between PAM score and HgA1C level?
- 3) Is there a significant change in PAM score following a 3-month RN telephone intervention or CHW intervention?

Measures

Patient Activation Measure. PAM was developed as a measure of patient engagement (Hibbard et al., 2004). The instrument is well-validated and has demonstrated good reliability (Rasch: 0.81); possible scores range from 0 to 100, corresponding to patient activation levels 1, 2, 3, and 4 (Hibbard et al., 2005). The measure has demonstrated strong associations with constructs such as preventative, self-management, and consumeristic behaviors (Hibbard et al., 2005). The short-form PAM-10, containing 10 items, was used for analysis (Hibbard et al., 2005).

Diabetes Educators' Self-Management Assessment Reporting Tool (D-SMART). In the pilot study, the number of self-reported diabetes recommendations met (*# DM REC met*) were extracted from the Diabetes Educators' Self-Management Assessment Reporting Tool (D-SMART) used by the RN and CHW interventionists. The American Diabetes Association of Diabetes Educators' (AADE) identification of seven diabetes self-management behaviors, otherwise known as AADE-7, was based on preliminary D-SMART development (Peyrot et al., 2007). Evaluation of behavioral outcomes includes seven areas of diabetes self-management: being active, healthy eating, taking medication, monitoring, problem-solving, reducing risks, and healthy coping (Peyrot et al., 2007).

Thirteen possible diabetes recommendations were coded as “met” if patients reported the following health care behaviors: HgA1C tested within the past 6 months; a doctor visit, foot exam from a health professional, blood pressure check, cholesterol check, or urine check for protein within the past 12 months; dilated eye exam, dental visit, or flu shot within the past 2 years; and any history of seeing a dietician, attending a diabetes education class, or receiving a pneumonia or hepatitis B vaccine.

Analytic Strategy

PAM scores and D-SMART data from the pilot study (Authors, 2016) were exported into SPSS data files for secondary analysis. Self-reported adverse events were extracted from the D-SMART at baseline and at 3 months. Adverse events included the total number of emergency department visits for high or low blood sugar within the past 3 months, number of hospital admissions within the past 3 months, and number of days missed from school or work. The total number of self-reported adverse events were

collapsed into a binary variable, coded as “0” for no adverse events and “1” for one or more adverse events.

Other analyzed covariates included HgA1C level (extracted from each patient’s electronic medical record) and demographic information collected at baseline, including gender, marital status, education, employment status, years of diagnosed diabetes, health insurance status, and literacy level.

The data analysis was based on 48 participants who completed the pilot study, drawn from the RN telephone intervention group ($n = 20$) and CHW intervention group ($n = 24$). The usual-care or control group ($n = 5$) was excluded from analysis due to an insufficient sample size. PAM scores and # *DM REC met* were analyzed at baseline and 3 months. Data collection for PAM occurred at baseline and at 1-, 2-, and 3-month intervals; however, only baseline and 3-month scores were incorporated for analysis. PAM scores were analyzed for descriptive statistics, independent samples *t*-test (RN vs. CHW), and a paired samples *t*-test (mean change baseline to 3 months). SPSS v.24 software was used for analysis.

Results

The independent samples *t*-test revealed no significant differences in PAM score means between the intervention groups. Comparisons of median PAM scores using the non-parametric Mann-Whitney test of independent samples also demonstrated non-significant differences between the RN telephone intervention and CHW intervention groups (baseline median PAM score: 56.0 [RN], 57.65 [CHW]; 3-month median PAM score: 59.3 [RN], 62.6 [CHW]). At baseline, mean PAM scores were 61.98 ($SD = 15.55$) for the RN telephone intervention group and 60.48 ($SD = 12.88$) for the CHW

intervention group. At 3 months, the mean PAM scores were 63.85 ($SD = 17.85$) for the RN telephone intervention group and 68.82 ($SD = 16.08$) for the CHW intervention group (see Table 1).

Table 1. *Statistical Results for CHW and RN Telephone Management Intervention Groups*

	CHW Intervention	RN Telephone Management
Baseline PAM score (mean)	60.48 ($SD = 12.9$)	61.98 ($SD = 15.5$)
3-month PAM score (mean)	68.82 ($SD = 16.1$)	63.85 ($SD = 17.8$)
Mean change	+ 8.57 **	+ 1.32 (ns)
Baseline PAM score (median)	57.65	56.0
3-month PAM score (median)	62.6	59.3
Mann-Whitney test	ns	ns

(** = $p < .01$; ns = not significant)

A paired samples t -test was conducted to evaluate the impact of the intervention on PAM scores. For the RN telephone management group, the mean increase in PAM scores from baseline to month 3 was +1.32, but the difference was not statistically significant ($p = .73$). A statistically significant increase in PAM scores was observed from baseline to month 3 in the CHW intervention group ($M = 60.31$, $SD = 13.3$ [baseline]; $M = 68.89$, SD

= 16.39 [month 3]), $t(22) = -2.924, p = .008$. The mean increase in PAM score was +8.57 at a 95% confidence interval [2.49, 14.65]. The CHW intervention exhibited an estimated medium effect size ($d = 0.58$).

Pearson correlations were performed with PAM scores, # *DM REC met*, and HgA1C levels at baseline and 3 months. At baseline, the mean # *DM REC met* was 8.9 ($SD = 1.89$); at 3 months, the mean rose to 9.5 ($SD = 1.73$) of 13 possible recommendations. A positive association emerged between PAM scores and self-reported #*DM REC met* ($r = .356, p = .014$) at the 3-month point but was not significant at baseline. A significant correlation was observed between PAM scores and HgA1C levels ($r = -.306, p = .029$) at baseline only. The mean HgA1C at baseline was 9.6 ($SD = 2.20$) compared to 8.59 ($SD = 1.71$) at 3 months.

Pearson correlations with PAM scores were tested using the following covariates: randomization group, gender, employment status, years of diagnosed diabetes, health insurance status, and literacy level. No significant correlations were found among PAM scores and covariates. Next, a simple linear regression was performed for PAM scores and # *DM REC met*; PAM scores increased by 3.6 points on average for every additional diabetes recommendation met. Pearson correlations were also determined between PAM scores and the number of adverse events. No significant associations emerged between PAM scores and total adverse events or between PAM scores and individual adverse events.

Poisson regression models were assessed using baseline and 3-month PAM scores as the predictor variable and # *DM REC met* as the dependent count variable. The model

did not result in a significant difference in log expected counts, nor did PAM scores predict # *DM REC met*.

Discussion

This secondary data analysis focused on a group of rural-dwelling adults living with type 2 diabetes. Results revealed a positive association between patient activation and reported use of diabetes preventive health services. Consistent with prior research, this study found PAM scores to be strong predictors of preventive health behaviors, such as following American Diabetes Association (ADA) recommendations for diabetes preventive services (Frosch et al., 2010; Hibbard & Greene, 2013). On average, PAM scores increased by 3.6 points for every additional diabetes recommendation met. These findings indicated that higher patient activation levels were associated with engagement in preventive health behaviors and medical care.

The preliminary findings of the pilot study, especially the face-to-face CHW intervention, demonstrated potential for a positive impact on patient activation, which could also facilitate patient engagement in recommended diabetes preventive health services. Diabetes self-management can be onerous; the ADA recommends more than 13 preventive activities (American Diabetes Association, 2018). Individuals with diabetes are initially responsible for seeking relevant preventive services; however, collaboration between the health care system and individuals with type 2 diabetes is crucial to promoting engagement in such services (Smith, Berman, Hiratsuka, & Frazier, 2015). Health care providers must consistently monitor patients for diabetes-related complications in addition to patients actively seeking preventive services. Thus, the burden of responsibility in adhering to ADA recommendations falls on both parties.

In the general population, the rate of participation in diabetes preventive health services is higher among women, adults older than 65, and those with higher education levels (CDC, 2018; Hale et al., 2010; Villaroel et al., 2015). Our study sample, which was predominantly older, female, and African-American, was consistent with similar populations in being relatively adherent to recommended diabetes preventive services. On average, our sample of rural-dwelling adults self-reported meeting approximately 9 of 13 diabetes recommendations (i.e., complying with 70% of recommendations). Although the sample had low educational attainment, participants' level of engagement in preventive services was fairly adequate.

Participants tended to have lower educational status, and approximately 50% reported having attended at least one diabetes class. According to the CDC (2018), attendance at diabetes education remains relatively low (54% on average) for persons with diagnosed diabetes. Rural populations are also less likely to participate in diabetes education, partly due to lack of access to diabetes self-management education (DSME) providers or programs. More than 60% of rural counties in the U.S. lack a DSME program (Rutledge, Masalovich, Blacher & Saunders, 2017). Several community-based DSME programs have been developed and show promise for improving diabetes self-management behavioral outcomes in various populations, including rural communities and minority groups (Lorig et al., 2010; Philis-Tsimikas et al., 2012; Samuel-Hodge et al., 2009; Towne, Smith, Ahn, & Ory, 2014). DSME programs have also demonstrated positive effects on patient activation (Flode, Iversen, Aarflot, & Haltbakk, 2017; Frosch et al., 2010; Ledford, Ledford, & Childress, 2013; Lorig, Ritter, Villa, & Armas, 2009, 2010). However, little is known about how DSME can facilitate patient activation and

engagement in diabetes preventive health services. Some studies using CHWs and peer coaches to deliver DSME interventions have found improvements in patient activation levels but did not identify clinically significant improvements in HgA1C levels (Lawson et al., 2013; Lorig et al., 2009; Safford et al., 2015). Although DSME can promote positive health outcomes, education alone may not be sufficient for sustained behavior change (Lepard, Joseph, Agne, & Cherrington, 2015; Norris, Lau, Smith, Schmid, & Engelgau, 2002).

The results of this secondary data analysis support prior evidence that the level of patient activation is associated with use of diabetes preventive health services as well as glycemic control. A retrospective study demonstrated that a 1-point increase in PAM score was associated with a 1.8% increased likelihood of reducing HgA1C less than 8% (Remmers et al., 2009). The high rate of poorly controlled diabetes in the present study's predominantly low socioeconomic, African-American sample of rural-dwelling adults reflects disparities in U.S adults with diagnosed diabetes. The baseline average HgA1C in this sample was 9.6%, exceeding the ADA recommendation of 7% or less (ADA, 2018). Moreover, the study population had other risk factors for uncontrolled diabetes, including a high poverty rate and median income of \$32,300. Living in poverty or in disadvantaged neighborhoods is another risk factor for uncontrolled diabetes (Tabaei et al., 2017).

Although improvements in HgA1C were not investigated in this analysis, a positive relationship between higher patient activation levels and glycemic control was found. Based on previous research, higher baseline HgA1C levels have been associated with larger improvements in glycemic control in patient activation interventions for adults with type 2 diabetes (Bolen et al., 2014). Consequently, individuals with poorly

controlled diabetes or with lower patient activation might benefit from CHW or RN telephone-assisted diabetes self-management interventions. The impact of diabetes interventions on long-term diabetes outcomes remains unknown, but improvements in glycemic control could help to prevent diabetes-related complications; a reduction of 1 absolute percentage point in HgA1C among adults with type 2 diabetes has been associated with a 21% reduction in mortality (Stratton et al., 2000).

The CHW intervention group in this study displayed significant improvements in diabetes outcomes (e.g., patient activation) compared to the RN telephone management group. A face-to-face intervention with CHW's could offer advantages for rural populations compared to telephone support modalities. In several studies, diabetes self-management interventions used a combination of in-person and telephone visits in accordance with patient preferences (Allen et al., 2011; Kangovi et al., 2017; Palmas et al., 2015; Tang et al., 2014). The convenience of either in-home or telephone visits also improved retention compared to travel required for DSME interventions (Lepard et al., 2015). Overall, regardless of the intervention modality, positive clinical outcomes have followed from CHW- and RN-assisted interventions (Rosal et al., 2014; Rothschild et al., 2014; Safford et al., 2015; Wolever et al., 2010). The effect of CHW interventions has demonstrated a more significant reduction of HgA1C levels in older adults, namely over 55 years, than younger counterparts (Campos et al., 2018). However, there remains insufficient evidence to determine whether in-person visits are superior to telephone visits (Ciemins, Coon, Peck, Holloway, & Min, 2011; Lepard et al., 2015; Rosal et al., 2014). Overall, adding collaborative goal setting and motivational support to CHW or peer support appears to offer an advantage over DSME alone (Lepard et al., 2015).

The relationship between PAM and health utilization, namely adverse events, remains unclear. Additionally, the effects of diabetes self-management interventions on lowering hospital admissions and emergency department visits have been inconsistent (Begum, Ozolins, & Dower, 2011; Lorig, 2012; Sacks et al., 2017). A recent randomized controlled trial using a CHW intervention demonstrated significant decreases in hospital admissions but non-significant improvements in PAM scores (Kangovi et al., 2017).

Limitations of our study include higher mean baseline PAM scores compared to similar intervention studies in rural areas (Safford et al., 2015; Schoenberg et al., 2017). Furthermore, more than 75% of the sample was at PAM Level 3 or higher at baseline. The sensitivity of PAM is lower for higher activation levels (Level 4), and ceiling effects have been identified (Hung et al., 2013). Overall, participants with higher baseline HgA1C levels experience greater improvements in clinical outcomes (Bolen et al., 2014). More research is therefore needed to clarify whether participants with lower baseline PAM scores would experience greater improvements in clinical outcomes compared to those with higher baseline scores.

To date, no systematic review or meta-analysis has evaluated the effects of diabetes-focused interventions on patient activation. Bolen et al. (2014) synthesized 138 randomized controlled trials of patient activation interventions for adults with type 2 diabetes; however, PAM levels were not assessed as a diabetes outcome. Patient activation can be a useful measure of diabetes self-management behaviors but has not been widely studied as a primary diabetes outcome (Brewster, Tarrant, & Armstrong, 2015). A comparative effectiveness trial using PAM as a primary outcome was recently designed to evaluate the impacts of diabetes self-management and social support (Page-

Reeves et al., 2017). Patient activation may function as a mediator; however, the mechanism of the relationship between patient activation and diabetes outcomes requires further substantiation (Parchman et al., 2010; Williams et al., 2005). More randomized controlled trials, especially among under-resourced, rural, and minority populations, are needed to fully evaluate the usefulness of PAM in health research.

Interventions focused on facilitating engagement in diabetes preventive health services could exert strong influences on diabetes-related long-term morbidity and mortality. The past decade has witnessed an increase in the use of diabetes preventive services along with a reduction in the rate of diabetes-related complications (CDC, 2018; Gregg et al., 2014). A recent 3-year longitudinal study showed that higher patient activation levels resulted in better diabetes outcomes and lower odds of developing diabetes in persons with pre-diabetes (Sacks et al., 2017). More longitudinal studies are needed to evaluate the effect of patient engagement in preventive health behaviors on long-term diabetes outcomes, but current evidence appears promising (Hibbard, Greene, Shi, Mittler, & Scanlon, 2015). A recent 3-year longitudinal study showed that higher patient activation levels resulted in better diabetes outcomes and lower odds of developing diabetes in persons with pre-diabetes (Sacks et al., 2017).

Conclusion

Results of secondary data analysis highlight the need to promote engagement in diabetes preventive services and minimize the risk of long-term complications associated with diabetes. More research is needed to determine whether facilitating engagement in diabetes preventive services could lead to a decrease in health disparities among rural, minority populations. Furthermore, lower rates of engagement in diabetes preventive

services found in younger adult populations, specifically those 18 to 39 years, warrant attention. Subsequent studies are needed to determine whether community-based interventions could benefit younger adult populations with diabetes, particularly in enhancing their engagement in relevant preventive services.

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CHAPTER THREE: RURAL PREP MICRORESEARCH GRANT PROPOSAL

Submitted to Rural Primary Care, Research, Education and Practice Collaborative,
2/28/2018

EXPLORING THE ENGAGEMENT IN PREVENTIVE HEALTH SERVICES AMONG RURAL, WORKING ADULTS WITH TYPE 2 DIABETES

Background

A significant number of working adults with diabetes fail to engage in recommended, preventive health services despite expanded health care access by the Affordable Care Act, more technology, and improved quality of diabetes care (Villarroel, Vahratian, & Ward, 2015). Younger adults with diabetes are less likely to engage in preventive health services, such as blood pressure checks, cholesterol screening, and contact with an eye or foot specialist, as compared to their older counterparts (Villarroel et al., 2015; Chou et al., 2012). Moreover, compared to top wage earners, low-wage earners are less likely to engage in preventive care and more likely to experience poor diabetes outcomes, with up to 4 times higher rates of avoidable hospital admissions for ambulatory care sensitive conditions and more than double the rate of diabetes-related deaths (Harris, Huang, Hannon, & Williams, 2011; Saydah & Lochner, 2010).

Patient activation, being informed and having the knowledge, skills, ability and willingness to take part in managing one's health and care, is one of the many factors that can affect diabetes self-management (Hibbard, Mahoney, Stockard, & Tusler, 2005). Patient activation is a developmental, cognitive process that leads to healthy behaviors. Low levels of patient activation have been associated with fewer preventive care

behaviors, such as cholesterol and HgA1C testing (Hibbard & Green, 2013; Remmers et al., 2009). However, little is known about the relationship of patient activation to the use of preventive health services in rural populations (Greene & Hibbard, 2012; Rask et al., 2009; Remmers et al., 2009).

Economic and health care resources are typically more limited in rural populations, or non-metropolitan areas with populations less than 50,000 (Meit et al., 2014). While advances in medical care and better management of risk factors have reduced diabetes-related complications, the U.S. health care system contributes a relatively small proportion to overall health outcomes (Gregg et al., 2014; Scott & Wilson, 2011; Williams, McClellan, & Rivlin, 2010). Social and economic conditions in homes, neighborhoods, schools, and workplaces may have a more significant impact on health outcomes than medical care (Braveman, Egerter, & Williams, 2011). Rural hospital closures continue to rise, forcing rural populations to travel longer distances for health care services (Kaufman et al., 2015). Specialty care may be limited in rural areas due to provider availability or insurance coverage. For example, an estimated 15% of counties in the U.S. lack eye care professionals and insurance coverage for dilated eye exams may be limited (Chou et al., 2012). These factors place a significant burden upon rural, working adults with type 2 diabetes and may impede engagement in preventive health services and regular medical care. (Hale, Bennett, & Probst, 2010; Karpman & Long, 2015).

The microresearch study will focus on a population that is particularly vulnerable to poor diabetes outcomes—rural, working adults with type 2 diabetes (DM) and low patient activation—in an effort to gain a better understanding of the critical (and

potentially modifiable) social and economic factors that impact the ability to engage in care. These findings will begin to address the research gap concerning the distinct issues of rural, working adult populations and help form an important foundation for the investigator's future research in community-based interventions.

Research Question

What are the leading individual, interpersonal, health system, and community factors that facilitate or hinder engagement and use of recommended, preventive health services among rural, working adults with type 2 DM?

Methods

Sample: Study participants will be working adults recruited from selected rural, tri-county area employers. Employees who are low-wage earners (earn less than \$50,000 annually) in the rural, tri-county area will be targeted, from an estimated pool of over 4,000 employees with diagnosed diabetes. Sample size is estimated at 15 participants, based on data saturation needed for this qualitative study.

Inclusion Criteria: Participants will be English-speaking, adults aged 18 to 65 years, employed for wages 20 or more hours per week, reside or work in the named tri-county rural area, documented type 2 DM who score low on the PAM (i.e., Level 1, 2, or 3), a 13-item well-validated questionnaire with possible scores ranging from 0 to 100 (patient activation levels 1, 2, 3, or 4) (Hibbard et al., 2005).

Exclusion Criteria: Individuals diagnosed with type 1 DM will be excluded.

Participant Identification and Recruitment: Participants will be recruited from worksites that have been participating in the employee health evaluation and wellness program conducted by the employer relations department of the regional tri-county hospital.

Working with this department, the primary investigator (PI) will identify worksites that employ low-wage earners. The PI and/or research assistant (RA) will arrange for a brief information session about the study with the employer and obtain consent to conduct recruitment activities and initial screening at the worksites. Worksite newsletters, flyers, and social media will be used to promote the study prior to the initial screening.

Recruitment may be expanded to other area employers not participating in the hospital-affiliated program, if needed.

Description of Methods and Procedures: The PI and RA will conduct face-to-face screenings at the worksite (e.g., lunch, after work hours). Participants may alternatively choose to complete an online eligibility survey. At the initial screening, demographic information (age, gender, occupation or job grade, insurance status, zip code) will be collected and the PAM will be administered by the RA. Participants identified with low PAM levels (1, 2, or 3) will then be invited to participate in an individual semi-structured interview. After obtaining informed consent, the PI will conduct the interview in a mutually agreed upon private location (e.g., private meeting room at local hospital). Participants will receive \$10 for their time conducting the initial screening and a \$50 gift card for their time in the interview.

Data Collection and Plan for Analysis: A semi-structured interview guide will be developed to explore the individual, interpersonal, system, and community factors that facilitate or hinder engagement and use of recommended, preventive health services for persons with type 2 DM. Preventive health services explored will be those recommended by American Diabetes Association: dilated eye exam, foot exam or podiatry care, dental visit, vascular screening, education class (diabetes or nutrition), cholesterol, HgA1C,

blood pressure, and urine protein/microalbumin screening (American Diabetes Association, 2018). The research will be guided by Fisher’s (2005) Resources and Supports for Self-Management Socioecological Model, which will provide the framework for interview questions as well as thematic data analysis. Interviews will be digitally recorded, transcribed verbatim, and exported for analysis with NiVivo software. Transcriptions will be coded, grouping similar data and predominant themes. The analysis will emphasize themes related to identifying specific resources and sources of support used to facilitate the use of preventive health services, but the investigator will remain open to emerging themes and patterns in the data (Denzin & Lincoln, 2011; Glasgow, Toobert, Barrera, & Strycker, 2005).

Expected Products/Dissemination

Research findings will form a foundation for future community-based research and help design effective interventions that enhance patient activation and health outcomes among rural, working adults with type 2 DM. Dissemination will include sharing the collective results within the community via a community publication (i.e., hospital newsletter), a manuscript submitted to a peer-reviewed journal that focuses on rural health care, and an abstract for presentation at the Rural PREP annual conference.

	Month	Month	Month	Month	Month	Month
ACTIVITY	1	2&3	4-6	7&8	9&10	11&12
Recruit staff, submit IRB application						
Meetings with local business organizations: pre-and post-data collection						
Train staff						

Prep. recruitment flyers, letters, surveys						
Meetings with employers: pre- and post-data collection						
Recruitment & data collection						
Analyze data						

Timeline

April 2018: Recruit and train research assistants; contact local employers and businesses for possible recruitment sites; obtain Human Subjects IRB approval

May – June 2018: Prepare and schedule participant recruitment dates; prepare data collection supplies; complete initial participant recruitment and screening by June 20, 2018; recruitment for semi-structured interviews

July – September 2018: schedule and conduct individual semi-structured interviews; begin demographic and NVivo data entry

October 2018 – January 2019: NVivo data entry and analysis

February 2019 – March 2019: Dissemination of results; meetings with employers/businesses for possible future interventional studies

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CHAPTER FOUR: THE "UPS AND DOWNS" OF LIVING WITH TYPE 2
DIABETES AMONG WORKING ADULTS IN THE RURAL SOUTH

MANUSCRIPT (in preparation)

Introduction

Diabetes is an extraordinary economic and health care burden in the United States (American Diabetes Association [ADA], 2018). The risk of death for adults with diabetes is 50% higher than for adults without diabetes and recent trends indicate that diabetes-related mortality and complication rates are increasing among younger adults, ages 18–44 years (Gregg, Hora, & Benoit, 2019). The number of deaths due to stroke increased from 9,956 deaths in 2000 to 12,116 deaths in 2015 for middle-aged (55–64 years) adults with diabetes (Yang et al., 2017). Moreover, hospitalization rates for diabetes-related lower-extremity amputation (LEA) increased by 75% in younger adults. This rise in LEA rates, between 2010 and 2015, was a reverse in significant trends for the previous two decades. (Centers for Disease Control and Prevention [CDC], 2019; Geiss et al., 2019).

Despite advances in medical care, better management of risk factors, and expanded health care access by the Affordable Care Act, a significant number of adults living with type 2 diabetes mellitus (T2 DM) fail to engage in recommended, preventive health services in the U.S. (Hong, Jo, & Mainous, 2017; Villarroel, Vahratian, & Ward, 2015). Rural-dwelling and younger adults with T2 DM are less likely to engage in diabetes preventive health services, such as cholesterol screening and contact with an eye or foot specialist, as compared to urban-dwelling and older counterparts (Villarroel et al., 2015; Ziller, Lenardson, Paluso, & Janis, 2019). Moreover, low-wage earners are less likely to engage in preventive care and more likely to experience worse health outcomes.

Low-wage earners also have a four times higher rate of avoidable hospital admissions for ambulatory care sensitive conditions than top wage earners (Callaghan, Towne, Bolin, & Ferdinand, 2017; Harris, Huang, Hannon, & Williams, 2011; Saydah & Lochner, 2010).

Other factors, besides income, age and place of residence, can influence health behavior and outcomes (Glanz, Rimer, Viswanath, 2015). Social and economic conditions in homes, neighborhoods, schools and workplaces may have a significant impact on health outcomes (Braveman, Egerter, & Williams, 2011; Christine et al., 2015). Community-level characteristics, such as higher physician density, access to healthy foods and adequate built environment for physical activity, have been associated with the likelihood that an individual will engage in diabetes preventive services (Berkowitz et al., 2015; Luo et al., 2014; Smalls, Gregory, Zoller, & Egede, 2014). However, the impact of workplace environment on engagement in preventive health services is not well established (Linnan, Fisher, & Hood, 2013; Smith et al., 2014).

Another important factor that can influence health behavior and self-management of chronic health conditions, such as diabetes, is *patient activation* (Hibbard, Mahoney, Stockard, & Tusler, 2005). Patient activation is a developmental, cognitive process that leads to healthy behavior. Patient activation consists of being informed and having the knowledge, skills, ability and willingness to take part in managing one's health and care. Low levels of patient activation have been associated with engagement in fewer preventive care behaviors, such as cholesterol and HgA1C testing (Hibbard & Green, 2013; Remmers et al., 2009). However, little is known about the relationship between patient activation and the use of diabetes preventive health services in rural populations (Greene & Hibbard, 2012; Rask et al., 2009; Remmers et al., 2009).

A number of known barriers exist that lead to low engagement in diabetes care among rural, low-income populations. Such barriers include lack of insurance, delayed care because of costs, transportation challenges, fewer paid days off for medical appointments, physician or provider shortages, lower education and literacy levels, and competing family priorities (Ross, Benavides-Vaello, Schumann, & Haberman, 2015; Talbot, Ziller, Lenardson, & Hartley, 2014). Other barriers to engaging in diabetes preventive health services may include a lack of social or formalized support for diabetes self-management and education (Berry et al., 2013).

The health system is ultimately responsible for providing diabetes preventive services. However, economic and health care resources are typically more limited in rural populations, or non-metropolitan areas with populations less than 50,000 (Meit et al., 2014). Rural-dwelling individuals are more likely to experience a lack of health care access and rural hospital closures have forced rural populations to travel longer distances for health care services (Agency for Healthcare Research and Quality, 2017; Kaufman et al., 2016; Spleen, Lengerich, Camacho, & Vanderpool, 2014). Further, specialty care providers may be limited in rural areas placing a significant burden upon rural, working adults with T2 DM to seek care outside their community. (Chou et al., 2012). Ultimately, these factors may impede engagement in preventive health services and regular medical care (Hale, Bennett, & Probst, 2010; Towne et al., 2017). This qualitative study addressed a population particularly vulnerable to poor diabetes outcomes; rural, working adults with T2 DM with low levels of patient activation (Kangovi et al., 2017; Sacks, Greene, Hibbard, Overton, & Parrotta, 2017; Schoenberg, Ciciurkaite, & Greenwood, 2017).

Methods

Using qualitative methodology of narrative description, this study sought to gain a better understanding of the critical, and potentially modifiable, factors that impact the ability of rural, working adults to engage in diabetes preventive health services and healthy behaviors (Wertz et al., 2011). In health professions disciplines, narrative description is a valuable research method (Hyden, 1997). Influential factors, such as the use of social and community resources, were explored as well as how they facilitate the use of preventive health services for this priority population. Hearing and analyzing personal accounts of rural dwelling adults living with T2 DM allowed for a deeper examination of the factors that influence engagement in diabetes care.

Design

This study used a socioecological approach to guide narrative inquiry (Braveman et al., 2011; Chase, 2018). The Patient Activation Measure (Hibbard & Mahoney, 2010) was used as a screening tool to identify individuals living with T2 DM and low levels of patient activation. Fisher's (2005) Resources and Support for Self-Management model was used to guide the development of interview questions and data analysis (Fisher et al., 2005). This socioecological model integrates four spheres of influence on individual health behavior with the services and support they receive from their environment and community (Figure 1). The model by Fisher et al. (2005) asserts that individual self-management skills needed for health behavior change are influenced by individual, interpersonal, institutional and environmental factors. Data was collected using semi-structured interviews, which explored the individual, interpersonal, health system and community factors that influence preventive health behaviors. The interviews allowed for

a collection of broad perspectives on beliefs, opinions and behaviors within the community about diabetes (Schensul, Berg, & Nair, 2013; Brinkmann, 2018). The study addressed two research questions:

1. What are the individual, interpersonal, health system, and community factors that facilitate, modify or hinder engagement and use of recommended, preventive health services among rural, working adults with T2 DM and low patient activation scores (<75), as measured by Patient Activation Measure?
2. How do the individual, interpersonal, health system, and community factors facilitate, modify or hinder engagement in recommended, preventive health services according to rural, working adults with T2 DM and low patient activation scores (<75), as measured by Patient Activation Measure?

The study was approved by the Institutional Review Board (IRB) of the University of Missouri and the local institutional IRB.

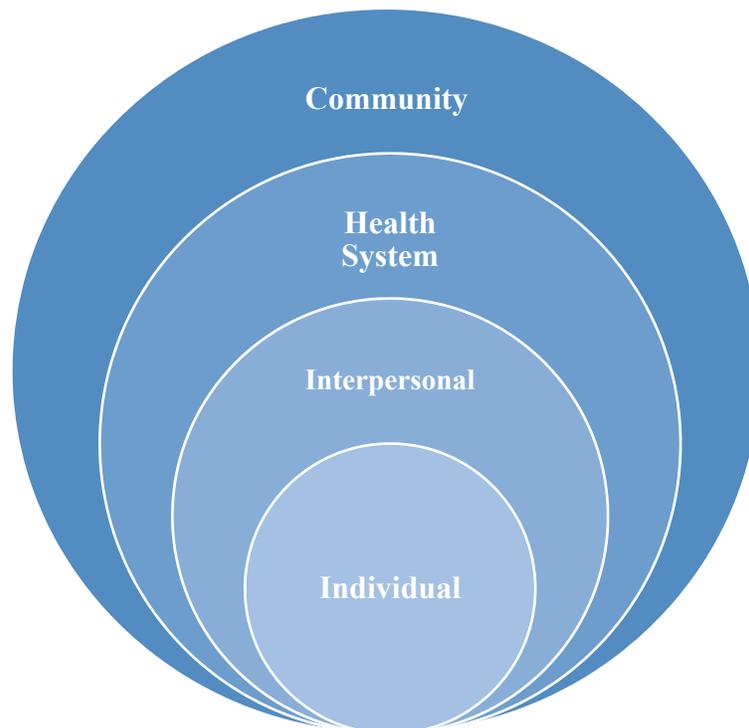


Figure 1. Resources and Supports for Self-Management Model. Adapted from “Ecological Approaches to Self-Management: The Case of Diabetes” by E. B. Fisher, C. A. Brownson, M. L. O’Toole, G. Shetty, V. V. Anwuri, and R. E. Glasgow, 2005, American Journal of Public Health, 95(9), pp. 1524.

Participants

Inclusion criteria were as follows: English-speaking adults, age 18 to 65 years, diagnosed type 2 DM, employed for wages 20 or more hours per week, reside or work in the named tri-county rural area, and patient activation score below 75 (i.e., level 1, 2 or 3). Exclusion criteria were: individuals diagnosed with type 1 DM, unemployed, not residing or working in named tri-county area, and patient activation score above 75 (level 4). Diagnosis of T2 DM was assessed via self-report by the participants.

Procedures

Rural working adults living with T2 DM in a tri-county rural area were recruited from local employers, such as elementary schools, hospital employees, and manufacturing companies. During routine health screenings and flu clinics conducted at the worksites, information about the study was provided to potential participants and small gift incentives (less than \$10 value) were provided for completion of the Patient Activation Measure (PAM-10).

The Patient Activation Measure (PAM-10) was used as a screening tool during recruitment to identify adults with T2 DM who were poorly engaged in care (i.e., PAM-10 score less than 75). The PAM-10 is a well-validated measure (Rasch: 0.81) of how people view themselves as managers of their own health (Hibbard & Mahoney, 2010). Patient activation is the cognitive appraisal of knowledge, skills, and confidence for managing one’s health, whereas engagement is considered actual health behavior (Mittler, Martsolf, Telenko, & Scanlon, 2013). The measure has demonstrated strong

associations with constructs such as preventive, self-management, and consumeristic behaviors (Hibbard et al., 2005). Scores on the PAM-10 range from 0 to 100, corresponding to patient activation levels 1, 2, 3, and 4 (Hibbard et al., 2005) See Appendix A. Individuals with PAM-10 scores <75, or levels 1, 2, and 3 (i.e., lower patient activation levels) were included in the study (Figure 1).

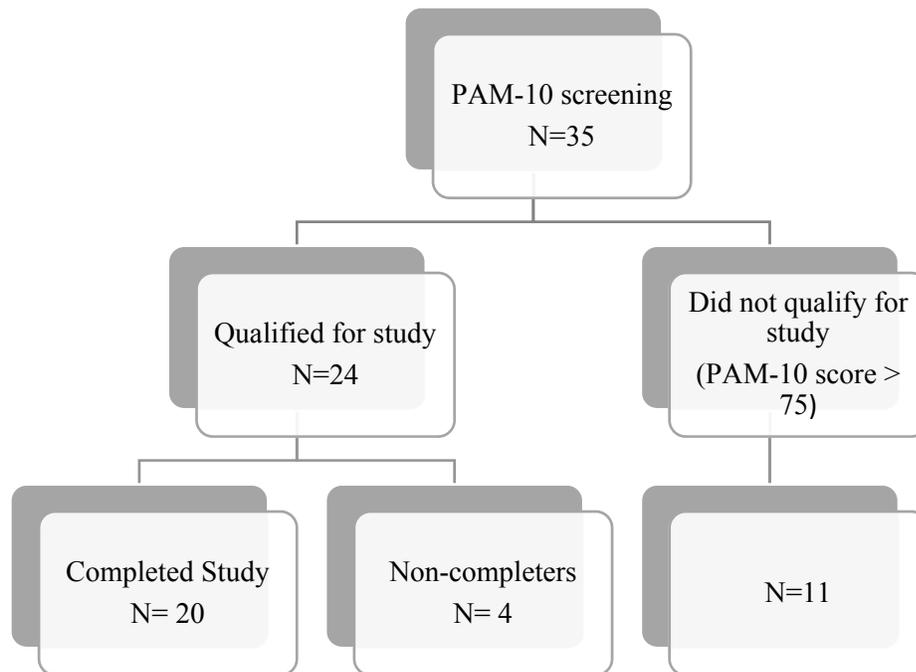


Figure 2. Screening: Patient Activation Measure (PAM-10).

Data Collection

Written informed consent was obtained from each participant prior to data collection (see Appendix C). One investigator (L.G.) conducted all interviews, which averaged 60 minutes in length. The interviews were conducted at a mutually convenient location, such as a private meeting room in local hospital, clinic or church. A semi-structured interview guide (Table 1) was used to explore the individual, interpersonal, system and community factors that facilitate or hinder engagement and use of

recommended, preventive health services for persons with T2 DM, based on the model from Fisher et al. (2005). Demographic data (age, race, gender, county of residence and employment, income, and insurance status) were collected using a paper and pencil questionnaire (see Appendix F). Interviews were digitally recorded.

Table 1. *Interview Guide*

SOCIOECOLOGICAL RESOURCES & SUPPORTS (FISHER ET AL., 2005)	QUESTIONS/PROBING QUESTIONS
A) Individual	
job position, diagnosis of DM, diabetes self-care, preventive behaviors and health service use, personal goals	<p>Tell me about ...</p> <p>yourself (your job/work)</p> <p>the story how you found out you had diabetes</p> <p>difficult things or challenges about managing your diabetes</p> <p>some of the specific things you do well to manage your diabetes</p> <p>tests or services do you think you need on a regular basis to manage your diabetes</p>
B) Interpersonal	
family and friends support, social network and activities, health promotion activities with others	<p>Tell me about ...</p> <p>your family and friends that help you manage diabetes/how do they help you?</p> <p>things you like to do with family and friends /that help manage your diabetes</p> <p>what you like to do in your free time</p>
C) Health System	
engagement with health care providers and services, decision making	<p>Tell me about ...</p> <p>your relationship with health care provider ...</p>

visits with your provider, the nurse, eye doctor, etc. ...

things that your doctor or nurse does that help you take care of your diabetes

complications of DM

Do you understand the results of tests that your doctor orders for diabetes?

Do you think your provider includes you as an equal partner in your care?

D) Community

Workplace, community engagement, resources for diabetes/health, built environment, neighborhood food and housing availability

Do you know the resources in your community or local area that can help prevent the complications of DM?

Do you attend wellness or health education programs at your workplace or local area?

What kind of programs would you like to see in your area/workplace?

Tell me about your job and policies for letting people go to doctor's appointments ...

Tell me about your neighborhood ... Are there parks? Restaurants or grocery stores with healthy food?

Data Analysis

Transcripts were transcribed verbatim and exported with NVivo qualitative software for data analysis; QSR International Pty Ltd., Version 11, released 2015. Data was coded, grouping similar data and predominant themes. Two investigators, one who conducted the interviews (L.G.) and another with experience in qualitative research (M.E.), conducted the data analysis. Content analysis of interview data emphasized themes related to identifying specific resources and sources of support used to facilitate the use of preventive health services (Sandelowski, 1995). The four major categories of the model by Fisher et al. (2005) (i.e. individual, interpersonal, health system, and community) were used for a priori coding and initial themes (Figure 1). However, the investigators were open to emerging themes and patterns in the data (Denzin & Lincoln, 2018). Transcripts were reviewed, additional codes were assigned, and predominant themes and patterns were discussed between both investigators. Themes and theme-related passages coded as code exemplars were agreed upon and reported as results. The participant quotes are presented in original, unedited form to reflect an accurate description of the phenomena of living with T2 DM among this rural, working adult population.

Results

Participants ($n = 20$) were rural-dwelling, working adults with type 2 diabetes, ranging in age from 25 to 65 years with low patient activation scores (i.e., level 1, 2, or 3 as measured by PAM-10). Almost half of the participants resided in the most rural counties, small-town core with urban cluster 2,500 to 9,999 population and small-town high commuting to small urban cluster, as defined by the Rural Urban Commuting Areas

(RUCA) designation. Most participants were female (70%), African American (60%), and had health insurance (75%). However, the majority of participants had annual incomes less than \$50,000 (65%), which is lower than the U.S. 2017 median income of \$61,732 (U.S. Census Bureau, 2018) and 80% worked full-time (Table 2).

Table 2. *Demographic Characteristics of Study Sample (n=20)*

Age (years)	47.3 (25–65)
Race (African American)	12 (60%)
White	7 (35%)
Other (Indian)	1 (5%)
Gender (Female)	14 (70%)
Male	6 (30%)
County of Residence (classification)	
Rural (RUCA >5)	8 (35%)
Rural (RUCA < 5)	2 (10%)
Micropolitan	9 (45%)
Metropolitan	1 (5%)
County of Employment (classification)	
Rural	10 (50%)
Micropolitan	8 (40%)
Metropolitan	2 (10%)
Employment Status	
Full-Time ~40 hours/wk.	16 (80%)
Part-Time ~20 hours/wk.	4 (20%)
Annual Income (Less than \$50,000/year)	13 (65%)
More than \$50,000/year	7 (35%)
Insurance (via employee benefits)	13 (65%)
Uninsured	5 (25%)
Medicare	1 (5%)
VA insurance	1 (5%)
Patient Activation Score (PAM-10)	59.4 (47.4–72.1) 6.8 s.d.

Note. RUCA = Rural Urban Commuting Areas

There were four themes with three subthemes and an overarching theme, “living with the ups and downs of diabetes” that emerged from the data. The major themes were

the “struggle”, “doing things together”, “diabetes is not the priority”, and “we’re lucky to have what we have”. The four major themes reflected the spheres of the model by Fisher et al. (2005), which were associated with individual, interpersonal, health system, and community resources and support that influence engagement in diabetes self-management and preventive health services (Table 3).

Table 3. *Themes and subthemes by level of influence* (Fisher et al., 2005)

Themes/ Level of Influence	Subthemes
Individual The “struggle”	Developing Responsibility
Interpersonal Doing things together	“You don’t talk about it”
Health System Diabetes is not the priority	Fear and Shame
Community “We’re lucky to have what we have”	Health care provider support

Overarching theme: Living with the “Ups and Downs” of Diabetes

The overarching theme, living with the “ups and downs” of diabetes, resonated within the data. This group of working adults ($n = 20$) experienced inconsistencies living with diabetes, described as an “up and down” phenomenon. Living with the “ups and downs” of diabetes was portrayed by both positive and negative experiences. The participants had experiences that described the ability, or inability, to make needed lifestyle changes. Adhering to healthful behaviors, such as healthy eating and exercise, was inconsistent, as was glucose control. As explained by one of the female participants:

Then I realize it's (blood sugar) going up again, go to the doctor and they get on me about it and then I go back to eating like I was supposed to eat. And then after a while when I feel like I'm comfortable with it again, I go eating what I want to eat. And it just up and down, up and down, up and down. Diabetes is something I just don't wish on my worst enemy.

Theme 1: The “Struggle”

The first theme characterized the individual factors related to being engaged in diabetes self-management and preventive health services. This theme portrayed the struggle of living with diabetes in a predominately poor, rural community in the Southern United States.

Denial, which led to a delay in the diabetes diagnosis, was common. Some participants had ignored their physical symptoms of diabetes for years before seeking a diagnosis, despite having risk factors for developing diabetes, such as a strong family history. As one participant stated: *“I thought that would never be me. But it ended up being me”*. Furthermore, the majority of the participants (12) had witnessed family members with diabetes-related complications. The participants described their strategies in diabetes self-management and expressed being fearfully motivated to avoid diabetes-related complications or end “up” like everyone else.

Many of the participants delayed seeking care, despite being encouraged to seek care by other family members. Fear was one of the main reasons cited for avoiding medical care, as one participant stated, *“And they kept telling me, ‘You got to go to the hospital. Go to the hospital.’ And I was scared to go”*. Some of the participants had difficulty recognizing the classic symptoms of diabetes and experienced severe,

debilitating symptoms, such as profound weakness, polyuria, and polydipsia. As recalled by one of the middle-aged, female participants:

I found out-- I was at my mom's house and I was laying on the floor. And I kept dropping to sleep and she didn't know what was going on. And my sister said-- it was unlike me. And evidently, my sugar got too high. I didn't even know I was a diabetic... I kind of figured something was wrong, but I didn't know what was wrong. I thought I was just tired. But then I really couldn't get up. And they were trying to-- I could hear them talking to me. But I couldn't wake up to get up off the floor.

Initially, their experience of living with diabetes reflected a sense of being overwhelmed as participants struggled to accept and adjust to the diagnosis of diabetes. Many participants described the difficulty adjusting to diabetes: “*dealing with it at first really depressed me*”, “*very hard*”, “*I hate being diabetic*”, “*a struggle*” and an “*uphill battle*”. Many fought to maintain blood sugar control and incorporate healthy eating and exercise into their lifestyle. Diabetes meant giving “up” their favorite foods such as sweets, sodas, rice and carbohydrates and trying to get “up” and exercise. At times, they were trying to adhere to diabetes care, or keep “up” with diabetes, but experienced inconsistency as blood sugars kept going “up and “down”.

The participants reported various emotions about living with diabetes, such as feelings of denial, feelings of regret and fear of developing diabetes-related complications. One young, single adult expressed the difficulty she endured while being the sole caretaker for her mother with diabetes-related complications. Recently, she was diagnosed with diabetes and described her feelings of deep regret about having diabetes:

It would be easier if I didn't have it. It would be easier...Yes. That would be the easiest part of it all, that I wouldn't have to do all this. Yeah. Just go for a little checkup and just be normal and just get on about my day. Yep. That would make it easier.

Subtheme: Developing individual responsibility. After struggling with the initial shock of being diagnosed with diabetes, many came to realize the importance of taking individual responsibility for their health. The participants struggled to develop new roles and healthful behaviors associated with diabetes and verbalized regret about their inability to make lifestyle changes- *“I probably need to do the exercise a little bit more per week than what I do”, “I know I should be walking”, “I should probably get back started”* or *“I know I shouldn't had it, but it was good”*. They also struggled to establish a daily routine for diabetes self-management, such as taking medications or checking blood glucose. The participants explained, *“I don't like checking my sugars...I just don't like sticking my fingers”, “I don't check my blood sugar sometimes when I'm tired”* and *“there's not a routine”*. The ability to establish a routine and make lifestyle changes was an important resource for the participants, but developed gradually as one stated, *“it took 10 years for me to get right with the exercising”*.

In addition, participants struggled with episodes of lacking self-control in eating certain foods, *“...it's just like being like an alcoholic, you want something that you know that you shouldn't be eating, but you enjoy it”* and *“some people drink, I'm an eater”*. Some of the participants took the blame for being inconsistent in diabetes self-management and struggling with self-control, verbalized as *“it's still me that doesn't take care of it”* or *“is totally my fault”*.

A significant proportion of the participants reported having family members affected by diabetes-related complications and expressed their fear of developing diabetes complications or “*I don’t want that to happen*”. The positive, or “upside”, of this fear seemed to give some of the participants a sense of motivation. This full-time working mother of two expressed her sense of individual responsibility and motivation:

But by seeing all that, and seeing what it can do to your body, it really made me take it a lot seriously as I do. I tease about it and everything, but I know in the long run if I don't take care of myself, nobody else will. So, I kind of do the best I can with what I can-- with what's available for me...It's a hard game, but it's a game that was brought at me that I know I got to work with. So, if I want to live to see my kids get grown, see my grandkids, then I got to do what I got to do. I got to take care of myself the best way I know how. I know I got to manage my diabetes

Theme 2: Doing Things Together

The theme “doing things together” and the subtheme “you don’t talk about it” emerged from the interpersonal resources and support category, based on the Fisher et al. (2005) model. Living with diabetes in a rural community included a sense of social support from friends and family. Specifically, the participants had a sense of belonging in their relationships with others and interpersonal support for diabetes self-management. Certain relationships provided emotional support, as well as a sense of accountability and motivation for diabetes self-management. The sources of social support also varied, which included family members, coworkers, friends, peers with diabetes, and role models in the community.

One of the younger participants expressed “...*once you have somebody that's helping you and kind of on the same track with you it's not as hard*”. This participant faced many stressors, including being hospitalized for uncontrolled diabetes and a skin infection, changing jobs, and experiencing family stress. He described a friend, who also has diabetes, that motivated him to take “better” care of himself and found it easier than “*trying to do it by yourself*”. Further, he felt that those who do not have diabetes lack understanding about diabetes as he described, “*It's hard for people who don't understand diabetes or don't have it, and is not going to realize someone else who has it and what kind of effect does it have on them because they don't have it*”.

A busy, middle-aged, working woman also described the sense of belonging and emotional support from others. She gave an account of a very supportive environment in a fitness “boot camp” she joined after being diagnosed with diabetes: “*And everybody was encouraging everybody. You could see a difference after the first 2 months, you can see a difference in everybody.... So, I really enjoy going there. It's the best thing since sliced bread for me*”. This support helped the participant to start exercising and lose 30 pounds. She also described having a very stressful job and the importance of receiving emotional support from a coworker, talking and going out to lunch together.

However, other participants reported not knowing friends who were living with diabetes and hence they sought diabetes-related support from other sources. One female participant, who had been living with diabetes since young adulthood, reported being engaged in “virtual” support via an online diabetes chatroom:

I am still friends with several of the people that I met through the AOL chat.

Unfortunately, about five or six of them that I met through the chat, we have since

lost. Some of the best lessons that I learned about managing diabetes, I learned talking to these people. Everything in moderation....so if I could sit in there and teach somebody else about just common sense for the disease, then it helped me learn it too. And I think the moderation was probably the best lesson learned there.

Subtheme: “You Don’t Talk about It”. Some interactions with family members, friends or coworkers were positive experiences, however, many were not. The “downs” included the difficulty of openly discussing their experiences living with diabetes. Overall, in conversations among family members or friends, participants avoided openly talking about diabetes itself. Instead, they were inclined to talk about food or eating. The participants explained that few social interactions involved talking about diabetes itself, as described “*very once in a blue moon it might come up*” and “*you don’t talk about it*”. Participants in this study seemed to prefer to “*keep it to myself*”. They indicated that their family did not talk about diabetes on a regular basis, although the participants had close family members with severe diabetes-related complications. Overall, their experiences talking about diabetes were mixed with reluctance, fear and shame amidst close, supportive relationships with friends and family.

One of the male participants described the experiences of living with his mother, who had faced adversity since childhood. His mother had suffered burns as a child, then later suffered diabetes-related complications as an adult. He described the relationship with his mother, one that was endearing, but yet conveyed authority. He stated, “*I grew up, in the kind of house I grew up, certain stuff is just not-- **You don’t talk about it.***” Moreover, he struggled with the lack of support from other family members for a healthy

lifestyle. He described family gatherings as having to “mentally set myself up” and “...because they would look at me when I first stopped eating pork and trying to get on the right thing. They would look at me like I was crazy”. In contrast, he was a source of support for healthy lifestyle to his students and fellow coworkers. He led yoga exercises at his workplace and enjoyed exercise as “socializing”.

Another participant, who was diagnosed more than 30 years ago, talked about her family experiences with diabetes. She has a living brother with diabetes, who suffered a stroke, and her mother died from end-stage renal disease and heart failure. She explained that her mother was reluctant to talk about diabetes with others.

“... when she(mother) found out she was a diabetic, to me, she was healthy. She was healthy, and she never talked to no one about her health issues. Even her closest friends that I still stay in contact with, she never told them nothing about her health.”

However, she encountered social support for diabetes self-management in her community, namely from a role-model at church:

And my spiritual mother, we would talk all the time. And anytime she would come up with something like the carrot juice, she would fix carrot and celery. She'd fix that in one and we'd drink that...She was as healthy as a mule. I just enjoyed talking with her. And we would talk when she would find different things. And books, she would give me books—good lord, to read, and I would just read, read, read. And that's how I found a lot of different things.

However, participants also described that having diabetes sometimes evoked feelings of shame or “being embarrassed”, guilt, and being judged as a diabetic. They had

encountered shame in their social interactions with family members, while exercising in gyms, with health care providers and at their workplaces. For example, one of the participants talked about the stigma associated with diabetes at her workplace, “...*she made a mistake of letting other people know she had it. So, when she wants to cheat, she can't cheat because they'll say, 'No, you can't have it'*”.

Theme 3: Diabetes is not the Priority

The third theme, “diabetes is not the priority”, incorporates the health system sphere of influence in the Fisher et al. (2005) model. The health system in the community provided access to diabetes preventive health services, including eye exams and regular laboratory screenings. Most of the participants had established a regular source of care, i.e., primary care provider, and reported having good communication and support from their health care provider. Overall, the participants had a basic understanding of the ADA recommended diabetes preventive services, such as HgA1C testing, blood pressure and cholesterol screening, urine microalbumin, foot exams and eye exams, but few participants were familiar with diabetic neuropathy screening.

The participants talked sparingly about routine diabetes preventive screenings during the interviews. Overall, the dialogue concerning diabetes preventive services was unemotional and matter of fact, such as “*I just go every year*”. For example, two of the participants discussed their reactions about getting screenings done: “*hated going to do blood work*” or “*I should have gone this year (to eye exam), but I went last year*”.

Other participants expressed an uncertainty or had a general lack of awareness about ADA recommended preventive services, as evidenced by statements such as, “*I don't know when the last time I had an eye test*”.

The participants faced challenges to being engaged in care and getting recommended preventive health services, such as having periods of lacking health insurance coverage, inadequate financial resources, or difficulty leaving work to obtain health care. The participants had other competing priorities that led to delay in care-- something with family or work would come “up”. Furthermore, some participants admitted being engaged with the health care system or engaged in diabetes preventive services out of necessity, as stated, “*the only reason I ever went to a doctor was getting my prescriptions*”. Certain jobs required annual medical clearance, such as HgA1C testing for commercial drivers’ license. Most participants explained that obtaining eye exams were also initiated on the basis of need, such as vision problems or need for new eyeglasses.

While participants realized the importance of diabetes self-management; it was not uncommon to delay seeking routine care for diabetes or for diabetes-related problems. Participants often had competing priorities that “trumped” diabetes. For example, one of the middle-aged female participants discussed her belief that her children’s needs were more important than her own health needs, which included getting her diabetes medications.

Sometimes, I have to decide what I'm going to do. What I'm going to do without, to make ends meet, you know? It's always I will do without or I will... but that's just me because I love for my family to be happy. So that's just me. Long as they're happy, I'm okay. And if I have to take half of the pill or whatever, I'm going to do what I've got to do but my family comes first.

Some participants struggled to make their health the priority and made statements such as “*I cared more about my job*”. Some did not perceive an urgency to seek health care, as explained by one participant “*I don't think it's that bad to the point where I got to go to the doctor and stuff like that*”.

In contrast, some participants did express the need to make health a priority, but experienced challenges, such as not having insurance. As one of the younger male participants explained:

I kind of didn't want to go (to the doctor) because I know I didn't have no insurance. I knew it was going to be high (cost), but as I got older, I know your health is more important. If you can't afford it at least try to pay.

Other challenges included taking time off work, as one of the other younger working adults expressed “*I couldn't take off to the doctor every time I turn around*” and “*I mean I know I'm supposed to go*”. Certain occupations seemed more challenging in scheduling time for medical appointments, such as teachers who had to find substitute teachers.

Some of the participants had strategies such as using paid-time off days, after working hours, and finding providers open on weekends. However, these participants did not report having difficulty with employers in missing or leaving work to seek health care.

The employers of the working adults in this sample provided support and described as “*understanding*”, “*knows I need to go to the doctor*” and “*well-managed with the administrators*”.

Subtheme: Fear and shame. Sometimes engaging in care provoked fear, related to the possibility of diabetes-related or other medical complications. The fear of developing diabetes-related complications in the future, such as having a stroke or kidney

failure, was verbalized by some of the participants. One of the younger, female participants had personally witnessed other close relatives with diabetes-related complications and discussed her fear:

I left there freaking out and I called my mom, because my granddaddy had kidney failure, so I knew what he went through and I seen it. And you would think that me seeing that and seeing how he suffered, that I would want to do better or at least try to get more involved in my health but...

Another participant expressed a sense of shame, as well as frustration, about having uncontrolled blood sugars and being overweight. He encountered a judgmental, chastising attitude by the health care providers and stated, *“I get tired of being preached at or judged...they make you feel guilty, they make you feel like crap, and I don't need that”*.

Subtheme: Health care provider support. Good communication, mutual respect and rapport with health care providers were evident among the participants. The participants described their interaction with health care providers as supportive, trusting, concerned, being a “good listener” and being treated “like a son”, “teammate”, or “sister-sister”. For some of the participants, it was a gradual process to become open with their providers and ask questions. However, despite these supportive relationships with health care providers, some of the participants still struggled to be consistently engaged in care. One of the participants, a middle-aged single mother, verbalized feelings of regret about not being regularly engaged in care, partly because of late working hours and not being able to wait in the doctors’ office.

She'll talk to me, and she'll sit down, and like I said, she'll sit and tell me what I need to do when-- she's more like a concerned doctor telling me about my health. And she was like, 'You got a daughter. You know that you need to be here, and you need to take care of yourself and what you're doing.' To me, she's like a sister-sister because I understand her more... because I know she's not just telling me that just to be telling that. She knows what's best for me, and I just take it because I know she's not going to tell me nothing bad to hurt me.

Another middle-aged mother described the difficulty in having frequent periods of lapsed insurance coverage and change of health care providers. After developing diabetes-related complications, she became more engaged and consistent with health care providers. She explained that the relationship with her health care provider was trusting and supportive, as well as instrumental in obtaining needed diabetes preventive health services.

I feel that she is a teammate, that it's not just me trying to figure out what to do... She is my manager. I really feel like she is my diabetes manager and wanted to help. And she has really taken on that role with me as to helping me manage all of these different things that are going on.

Consequently, the supportive relationship with health care providers facilitated diabetes self-management, but the participants gradually accepted the burden of individual responsibility as described: *“it's you being consistent taking care of yourself. The doctor's only going to be able to help you a little bit.”*

Theme 4: “We’re Lucky to Have What We Have”

The fourth theme encompassed the community sphere of influence in the Fisher et al. (2005) model. The fourth theme portrayed living in the rural south with limited resources and community support for a healthy lifestyle. This theme was highlighted by an expression of gratitude and contentment about living in their rural community by saying “we’re lucky to have what we have”. The participants faced the “ups and downs” of living in a rural community and acknowledged the positive aspects of their community, such as opportunities for physical activity and health promotion activities. The participants realized the importance of employer-based health benefits and ability to access health care. Nevertheless, the participants experienced inadequate resources in their community to support healthy lifestyles and expressed a desire for more choices. Yet, when asked “*Can you think of anything that we have in this community that helps your diabetes?*” many participants stated “*nothing*” or “*I have no idea*”.

With regard to healthy food options, they described it as “*pretty much fast food*” with limited choices in grocery stores. Only 4 of the 20 participants identified grocery stores and restaurants in their community with healthy food options. Access to healthy food was challenging, but as one of the participants explained: “***We're lucky to have what we have. In fact, they took one away from us. So, we just have an IGA and the Walmart and mostly fast food. We do have a few decent restaurants. It's hard though***”. Financial resources to purchase healthy food were also limited. Many participants described the financial burden of buying healthy food, “*You go to the store the healthier the food is, the more it costs*” and “*...it's all about trying to get them. Because I love that healthy stuff, just like I said some of that stuff is just kind of high.*”

Many working adults in this sample were able to identify resources for physical activity in their community. Venues for exercise included walking trails in their neighborhood, tracks at local schools and colleges, parks and gyms. Activities at church were predominantly social activities, however, a few participants mentioned that their church had health promotions activities, such as blood pressure and diabetes screenings offered by the local hospital. A few of the employers also offered resources for physical activity, such as free access to exercise equipment and \$5 on-site gym membership fee for employees. Participants talked about employer related health programs, such as a smartphone-based diabetes management program and access to healthy eating videos. There were a few employers that had weight loss programs, similar to “The Biggest Loser”.

Another essential resource for participants was employer-based health insurance. Having health insurance facilitated access to a regular source of health care and engagement in preventive health services. Health insurance usually included coverage for diabetes preventive health services, such as eye exams, and pharmaceutical plans to obtain diabetes medications. The prescription plans varied but facilitated the ability to obtain medication for diabetes. Participants felt their ability to engage in health services was also aided by having adequate financial resources for out-of-pocket expenses, such as prescription and office co-pays. Furthermore, being employed provided financial stability as explained by this female participant:

And I look at the fact that because we don't have insurance a lot of times, we stay on jobs longer. We tear down the body longer because we don't have insurance.

So, therefore, we got to stay here and do this. Like I'm 57. I wanted to leave my job when I get 60. I actually wanted to leave at 55, but I can't afford it.

Being engaged in care and getting recommended preventive health services, such as diabetic eye exams were usually delayed if insurance coverage or financial resources were not available. The majority of the participants had health insurance coverage when the research study was being conducted, but 7 of the 20 working adults in this sample experienced periods of lacking health insurance or adequate financial resources to obtain health care. Furthermore, a few of the participants were not able to afford some of the diabetes medications due to out-of-pocket expenses or high co-pays. One participant reported being out of insulin and other diabetes medications for at least 3 months after losing Medicaid insurance and another said “*I just do without it*” when he cannot afford co-pays. For those with financial constraints and for the participants lacking insurance coverage, some utilized the \$4 Walmart drug list and shopped around for the best prices on certain medical supplies, such as glucose testing strips or eyeglasses. Although diabetes eye exams were usually covered by insurance, a few stated they had difficulty paying for eyeglasses.

Discussion

This study focused on gaining a better understanding of the factors that enhance, or hinder, engagement in diabetes care among rural, working adults with T2 DM. Findings from this study highlight the importance of considering all influences (individual, interpersonal, health system and community spheres) when aiming to enhance healthful behaviors in this group. At the individual level, some of the participants were developing responsibility for diabetes self-management yet many

seemed to lack personal accountability for being engaged in recommended diabetes preventive health services. In particular, participants perceived that the burden of responsibility for engagement in diabetes preventive health services fell on the health system. Often, the participants seemed passive and only took initiative for urgent health needs, such as need for eyeglasses or HgA1C testing for job qualifications. Furthermore, a pattern of health care avoidance prevailed, as they did not fully acknowledge the importance of engaging in diabetes preventive health services.

Of note, all participants in the study had lower levels of engagement in diabetes care, despite the fact that 75% of the participants had health insurance. The participants were at different stages of actively participating in their diabetes care and striving towards wellness, as represented by their level of patient activation. Individuals with higher levels of patient activation, or the stage characterized by “taking action”, might be more likely to engage in diabetes preventive health services (Glenn, Nichols, Enriquez & Jenkins, in press; Hibbard & Greene, 2013). Some had developed a consistent “routine” in diabetes self-management, had regular visits with their health care provider, and seemed more likely to be engaged in diabetes preventive health services. Conversely, other participants were inconsistent, or not regularly engaged, with diabetes self-management and preventive diabetes care. This pattern of inconsistency and health care avoidance parallels a lower patient activation level (i.e., level 2) or defined as “becoming aware but still struggling” (Hibbard et al., 2005). Some identified effective coping strategies, but others had maladaptive coping mechanisms, such as indulging in food as a way of dealing with stress. Some compared their lack of self-control to the inability to

curb intake in alcoholism, despite knowing its' harmful physical effects (National Institute on Alcohol Abuse and Alcoholism, 2018).

Being poorly engaged in diabetes self-management and preventive behaviors in this vulnerable population might be partially explained by a sense of powerlessness or diabetes fatalism. Diabetes fatalism, characterized by perceived despair, hopelessness and powerlessness, can have negative effects on self-care behaviors, but independent of depression (Walker et al., 2012). These participants might have held the belief that developing diabetes is inevitable and developing complications were accepted as the “normal” course of diabetes, based on the strong family history of diabetes and prevalence of diabetes-related complications in this community. A limited understanding of diabetes, as well as misperceptions about the longevity and seriousness of the disease may explain these beliefs (Ledford, Seehusen, & Crawford, 2019). Furthermore, these misperceptions of diabetes may represent the geographical and racial differences that exist (Ledford et al., 2019).

Interpersonal factors, such as having other family priorities, impeded engagement in care among this group of rural dwelling, working adults. Furthermore, working adults might be more inclined to seek health care for illness-related concerns, rather than for regular preventive services (Murimi & Harpel, 2010). “Present” bias, or an overemphasis on the “present” benefits over future, long-term benefits, may partially explain why participants delayed seeking care or were not consistently engaged in diabetes preventive health services (Williams, Liu, Muir, & Waxman, 2018). Other life priorities or financial barriers could have overshadowed the immediate benefits of seeking preventive care, such as an eye exam when asymptomatic (Williams et al., 2018). Some of the newer

approaches, such as the use of behavioral economics, might be effective in facilitating working adult populations to engage in diabetes preventive health services (Williams et al., 2018). Specifically, default scheduling, financial incentives, personalized reminder messages and behavioral coaching have demonstrated significant increases in diabetes eye examination rates (Williams et al., 2018).

The level of patient activation can be associated with the availability of social support and economic resources (Berkowitz et al., 2015; Weaver, Lemonde, Payman, & Goodman, 2014). Their social support did not facilitate being regularly engaged in care or diabetes preventive health services. Social support has been associated with positive diabetes health outcomes; however, the existing literature is unclear whether social support can have a positive impact on engagement in diabetes preventive health services (Weaver et al., 2014). More support was needed at the interpersonal level for talking about the burden of diabetes and related complications. They vividly recalled their experiences of despair and deep sorrow concerning family members who died from diabetes-related complications. The emotional burden of living with diabetes was clearly evident among the participants, but ironically, talking about diabetes with others was infrequent according to most of the participants. In contrast, the National Social Life, Health and Aging Project (NSHAP) found that a high proportion of rural-dwelling adults reported being able to “open up” to friends and family, especially for women (Henning-Smith, Moscovice, & Kozhimannil, 2019). Being reluctant to talk about diabetes with family or friends could be due to stigma, social norms, negative emotions associated with diabetes or being scorned for unhealthy behaviors. The interviews may have provided therapeutic listening, as the participants were able to talk openly and willingly about their

experiences living with T2 DM. Interventions, such as peer-led interventions or group medical visits, aimed at facilitating more open, in-depth discussion about diabetes could potentially lead to a greater sense of perceived social support, as well as improve diabetes outcomes in this population (Housden & Wong; 2016; Menon et al., 2017; Patil et al., 2016).

Diabetes-related distress, is common among rural, African American populations, especially worrying about future diabetes complications and having feelings of fear, guilt and anxiety (Miller, 2011; Nicolucci et al., 2013; Polonsky et al., 2005). The psychological impact of living with diabetes was significant in this group of working adults with T2 DM and highlights the crucial need for clinicians to monitor for signs of diabetes-related distress, depression and ineffective coping strategies. Numerous depression screening tools and diabetes-distress measurements are readily available for use in health care settings, however, less than 25% of health care providers ask how diabetes impacts their life (Nicolucci et al., 2013). Furthermore, targeted efforts to help persons with diabetes learn to cope with the psychological impact of chronic disease can improve health outcomes, such as reductions in diabetes-related distress and HgA1C (Schmidt, van Loon, Vergouwen, Snoek, & Honig, 2018).

Besides being poorly engaged in care, socioeconomic factors make this group of predominately low-income, African American adults at risk for poor health outcomes. The participants had little control over some of the barriers to self-management, such as a lack of finances, healthy food options and resources in their rural community. The majority of the participants (65%) had low incomes, which is a known risk factor for poor health outcomes. Furthermore, this group of working adults did not use social capital for

diabetes related needs, but instead skipped medications and delayed care when financial resources were limited (Vest et al., 2013). Despite having limited resources, living in a rural area might offer some health-related benefits. This sample of working adults described close relationships with family and friends and did not seem socially isolated. These relationships and lack of social isolation could be a protective factor in their overall health (Holt-Lunstad, Smith, Harris, & Stephenson, 2015; Stein, Gennuso, Ugboaja, & Remington, 2017). In contrast, premature “deaths of despair”, such as suicide, have recently increased among non-Hispanic White, middle-aged (45-64 years) populations living in rural areas and may represent hopelessness, lack of social support and addiction (Stein et al., 2017).

Rural residents are also more likely to have a usual source of care and rural providers impose fewer barriers to care, regardless of insurance status, compared to urban residents (Ziller, 2012). Similarly, most of the participants had a usual source of care and a trusting, supportive relationship with their health care provider which facilitated being engaged in care. Transportation or access to care did not seem to be significant barriers. Lastly, the majority of the participants had lower incomes, but financial constraints might be a negligible contributing factor to forgone medical care in rural areas (Kullgren, McLaughlin, Mitra, & Armstrong, 2012; National Center for Health Statistics, 2018).

Another critical factor to being engaged in care was having stable employment, which provided the participants access to health insurance benefits and resources for seeking health care. A significant proportion (75%) had health insurance, which may have lessened the impact of financial barriers to engaging in care for this sample of rural, dwelling adults. But overall the participants had little influence regarding workplace

policies and health initiatives. Employers in this rural community lacked the infrastructure needed to promote healthy lifestyles and encourage preventive health behaviors. A few of the participants in this study had an active role in promoting health at their workplace, such as leading yoga with coworkers and students and another trying to get healthier vending machine options for employees. Employers did not offer health resources equitably, such as making exercise equipment available to all employees. Thus, there is a need for employers to offer incentives and health resources equitably as well as empower their employees to take a more pivotal role in establishing a healthier work environment.

Early diagnosis and treatment of T2 DM, especially for younger and middle-aged adult populations, is also needed. It was difficult to discern whether the participants fully acknowledged the higher prevalence of diabetes in their rural community, 15-18% compared to the general U.S. population, 9%. Ideally, the diagnosis of diabetes should happen early in the course of the disease to avoid complications. The reported delay in the initial diagnosis of diabetes in this sample of rural, working adults is consistent with an estimated 5 million adults having undiagnosed diabetes in the general U.S. population (CDC, 2017). Almost one-third of adults between 18 and 64 years old have prediabetes and at risk for developing complications before the formal diagnosis of diabetes, including early stages of nephropathy, retinopathy and neuropathy (Edwards & Cusi, 2016). Successful efforts towards earlier diagnosis are growing and needed for underserved populations, such as the Diabetes Prevention Program (Ely et al., 2017; Diabetes Prevention Program Research Group, 2009; Dunkley et al., 2014).

A strength of this study were the successful strategies used for recruitment of individuals who were not consistently engaged in diabetes self-management. Worksites proved to be a feasible point of access for screening potential study participants. Collaborating with a local institution's employer relations department was a good point of contact that facilitated access to potential study participants at their worksites. It should be pointed out that there were some challenges to conducting research activities at worksites due to corporate policies and some of the PAM screenings had to be conducted via telephone due to time constraints at worksite health screenings. Engaging with other community leaders, such as a local diabetes educator and a local health coalition, and assisting with the local hospital's diabetes fair, also enhanced recruitment.

Limitations

This study had limitations that must be considered when interpreting the results. As this was a qualitative study with a small number of participants, the results are not generalizable. Further, researcher bias could have influenced the interview data, as the researcher conducting the interviews was familiar with the local community as a health care provider. Finally, while data saturation was achieved, the majority of the participants had PAM-10 scores at level 3 and may not adequately represent disengaged, working adults living with T2 DM.

Conclusions

The “ups and downs” of living with T2 DM was characterized by an inconsistency in diabetes self-management and engagement in diabetes preventive health services. The findings from this study show that taking individual responsibility, a sense of urgency, having good rapport with health care providers, and employer health benefits

facilitated engagement in diabetes self-management and preventive health behaviors. In contrast, competing family and/or work priorities and lack of resources hindered diabetes self-management and engagement in diabetes care.

Results from this study have implications for research, health policy and clinical practice. Adults living with T2 DM who are not engaged in self-management and preventive care, might benefit from interventions aimed at enhancing patient activation. Such interventions could enhance glucose control and diabetes health outcomes (Bolen et al., 2014). Novel evidence-based psychological interventions are needed to address the unique needs of working, rural dwelling adults living with T2 DM. Community-based participatory research might be particularly amenable to addressing issues that working, rural dwelling adults with T2 DM face (Philis-Tsimikas et al., 2012). In community-based participatory research, an important strategy is to emphasize the strengths and resources within a community, instead of focusing on community needs and problems (Israel et al., 2013). Utilizing identified strengths, such as having strong social networks, could enhance health in this rural community.

Decreasing the diabetes-related health disparities among vulnerable populations should remain a priority. Health policies should enhance support and resources to rural communities. Ultimately, employers have the potential to positively influence health behavior. Employers could play a vital role in maximizing resources and social networks within their respective diabetes community. Finally, clinicians could help facilitate engagement in diabetes care by assessing the individual, interpersonal, health system, and community support and resources that are available to their patients.

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CHAPTER FIVE: CONCLUSION

Summary and Synthesis of Findings

Health disparities need to be addressed beyond individual health behavior. A socioecological approach was used in this dissertation research to gain a better understanding of these health disparities among rural, predominately low-income and African American adults living with type 2 diabetes. Chapter 2 reported on a secondary data analysis that examined the association between level of patient activation, as measured by PAM-10 scores, and engagement in preventive health behavior in a rural, minority population. Chapter 4 reported on a qualitative research study that extended the use of PAM-10 to identify working, rural-dwelling adults with T2 DM who were poorly engaged in diabetes preventive health services.

The aim of the study was to gain a better understanding of the critical, and potentially modifiable, factors that impact the ability of rural, working adults to engage in diabetes preventive health services. Individual, interpersonal, health system and community spheres of influence were explored and how they facilitate the use of preventive health services in this priority population.

The first theoretical assumption of the research study was that lower levels of patient activation can predict being poorly engaged in diabetes care and preventive health services (Hibbard & Greene, 2013). The secondary data analysis was consistent with previous studies that an association between patient activation levels and preventive health behaviors exists (Glenn, Nichols, Enriquez, & Jenkins, 2019). On an individual level, having a sense of individual responsibility and need for health services facilitated engagement in both diabetes self-management and preventive health services. Those

who had a “routine” in diabetes self-management and developing a more consistent pattern of being engaged in diabetes care reflected a higher level of patient activation. Conversely, those with inconsistency in diabetes self-management and a pattern of health care avoidance represented lower levels of patient activation. Instead, those who were more likely to seek care for acute illnesses or engage in preventive health services for job-related requirements may have lower activation levels.

The next theoretical assumption of the research study was based on the Fisher et al. (2005) model, Resources and Supports for Self-Management. Due to a lack of social and economic capital or resources, rural, working adult populations with type 2 diabetes are poorly engaged in diabetes preventive services compared to their urban counterparts or those with higher socioeconomic status (Vest et al., 2013; Weaver, Lemonde, Payman, & Goodman, 2014). Interpersonal factors had both a positive and negative influence on how rural, working adults with T2 DM engaged in diabetes self-management and preventive health services. Thus, the interpersonal sphere of influence modified their engagement in diabetes preventive health services. Some of the participants were motivated as a result of experiencing other family members suffer the consequences of diabetes-related complications. Strong social networks provided emotional support but did not have much impact on being engaged in diabetes preventive health services. However, support for talking openly about diabetes and the significance of diabetes-related complications was uncommon in their interactions with others. Family priorities interfered with being engaged in care and diabetes care did not take precedence.

Having employer-based health insurance and trusting, satisfactory relationships with health care providers were critical factors that contributed to being regularly

engaged in diabetes care. However, the initial diagnosis of diabetes was delayed, possibly due to fear or denial. Otherwise, the health system provided support for diabetes self-management and access to diabetes preventive health services. The health system also had the burden of responsibility for diabetes preventive health services. The working adults occasionally took initiative for health needs, such as finding a podiatrist or getting an eye exam done when glasses were needed.

The available community resources, such as access to healthy food and spaces for physical activity, facilitated diabetes self-management. However, the resources to support engagement in healthy lifestyles and regular diabetes care were limited. Their workplace environment also had little influence on diabetes self-management or preventive health behaviors. Most participants verbalized that their employers did not hinder their ability to seek health care, however, it was difficult to miss work due to job responsibilities.

Thus, the significant factors to engaging in diabetes preventive health services were potentially due to lower patient activation levels along with a lack of adequate support and socioeconomic resources among low-income, rural, working adults.

Significance of Research

The research study contributed to a comprehensive understanding of the lived experiences of rural, working adults with T2 DM. The study gained valuable insights regarding the multiple factors that influence being engaged in diabetes self-management and preventive health services in this population. The consideration of factors beyond individual diabetes self-management allowed a broader perspective. The study also

highlighted that adequate resources are critical to being regularly engaged in diabetes care, such as employer health benefits.

The study also concurred with previous findings that competing family priorities and other non-financial barriers might have a more significant role than financial or health system-related factors. (Kullgren et al., 2012; Murimi & Harpel, 2010; Ross, Benavides-Vaello, Schumann, & Haberman, 2015). “Present bias”, denial, fear, and not fully acknowledging the significance of diabetes preventive health services may partially explain their pattern of health care avoidance.

The study highlights the need for adequate support and resources for rural, working adults living with T2 DM. More psychological support is needed to address possible diabetes-related distress in this vulnerable population. Diabetes-related distress and depression have been found in similar rural, African American populations with T2 DM and may mediate the influence of socioeconomic factors on diabetes control (Bhattacharya, 2012; Kogan, Brody, & Chen, 2009). Psychological support should include teaching healthy coping skills to deal with family and job-related stressors. This need for coping skills is congruent with American Association of Diabetes Educators’ (AADE) Position Statement on AADE-7 self-care behaviors and has proven to benefit diabetes outcomes (Powers et al., 2015; Thorpe et al., 2013).

The research findings also revealed that it was challenging for participants to take an active role in their health. In general, the participants did not try to advocate or initiate policy changes to promote health in their social networks, workplace, or community. Support for shared-decision making is also needed for health care consumers. Patients should have personal accountability for obtaining diabetes preventive health services,

rather than the burden of responsibility being on health care providers. Taking initiative and gaining more control in health care decisions requires a higher level of patient activation, such as scheduling an annual diabetes eye exam.

The delay in diagnosis of diabetes, along with the high prevalence of diabetes and diabetes-related complications in rural dwelling, minority adult populations is significant. Misperceptions and the normalization of diabetes and related complications may contribute to health disparities in this vulnerable population. Instead, not fully acknowledging the importance of engaging in diabetes preventive health services remains problematic.

Strengths and Limitations

The study used a novel approach for recruitment and readily identified the targeted sample of rural, working adults with T2 DM and lower patient activation levels. Although time constraints and corporate policies were barriers to recruitment at worksites, the research was conducted within the real environmental context of the participants. Furthermore, the study gave the participants an opportunity to talk openly about their experiences living with T2 DM and therapeutically gave them voice.

The study had limitations that must be considered when interpreting the results. The results are not generalizable, due to a small number of participants and being a qualitative research design. Further, researcher bias could have influenced the interview data, as the researcher conducting the interviews was familiar with the local community as a health care provider. Finally, data saturation was achieved, but the majority of the participants had PAM-10 scores at level 3 and may not adequately represent disengaged, working adults living with T2 DM.

Future Directions

The burden of diabetes necessitates multidisciplinary resources and support in the health system, workplace and community. Other health care professionals, such as social workers, wellness coaches, and pharmacists ideally should be integrated in the health system in rural areas. Furthermore, health behavior change demands a multi-faceted approach and consideration of the social determinants of health. A socioecological perspective may predict behavior more accurately, based on the situations people are in rather than solely on individual attributes (Sallis & Owen, 2015). On the other hand, the complexity of multi-level interventions can be challenging in understanding how the different levels of influence interact with each other (Sallis & Owen, 2015). Moreover, it may be difficult to sustain the community infrastructure or workplace policies needed to support behavioral interventions. Using socioecological models, such as Fisher's (2005) Resources and Supports for Self-Management model, allow multiple levels of influence to be considered when developing interventional studies.

Nurse case-management and peer-led interventions should be considered for rural and minority populations with lower levels of patient activation and at high risk for diabetes-related complications. Nurse case-management interventions have demonstrated improvements in engaging patients in preventive screenings, as well as psychological and diabetes health outcomes (Gabbay et al., 2013; Welch et al., 2010). Peer-led interventions are another effective approach to enhancing diabetes outcomes (Fisher et al., 2017). Interventions should also focus on maximizing interpersonal, health system and community resources for psychological support.

Developing workplace-based initiatives would be another approach to promote engagement in diabetes preventive health services and healthy lifestyles (Bevis et al., 2014; Linnan, Fisher, & Hood, 2013; Stiehl et al., 2018). Lastly, community-based participatory research is needed to diagnose diabetes and identify high-risk individuals early in the course of the disease. One such successful community-based effort is the Diabetes Prevention Program (DPP). The translation of this program is needed in rural communities and could enhance diabetes-related outcomes in this population.

More research is needed to validate the relationship between the level of engagement in diabetes care and health outcomes, especially among rural and minority populations (Schoenberg, Ciciurkaite, & Greenwood, 2017). Social support has been associated with positive diabetes health outcomes; however, the existing literature is unclear whether social support can have a positive impact on engagement in diabetes preventive health services (Weaver et al., 2014). Thus, a gap remains in understanding the multiple socioecological levels of influence that mediate preventive health behaviors.

Health disparities in rural and minority populations still persist, despite expanded health care access by the Affordable Care Act, more technology and the evolution of patient-centered care (Callaghan, Towne, Bolin, & Ferdinand, 2017, 2019; CDC, 2017b; Garcia et al., 2017). However, with a socioecological approach, workplace health initiatives and community-based interventions show promise in addressing these health disparities.

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doi:10.1016/j.diabres.2009.12.026

APPENDICES

Appendix A: Levels of Patient Activation

Level 1	Perspective	PAM Score Range (0-100)
DISENGAGED AND OVERWHELMED		
Individuals are passive and lack confidence. Knowledge is low, goal-orientation is weak, and adherence is poor.	Their perspective: “My doctor is in charge of my health.”	0 - 47
Level 2		
BECOMING AWARE, BUT STILL STRUGGLING		
Individuals have some knowledge, but large gaps remain. They believe health is largely out of their control, but can set simple goals	Their perspective: “I could be doing more.”	47-55
Level 3		
TAKING ACTION		
Individuals have the key facts and are building self-management skills. They strive for best practice behaviors and are goal oriented.	Their perspective: “I’m part of my health care team.”	55-75
Level 4		
MAINTAINING BEHAVIORS AND PUSHING FURTHER		
Individuals have adopted new behaviors but may struggle in times of stress or change. Maintaining a healthy lifestyle is a key focus.	Their perspective: “I’m my own advocate.”	75-100



Adapted from: Patient Activation Measure (PAM), Insignia Health.
Retrieved from <http://www.insigniahealth.com/products/apm-survey>

PAM Scoring based on:

Glenn, L. E. (2019). [Impact of a Community-Based Approach to Patient Engagement in Rural, Low-Income Adults with Type 2 Diabetes]. Unpublished data.

Appendix B: IRB Approval Letters



Institutional Review Board
University of Missouri-Columbia
FWA Number: 00002876
IRB Registration Number: 00000731

190 Galena Hall
Columbia, MO 65201
573-882-3181
irb@missouri.edu

June 15, 2018

Principal Investigator: Lynn E Glenn
Department: Nursing-PHD

Your IRB Application to project entitled "Exploring the Engagement in Preventive Health Services among Rural, Working Adults with Type 2 Diabetes" was reviewed and approved by the MU Institutional Review Board according to the terms and conditions described below:

IRB Project Number	2011521
IRB Review Number	237762
Funding Source	Health Resources & Services Administration (PHS) (HRSA)
Initial Application Approval Date	June 15, 2018
IRB Expiration Date	June 15, 2019
Level of Review	Expedited
Application Status	Approved
Project Status	Active - Open to Enrollment
Expedited Categories	45 CFR 46.110.a(f)(6) 45 CFR 46.110.a(f)(7)
Risk Level	Minimal Risk
Type of Consent	Written Consent Consent with Waiver of Documentation
HIPAA Category	No HIPAA
External Funding	External Grant (ex. Federal funding, foundation funding)

IRB Approved Consent Document - Actual Study
IRB Approved Consent Document - eligibility screening

August 24, 2018

Lynn E. Glenn, MSN, APRN-C, PhD(c) student
Kimberly B. Pugh, M.D., Regional Medical Center

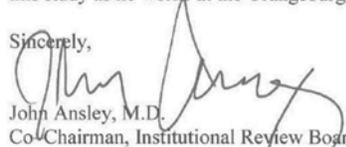
Dear Ms. Glenn and Dr. Pugh:

This letter is to inform you that I have reviewed, via expedited review, the material submitted regarding the study titled, "Exploring the Engagement in Preventive Health Services among Rural, Working Adults with Type 2 Diabetes". Included in the items reviewed were the following:

- IRB Protocol Submission Checklist
- Protocol Summary Coversheet; signed by Dr. Pugh 08/21/2018; signed by Ms. Glenn 07/27/2018
- Investigator Conflict of Interest and Financial Disclosure Statement; signed by Dr. Pugh 08/21/2018; signed by Ms. Glenn 07/27/2018
- Review Type Requested form – Expedited Review; signed by Dr. Pugh 08/21/2018; signed by Ms. Glenn 07/27/2018
- Hospital Department Resources form
- Letter from Ms. Glenn introducing study and partnership with RMC – Employer Relations Department
- Letter from Cindy Goodroe, RN, Medical Director at Orangeburg Free Medical Clinic regarding recruitment
- Research Study flyer
- University of Missouri IRB Approval Letter; June 15, 2018
- Rural Prep Grant Approval Letter; March 12, 2018
- Protocol Version 3 – Exploring the Engagement in Preventive Health Services among Rural, Working Adults with Type 2 Diabetes; 20 pages
- Informed Consent to Participate in a Research Study form; 3 pages
- Qualifications of Investigator – Lynn E. Glenn, MSN, APRN-C, PhD (c) student
- Qualifications of Investigator – Kimberly B. Pugh, M.D.
- Letter from University of Missouri exempting Dr. Pugh from completing CITI Human Subjects research training, as she is not actively involved in research activities.

The materials were received in the IRB office between July 27, 2018 and August 23, 2018. The IRB approval # is 0718. The RMC IRB official approval date for the study is August 24, 2018 with expiration date of August 24, 2019. Dr. Michael Greene, Co-Chairman of the IRB recused himself from review of this study as he works at the Orangeburg Free Medical Clinic with Ms. Glenn.

Sincerely,


John Ansley, M.D.
Co-Chairman, Institutional Review Board
The Regional Medical Center of
Orangeburg and Calhoun Counties

Appendix C: Informed Consent Forms

CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY

Researcher's Name(s): Lynn E. Glenn MSN, PhD (c), University of Missouri
Dr. Kimberly Pugh, Regional Medical Center

Project Number: 2011521

Project Title: Exploring the Engagement in Preventive Health Services among Rural, Working Adults with Type 2 Diabetes

INTRODUCTION

This consent may contain words that you do not understand. Please ask the investigator or the study staff to explain any words or information that you do not clearly understand.

You are being asked to participate in a research study. **This research is being conducted to help understand the resources that are needed to seek diabetes services in rural areas.** When you are invited to participate in research, you have the right to be informed about the study procedures so that you can decide whether you want to consent to participation. This form may contain words that you do not know. Please ask the researcher to explain any words or information that you do not understand.

You have the right to know what you will be asked to do so that you can decide whether or not to be in the study. Your participation is voluntary. You do not have to be in the study if you do not want to. You may refuse to be in the study and nothing will happen. If you do not want to continue to be in the study, you may stop at any time without penalty or loss of benefits to which you are otherwise entitled.

This research is funded by Rural Primary Care, Research, Education and Practice (Rural PREP) with support from Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS).

WHY IS THIS STUDY BEING DONE?

The purpose of this research is to learn more about how certain social and economic factors can affect the use of health services in rural, working adults with type 2 diabetes.

HOW MANY PEOPLE WILL BE IN THE STUDY?

About 20 people will take part in this study in the tri-county area (Bamberg, Calhoun and Orangeburg Counties).

WHAT AM I BEING ASKED TO DO?

You will be asked to answer a series of questions regarding how you use health services that can help prevent problems related to diabetes. The interview will last approximately 60 minutes and will be audio-recorded.

MU IRB: CONSENT	TRMC IRB APPROVED DATE: <u>08/24/2018</u> IRB #: <u>0718</u>	HS IRB USE ONLY Approval Date: Expiration Date:	PAGE 1 of 1
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HOW LONG WILL I BE IN THE STUDY?

This study will take approximately 60 minutes to complete. You can stop participating at any time without penalty.

WHAT ARE THE BENEFITS OF BEING IN THE STUDY?

Working adults are often very busy, struggling financially to afford health care, as well as finding time to seek health services. Your participation will help identify the resources needed and find better ways to provide health care to rural, working adults with diabetes. Your participation in the study can benefit the health of your fellow employees and the overall health of your community.

WHAT ARE THE RISKS OF BEING IN THE STUDY?

There is minimal risk to being in the study. If emotional distress occurs during the study, you can choose to withdrawal from the study.

WHAT ARE THE COSTS OF BEING IN THE STUDY?

There is no cost to you.

WHAT OTHER OPTIONS ARE THERE?

You also have the option of not participating in this study and will not be penalized for your decision.

CONFIDENTIALITY

Your information will be kept strictly confidential and only the investigator has access to the information. Your information will not be disclosed to anyone, including your employer, health care provider, or the hospital Employer Relations department.

Information produced by this study will be stored in the investigator's file and identified by a code number only. The code key connecting your name to specific information about you will be kept in a separate, secure location. Information contained in your records may not be given to anyone unaffiliated with the study in a form that could identify you without your written consent, except as required by law.

WILL I BE COMPENSATED FOR PARTICIPATING IN THE STUDY?

You will be compensated \$50 for completion of the duration of the study. You will be paid \$50 after completion of the interview. If you decide to stop before finishing the interview and complete at least 50% of the interview, you will be compensated \$25. If you decide to stop before finishing the interview and complete less than 50% of the interview, you will be compensated \$15.

WHAT ARE MY RIGHTS AS A PARTICIPANT?

Participation in this study is voluntary. You do not have to participate in this study.

MU IRB: CONSENT	TRMC IRB APPROVED DATE: <u>08/24/2018</u> IRB #: <u>0718</u>	<table border="1"><tr><td>HS IRB USE ONLY Approval Date: Expiration Date:</td></tr></table>	HS IRB USE ONLY Approval Date: Expiration Date:	PAGE 2 of 2
HS IRB USE ONLY Approval Date: Expiration Date:				

You will also be informed of any new information discovered during the course of this study that might influence your health, welfare, or willingness to be in this study.

WHO DO I CONTACT IF I HAVE QUESTIONS, CONCERNS, OR COMPLAINTS?

Please contact Lynn Glenn (study investigator) if you have questions about the research. Additionally, you may ask questions, voice concerns or complaints to the research team.

WHOM DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?

If you have any questions regarding your rights as a participant in this research and/or concerns about the study, or if you feel under any pressure to enroll or to continue to participate in this study, you may contact the chairman of the Institutional Review Board at Regional Medical Center at 803-395-3002 or University of Missouri Institutional Review Board (which is a group of people who review the research studies to protect participants' rights) at (573) 882-3181 or umcresearchcirb@missouri.edu.

You may ask more questions about the study at any time. For questions about the study or a research-related injury contact *Lynn Glenn* at 843-686-5243, *Dr. Kimberly Pugh* at 803-395-3891 or *Dr. Maithe Enriquez* at 816-686-3242

A copy of this Informed Consent form will be given to you before you participate in the research.

SIGNATURES

I have read this consent form and my questions have been answered. My signature below means that I do want to be in the study. I know that I can remove myself from the study at any time without any problems.

Subject

Date

MU IRB: CONSENT

TRMC IRB APPROVED
DATE: 08/24/2018
IRB #: 0718

HS IRB USE ONLY Approval Date: Expiration Date:
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PAGE 3 of 3

WAIVER OF DOCUMENTATION OF CONSENT

INVESTIGATOR'S NAME: LYNN E. GLENN APRN, MSN, PHD(C)

PROJECT # 2011521

STUDY TITLE: EXPLORING THE ENGAGEMENT IN PREVENTIVE HEALTH SERVICES AMONG RURAL, WORKING ADULTS WITH TYPE 2 DIABETES

1. I would like to ask you to participate in a study that involves research.
2. Participation is voluntary and your decision not to participate will not involve any penalty or loss of benefits. You can withdraw from the study at any time.
3. For this study, you will be asked to complete a 10-question survey about your health. It will take about 5 minutes to complete the survey. If you need help reading the survey, the researcher or research assistant can read the survey to you.
4. The purpose of our study is to help identify the resources needed and find better ways to provide health care to rural, working adults with diabetes. Your participation in the study can benefit the health of your fellow employees and the overall health of your community.
5. We are asking approximately 75 subjects to participate in this part of the study.
6. The study staff may withdraw you from the study at any time after explaining to you the reason for withdrawal.
7. While on the study, it is not anticipated that you will experience any emotional discomfort. If you think you may be at risk for becoming emotionally distressed during the study, you should discuss this with the investigator.
8. If you agree to take part in this survey, you might be eligible to participate in an individual interview. You may expect to benefit from taking part in this research to the extent that you are contributing to medical knowledge.
9. If you change your mind and would like to participate in the survey at a later time, you can contact the researcher at the contact number below and schedule a time to complete the survey.
10. If you choose to participate, your survey answers will be kept confidential and stored in a secure, locked cabinet by the researcher. Your fellow employees and employer will not have access to your survey results.
11. There is no cost to do this study.
12. There is a small gift that will be given to you for participation in this survey. If you are eligible to participate in the interview portion of this study, you will receive \$50 Wal-Mart gift card.
13. If you have any questions regarding your rights as a participant in this research and/or concerns about the study, or if you feel under any pressure to enroll or to continue to participate in this study, you may contact the University of Missouri Institutional Review Board (which is a group of people who review the research studies to protect participants' rights) at (573) 882-3181.
14. If you have any problems or questions, you may contact Lynn Glenn, study investigator, at 843-686-5243 or Maithe Enriquez, advisor, at 816-686-3242.
15. I would be happy to answer any questions that you may have.
16. A copy of this script will be given to you to keep.

I agree to participate in this research screening and complete the survey. I understand that I might be eligible to participate in an interview to be scheduled at a later time, outside the work setting (place check mark in box if you agree to participate).

Appendix D: Approval Letter and Employer Permission Letters



May 4, 2018

Lynn E. Glenn, APRN-C
University of Missouri
Sinclair School of Nursing
Columbia, MO 65211

Dear Lynn,

On behalf of the Regional Medical Center of Orangeburg and Calhoun Counties, I support your “Exploring the Engagement in Preventive Health Services among Rural, Working Adults with Type 2 Diabetes” research project. The community-based approach of this research will be extremely valuable to improving the health of our area. We share a common vision in striving to make healthcare more accessible for all in our community.

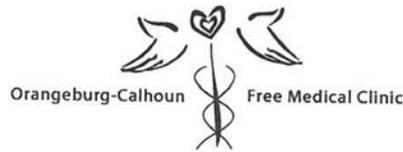
Engaging working adults in preventive health services is challenging on many levels for the individuals, employers and the healthcare system. The Employer Relations program at the Regional Medical Center promotes health through on-site screening, education and health promotion activities. The RMC Employer Relations manager has committed to assist you in connecting with local employers and the workforce.

We look forward to collaborating with you on your upcoming research project. We feel your project is targeting a priority population that face many barriers to care, including competing work and family demands, costs of healthcare and living in a rural area. With this partnership, we can find effective solutions to rural, working adults with diabetes who are not actively engaged in preventive health services.

Sincerely,

A handwritten signature in cursive script that reads 'Charles E. Williams'.

Charles E. Williams, FACHE
President and CEO



May 22, 2018

University of Missouri-Columbia
Health Sciences Institutional Review Board
Office of Research, 482 McReynolds Hall
University of Missouri
Columbia, MO 65212

Dear IRB Members,

After reviewing the proposed study entitled "Exploring the Engagement in Preventive Health Services among Rural, Working Adults with Type 2 Diabetes", presented by Lynn E. Glenn MSN, APRN-C, PhD student, I have granted permission for the study to be conducted at Orangeburg Calhoun Free Medical Clinic. Lynn E. Glenn MSN, APRN-C, PhD also has permission to recruit at Orangeburg Calhoun Free Medical Clinic.

The purpose of the study is to determine how individual, interpersonal, health system, and community factors influence the use of preventive health services among rural, working adults with type 2 diabetes. The primary activity will be face-to-face individual interviews.

I understand that face-to-face interviews with research participants will occur for approximately 60 minutes per participant, scheduled on Fridays or Saturdays, non-office hours. I expect that this project will end no later than December 15, 2018.

I understand that Lynn E. Glenn MSN, APRN-C, PhD student will receive written, signed consent for all participants. Any data collected by Lynn E. Glenn MSN, APRN-C, PhD student will be kept confidential.

If the IRB has any concerns about the permission being granted by this letter, please contact me at the phone number listed below.

Sincerely,

Cindy Goodroe, RN

Cindy Goodroe, RN, Medical Director
Orangeburg Calhoun Free Medical Clinic
803-534-7200

www.OCfreeclinic.com
803.534.7200 phone
803.534.8899 fax

Clinic Address:
141 Centre Street
Orangeburg, SC 29115

Mailing Address:
Post Office Box 505
Orangeburg, SC 29116



October 4, 2018

University of Missouri-Columbia
Institutional Review Board
Office of Research, 482 McReynolds Hall
Columbia, MO 65212

Dear IRB Members,

After reviewing the proposed study entitled "Exploring the Engagement in Preventive Health Services among Rural, Working Adults with Type 2 Diabetes", presented by Lynn E. Glenn, PhD student. I have granted permission for the study to be conducted at Sunshine Recycling. Lynn E. Glenn, principal investigator, also has permission to recruit at Sunshine Recycling.

The purpose of the study is to determine how individual, interpersonal, health system, and community factors influence the use of preventive health services among rural, working adults with type 2 diabetes. The primary activity will be face-to-face individual interviews.

I understand that screening questionnaires will be conducted with potential research participants and will occur approximately 5 – 10 minutes per participant. I understand that face-to-face interviews with research participants will occur for approximately 60 minutes per participant, to be scheduled outside of business hours, at a scheduled convenience time for the participant. I expect that this project will end no later than December 15, 2018.

I understand that Lynn E. Glenn MSN, APRN-C, PhD student will receive signed, written consent for all participants. Any data collected by Lynn E. Glenn MSN, APRN-C, PhD student (principal investigator) will be kept confidential.

If the IRB has any concerns about the permission being granted by this letter, please contact me at the phone number listed below.

Sincerely,

Joseph Rich, CEO and owner Sunshine Recycling
1105 Southland Road
Orangeburg, SC 29115
(803)531-4408

University of Missouri Permission Letter Template
Released: April, 2013

1105 Southland Road • Orangeburg, SC 29115 • Phone (803) 531-4408 • Fax (803) 381-9742 • www.sunshinerecycle.com



October 8, 2018

University of Missouri-Columbia
Institutional Review Board
Office of Research
482 McReynolds Hall
Columbia, MO 65212

Dear IRB Members:

After reviewing the proposed study entitled "Exploring the Engagement in Preventive Health Services among Rural, Working Adults with Type 2 Diabetes", presented by Lynn E. Glenn, PhD student, I have granted permission for the study to be conducted at the Regional Medical Center. Lynn E. Glenn, principal investigator, also has permission to recruit at the Regional Medical Center.

The purpose of the study is to determine how individual, interpersonal, health system, and community factors influence the use of preventive health services among rural, working adults with type 2 diabetes. The primary activity will be face-to-face individual interviews.

I understand that screening questionnaires will be conducted with potential research participants and will occur approximately 5 – 10 minutes per participant. I understand that face-to-face interviews with research participants will occur for approximately 60 minutes per participant, to be scheduled at the Healthy Living Center and Occupational Medicine Clinics. I expect that this project will end no later than December 15, 2018.

I understand that Lynn E. Glenn MSN, APRN-C, PhD student, will receive signed, written consent for all participants. Any data collected by Lynn E. Glenn MSN, APRN-C, PhD student (principal investigator), will be kept confidential.

If the IRB has any concerns about the permission being granted by this letter, please contact me at the phone number listed below.

Sincerely,

A handwritten signature in black ink that reads 'Rachelle K. Ball'. The signature is written in a cursive style with a large initial 'R'.

Rachelle K. Ball, MHA
Vice President, Physician Services

3000 St. Matthews Road ■ Orangeburg, South Carolina 29118
p 803-395-2200 ■ www.trmchealth.org



October 18, 2018

University of Missouri-Columbia
Institutional Review Board
Office of Research, 482 McReynolds Hall
Columbia, MO 65212

Dear IRB Members,

After reviewing the proposed study entitled "Exploring the Engagement in Preventive Health Services among Rural, Working Adults with Type 2 Diabetes", presented by Lynn E. Glenn, PhD student. I have granted permission for Lynn E. Glenn, principal investigator, to recruit potential research participants at Denmark Technical College.

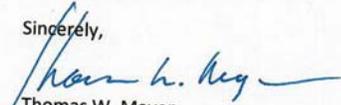
The purpose of the study is to determine how individual, interpersonal, health system, and community factors influence the use of preventive health services among rural, working adults with type 2 diabetes. The primary activity will be face-to-face individual interviews.

I understand that screening questionnaires will be conducted with potential research participants and will occur approximately 5 – 10 minutes per participant, to be scheduled outside of work hours. I understand that face-to-face interviews with research participants will occur for approximately 60 minutes per participant, to be scheduled between the researcher and participant, outside of work hours. I expect that this project will end no later than December 15, 2018.

I understand that Lynn E. Glenn MSN, APRN-C, PhD student will receive signed, written consent for all participants. Any data collected by Lynn E. Glenn MSN, APRN-C, PhD student (principal investigator) will be kept confidential.

If the IRB has any concerns about the permission being granted by this letter, please contact me at the phone number listed below.

Sincerely,


Thomas W. Mayer
Director, Human Resource Services



2276 Rowesville Road
Orangeburg, SC 29115
Telephone: (803) 531-2890
FAX: (803) 531-2902
E-Mail: orangeburg@okonite.com

November 1, 2018

University of Missouri-Columbia
Health Sciences Institutional Review Board
Office of Research, 482 McReynolds Hall
University of Missouri
Columbia, MO 65212

Dear IRB Members,

After reviewing the proposed study entitled "Exploring the Engagement in Preventive Health Services among Rural, Working Adults with Type 2 Diabetes", presented by Lynn E. Glenn MSN, APRN-C, PhD student, I have granted permission for Lynn E. Glenn MSN, APRN-C, PhD student to recruit participants at Okonite Company in Orangeburg, South Carolina.

The purpose of the study is to determine how individual, interpersonal, health system, and community factors influence the use of preventive health services among rural, working adults with type 2 diabetes. The primary activity will be face-to-face individual interviews.

I understand that face-to-face interviews with research participants will occur for approximately 60 minutes per participant, scheduled outside of working hours. I expect that this project will end no later than December 15, 2018.

I understand that Lynn E. Glenn MSN, APRN-C, PhD student will receive written, signed consent for all participants. Any data collected by Lynn E. Glenn MSN, APRN-C, PhD student will be kept confidential.

If the IRB has any concerns about the permission being granted by this letter, please contact me at the phone number listed below.

Sincerely,

Kelly Evans, Human Resources Administrator
The Okonite Company
(803)531-2890, ext.1343



BAMBERG SCHOOL DISTRICT TWO
OUR FOCUS: STUDENT ACHIEVEMENT, ACCOUNTABILITY, ATTENDANCE—TURNING IT ALL AROUND



DENMARK-OLAR ELEMENTARY SCHOOL

"HOME OF THE VIKINGS"
1459 SOLOMON BLATT BOULEVARD
DENMARK, SC 29042

Dr. Lorraine J. Peeples, Principal
Ms. Lindsey Toomer, Assistant Principal
Education: Our Children Deserve It. The World Demands It.

April 10, 2019

University of Missouri-Columbia
Institutional Review Board
Office of Research, 482 McReynolds Hall
Columbia, MO 65212

Dear IRB Members,

After reviewing the proposed study entitled "Exploring the Engagement in Preventive Health Services among Rural, Working Adults with Type 2 Diabetes", presented by Lynn E. Glenn, PhD student. I have granted permission for the study to be conducted at Bamberg School District Two. Lynn E. Glenn, principal investigator, also has been given permission to recruit at Bamberg School District Two.

The purpose of the study is to determine how individual, interpersonal, health system, and community factors influence the use of preventive health services among rural, working adults with type 2 diabetes. The primary activity will be face-to-face individual interviews.

I understand that screening questionnaires have been conducted with potential research participants, approximately 5-10 minutes per participant. I understand that face-to-face interviews with research participants have been conducted, approximately 60 minutes per participant, scheduled outside working hours. This project was completed on this campus December 17, 2018.

I understand that Lynn E. Glenn MSN, APRN-C, PhD student has received signed, written consent for all participants. Any data collected by Lynn E. Glenn MSN, APRN-C, PhD student (principal investigator) will be kept confidential.

If the IRB has any concerns about the permission being granted by this letter, please contact me at the phone number listed below.

Sincerely,

Lorraine J. Peeples
Principal

Phone: 803-793-3112

Fax: 803-793-2020

Website: www.bamberg2.org

Richard Carroll Elementary School

November 15, 2018

University of Missouri-Columbia
Institutional Review Board
Office of Research, 482 McReynolds Hall
Columbia, MO 65212

Dear IRB Members,

After reviewing the proposed study entitled "Exploring the Engagement in Preventive Health Services among Rural, Working Adults with Type 2 Diabetes", presented by Lynn E. Glenn, PhD student. I have granted permission for the study to be conducted at Bamberg School District One. Lynn E. Glenn, principal investigator, also has permission to recruit at our Bamberg School District One.

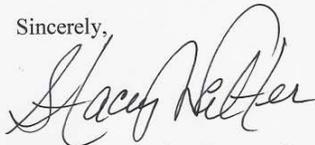
The purpose of the study is to determine how individual, interpersonal, health system, and community factors influence the use of preventive health services among rural, working adults with type 2 diabetes. The primary activity will be face-to-face individual interviews.

I understand that screening questionnaires will be conducted with potential research participants and will occur approximately 5 – 10 minutes per participant. I understand that face-to-face interviews with research participants will occur for approximately 60 minutes per participant, to be scheduled outside working hours. I expect that this project will end no later than December 15, 2018.

I understand that Lynn E. Glenn MSN, APRN-C, PhD student will receive signed, written consent for all participants. Any data collected by Lynn E. Glenn MSN, APRN-C, PhD student (principal investigator) will be kept confidential.

If the IRB has any concerns about the permission being granted by this letter, please contact me at the phone number listed below.

Sincerely,



*Mrs. Stacey Walter, Principal
Richard Carroll Elementary*

University of Missouri Permission Letter Template
Released: April, 2013

RESEARCH STUDY:

EXPLORING THE ENGAGEMENT IN PREVENTIVE HEALTH SERVICES AMONG RURAL, WORKING ADULTS WITH TYPE 2 DIABETES

To qualify for study, you must:

- Be 18 TO 65 years old
- Have Type 2 Diabetes
- LIVE or WORK in Bamberg, Calhoun, or Orangeburg County
- Speak English

Receive a gift for 5 minute survey & a \$50 gift card for scheduled 60 minute interview

Date: TBA
Time: TBA

+ rmc

the Regional Medical Center

CONTACT: LYNN GLENN, RESEARCHER
Tel: (843) 686 - 5243 | Email: wdlynnglenn@gmail.com

Appendix F: Screening Forms

THANK YOU FOR YOUR INTEREST IN THIS STUDY. THIS RESEARCH STUDY SEEKS TO HELP IMPROVE THE OVERALL HEALTH OF WORKING ADULTS WITH DIABETES IN ORANGEBURG, BAMBERG AND CALHOUN COUNTIES.

I have been a nurse practitioner for the past 25 years, and most of my experience has been serving the people of the Bamberg and Orangeburg area. I currently am pursuing a doctorate in nursing. As part of my graduate program, I will be conducting a research study. I have chosen to work with rural, working adults with diabetes.

Priorities: An important need in our counties is finding new and better ways to provide health care to working adults. Working adults are often very busy and sometimes do not have the time or money to get health care.

Short-term goal: In this study, I will ask working adults with diabetes in Bamberg, Calhoun, and Orangeburg counties about their health. The study will involve a short screening survey and an interview.

- The 10-question screening survey can be completed in less than 5 minutes.
- Based on the survey results, if you qualify to participate in an interview, you will be invited to volunteer for an interview (outside of the work setting). The interview will take approximately 60 minutes and it will be scheduled at a convenient time for you.

Long-term goal: The results of this study will let local health care providers, employers, and other key community members find better ways to help working adults get the health care they need and hopefully, improve the overall health of our community

You qualify to take this survey if you meet ALL of the below:

- WORK at least 20 hours per week in Bamberg, Calhoun or Orangeburg County
- OR work at least 20 hours per week and LIVE in Bamberg, Calhoun or Orangeburg County
- 18 to 65 years old
- Have Type 2 Diabetes
- Speak English

Place an "X" on the line to the LEFT of your answer. One answer only please.

1. When all is said and done, I am responsible for taking care of my health.
Disagree strongly ___ Disagree ___ Agree ___ Agree Strongly ___ Not
Applicable ___
2. Taking an active role in my own health care is the most important thing that
affects my health.
Disagree strongly ___ Disagree ___ Agree ___ Agree Strongly ___ Not
Applicable ___
3. I know what each of my prescribed medications do.
Disagree strongly ___ Disagree ___ Agree ___ Agree Strongly ___ Not
Applicable ___
4. I am confident that I can tell whether I need to go to the doctor or whether I can
take care of a health problem myself.
Disagree strongly ___ Disagree ___ Agree ___ Agree Strongly ___ Not
Applicable ___
5. I am confident that I can tell a doctor concerns I have even when he or she does
not ask.
Disagree strongly ___ Disagree ___ Agree ___ Agree Strongly ___ Not
Applicable ___
6. I am confident that I can follow through on medical treatments I may need to do
at home.
Disagree strongly ___ Disagree ___ Agree ___ Agree Strongly ___ Not
Applicable ___
7. I have been able to keep up with lifestyle changes, like eating right or exercising.
Disagree strongly ___ Disagree ___ Agree ___ Agree Strongly ___ Not
Applicable ___
8. I know how to prevent problems with my health.
Disagree strongly ___ Disagree ___ Agree ___ Agree Strongly ___ Not
Applicable ___
9. I am confident when new problems arise with my health.
Disagree strongly ___ Disagree ___ Agree ___ Agree Strongly ___ Not
Applicable ___
10. I am confident that I can maintain lifestyle changes, like eating right and
exercising, even during times of stress.
Disagree strongly ___ Disagree ___ Agree ___ Agree Strongly ___ Not
Applicable ___

Demographic Information Form

1. Age _____
2. Female or Male (circle one)
3. Caucasian Black/African American Asian Hispanic Latino (circle one) Other _____
4. County of Residence (Home)
5. Zip Code (Home)
6. County of Employment
7. Approximate Working Hours per Week _____
Part-time (20 to 40 hours a week) OR Full-Time (40 hrs./week or more)
8. Job title or job position
9. Number of people in household
10. Approximate yearly income (circle one)
Less than \$50,000 per year More than \$50,000 per year
11. Insurance (circle one)

Medicaid

Medicare

Private Insurance (Employee benefits)

Private Insurance (Individual policy, i.e. Obamacare)

No Insurance

Appendix G: Interview Guide

Introduction:

Thank you for meeting with me to take part in this important study. Diabetes is a common health problem in our area. It is very important for people with diabetes to get certain health screenings to prevent problems in the future, like eye, kidney, heart or circulation problems. By talking about your experience managing your diabetes, we can learn more about what might help you get the health services you need. Also, we would like to learn how you have used support and other resources to help manage your diabetes, such as a family member who helps you manage diabetes and get the services you need.

Please remember that there are NO right answers to the questions I am asking you, and that I am most interested in your experiences and thoughts. This interview will be tape-recorded, because I want to be able to remember what we talk about, and your thoughts and ideas are very important to me. Later on, I will transfer the tape recording of this interview to a paper document, and then I'll destroy the tape. All information that you give me will be locked up in my office. Your name won't be on any of the information. Also, if you say anything when we're talking that I think might identify you or someone else, I will delete that from the recording. Your privacy is very important to me. If at any point you want me to turn the tape recorder off, please tell me. If at any point you want to stop the interview, please tell me. Do you have any questions for me? Are you ready for me to turn the recorder on and to begin?

SOCIO-ECOLOGICAL FRAMEWORK RESOURCES & SUPPORTS	QUESTIONS <i>PROBING QUESTIONS</i>
Individual factors	
<ul style="list-style-type: none"> ▪ job position ▪ diagnosis of diabetes ▪ diabetes self-care ▪ preventive behaviors and health service use ▪ personal goals 	<p>Please tell me about yourself and your job.</p> <p>Please tell me about your personal experience with diabetes.</p> <p><i>Probing questions:</i></p> <p><i>Tell me about how long you have had diabetes.</i></p> <p><i>How did you find out you had diabetes?</i></p> <p><i>Are you taking any medicines for your diabetes?</i></p> <p><i>What things you feel you do well to manage your diabetes?</i></p>

	<p><i>Are there certain things about managing your diabetes that are hard or challenging?</i></p> <p><i>What tests or services do you get on a regular basis to manage your diabetes?</i></p> <p><i>Are there tests or services you would like to get but are not able to get?</i></p>
Interpersonal factors	
<ul style="list-style-type: none"> ▪ family and friends support ▪ social network and activities ▪ health promoting activities 	<p>Next, please tell me about your family and friends and how they help you manage your diabetes.</p> <p><u><i>Probing questions:</i></u></p> <p><i>Do any of your family or friends help you manage your diabetes or help you learn more about diabetes?</i></p> <p><i>How have they helped you with your diabetes?</i></p> <p><i>Tell me about your social life or what you like to do in your free time.</i></p> <p><i>Do you participate in any activities with your family and friends that help manage your diabetes (for example, exercising together, sharing healthy recipes)?</i></p>
Health System factors	
<ul style="list-style-type: none"> ▪ engagement with health care providers and services ▪ decision-making 	<p>Tell me about your experience in getting health care to manage your diabetes.</p> <p><u><i>Probing questions:</i></u></p> <p><i>What are the recommended tests you get on a regular basis for diabetes, such as having an eye exam every year?</i></p> <p><i>What are some of the specific things that your doctor or other health care worker do to help you manage diabetes?</i></p> <p><i>Does your doctor or nurse tell you about the importance of tests that you need done to manage your diabetes? Do they talk about the results and help you understand the results?</i></p> <p><i>Do you think your doctor/other provider has let you help make decisions about your diabetes?</i></p>

Community & Neighborhood factors	
<ul style="list-style-type: none"> ▪ workplace ▪ community engagement ▪ resources for health or diabetes; built environment ▪ neighborhood food and housing availability 	<p>Tell me about the resources that are available in your community or local area that can help prevent the complications of diabetes? (blindness, heart disease, high blood pressure, high cholesterol, kidney disease, neuropathy, and diabetic foot ulcers)</p> <p><i><u>Probing questions:</u></i></p> <p><i>Does your workplace have policies that make it easier to manage your health (i.e. no smoking policies, time off for medical appointments)? What makes it difficult?</i></p> <p><i>Do you like to go to wellness or health education programs at your workplace or in your local area, or if available?</i></p> <p><i>Are there any facilities in the neighborhood to improve your health (i.e. parks, walking trails) or any restaurants that serve healthy food? What kinds of things would you like to have nearby in your community to help your diabetes?</i></p>

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